MEDINFO 2010

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This book series was started in 1990 to promote research conducted under the auspices of the EC programmes' Advanced Informatics in Medicine (AIM) and Biomedical and Health Research (BHR) bioengineering branch. A driving aspect of international health informatics is that telecommunication technology, rehabilitative technology, intelligent home technology and many other components are moving together and form one integrated world of information and communication media. The complete series has been accepted in Medline. Volumes from 2005 onwards are available online.

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MEDINFO 2010

Proceedings of the 13th World Congress on Medical Informatics

Part I

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Dedicated to Steven A. Huesing
IMIA Executive Director, 1997–2009
An outstanding person and professional

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Editorial

The 13th World Congress on Medical and Health Informatics, Medinfo 2010, held in Cape Town, South Africa has many forms of participation from preconference tutorials, workshops, keynotes, invited presentations, scientific presentations, panels, demonstrations, and posters. The Organizing Committee, led by Dr. Lyn Hanmer from South Africa, collaborated with the Scientific Program Committee, led by Drs. Riccardo Bellazzi from Italy and Johanna Westbrook from Australia, to sculpt an outstanding program. The Editorial Committee has tried to organize a subset of this rich content, the scientific papers and abstracts of posters, into the Proceedings.

Our greatest challenge has been to make each paper have identical formatting. Only 10% of all submitted papers exactly complied with the organizers instructions. Further work break down analysis shows total editorial time (excluding meetings) of approximately 200 hours, evenly spread between posters and papers. Of that 200 hours, two-thirds are corrections in to conference requirements, and one-third is formatting in to publisher's requirements. We thank Christine Archuleta for her diligent copy editing.

We have organized the paper Proceedings into 20 chapters, where the last chapter is comprised of the abstract of posters organized by the authors self-selected theme. We have attempted to organize the scientific papers in 19 chapters starting with the individual and moving through an ever expanding view of organization and systems.

Of course, most papers could easily have fit into multiple sections, so we not only provide a keyword index, but also a searchable CD-ROM version.

Charles Safran, MD, MS
Shane Reti, MCHCB
Heimar Marin, RN, PhD

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Preface from the Scientific Program Co-Chairs

The theme for the International Medical Informatics Association's (IMIA) 13th World Congress on Medical and Health Informatics, Medinfo 2010 is Partnerships for effective e-Health solutions. It is well recognised that information and communication technologies have enormous potential for improving the health and lives of individuals. Innovative and effective change using such technologies is reliant upon people working together in partnerships to create innovative and effective solutions to problems with particular regard to contextual and environmental factors.

Medinfo 2010 brings together the health informatics community from across the globe with a focus on how we can work together and share our experiences and knowledge to promote sustainable solutions to the challenges presenting to us all. This will be an historical event as Medinfo 2010 is hosted in Africa for the first time.

The Scientific Program Committee (SPC) was presented with a strong field of 905 submissions meeting the call of the congress challenge. This included 603 papers, 203 posters, 41 workshops/tutorials, 37 panels and 21 scientific demonstration applications. The final paper acceptance rate was 43%. All papers were assigned to two or three reviewers who scored each of the papers and provided feedback to authors. All submissions were categorised into one of four major themes (Hospital information systems, Consumer-health informatics, Knowledge management, National and International Health IT) and submissions within each of these theme areas were re-reviewed by assigned members of the SPC.

The final program covers all aspects of modern health informatics, ranging from traditional topics, such as hospital information systems, patient registries, nursing informatics, data integration, standards, interoperability issues and decision support, to new topics such as translational bioinformatics, text mining, intelligent data analysis, emerging technologies, quality, social networking, workflow and organizational issues. The papers have been selected with the guiding principle of including in the program both high quality methodological research and high impact applications of health informatics. In some cases, the authors achieved both goals.

A distinguishing feature of Medinfo 2010 program is the presence of several sessions on public health and national and international initiatives to promote health IT. The scientific challenges to implement large-scale initiatives are strongly related to the conference theme, as they rely on effective partnerships between all actors involved in health care informatics. The scientific rigor of the congress papers can be seen both as a consequence and reflection of IMIA's strategic decision to see its role as a promoter of science and health IT throughout the world. Health Informatics researchers internationally are rising to the challenge of providing robust evidence of the transformational effects of effective health information exchange.

The Scientific Program Committee thanks all those who made submissions to Medinfo. Special thanks also go to the worldwide team who reviewed these submissions and provided feedback. For the first time the SPC organised a mentor scheme which provided the opportunity for researchers seeking to

submit papers to Medinfo to have their work reviewed by an international expert prior to the Congress submission closing date. 42 papers were reviewed as part of this process. We thank the team of mentors who generously gave their time to support their colleagues as part of this scheme.

Riccardo Bellazzi, PhD
University of Pavia
Pavia, Italy

Johanna Westbrook, PhD
The University of Sydney
Lidcombe, New South Wales, Australia

Message from the IMIA President

Medinfo 2010 is the 13th World Congress on Medical Informatics and the first held in Africa! The Convention Center in Cape Town, South Africa is an outstanding conference site with excellent facilities to hold the premier triennial international meeting for the medical informatics community. The conference theme selected for Medinfo 2010 is a topic that most countries are currently addressing: Partnerships for effective eHealth solutions – Innovative collaborations promote solutions to health challenges.

A Medinfo conference brings together world leaders in this field to share knowledge and experiences. Medinfo 2010 is a unique opportunity to meet these leaders and to hear of, and contribute to, advances in biomedical and health informatics. There is nothing else like a Medinfo conference.

A Medinfo conference is the official conference of the International Medical Informatics Association (IMIA). IMIA's goals and objectives include:

- the promotion of informatics in health care and biomedical research,
- the advancement of international cooperation,
- the stimulation of research, development and education, and
- the dissemination and exchange of information.

For more than 40 years, IMIA has been a bridging organisation, as medical informatics is an integrative discipline. IMIA supports and stimulates high-quality translational communication, research, education, and practice in biomedical and health informatics. In IMIA's Medinfo conferences this is done by bringing together, from a global perspective, scientists, researchers, informatics practitioners, vendors, consultants and suppliers in an environment of cooperation and sharing. This Medinfo includes a special focus on the needs of and solutions from developing countries, in Africa and beyond.

These conference proceedings will help to share the knowledge, presented and discussed at this Medinfo. As for the previous Medinfo conferences, the proceedings contain important results in research and education, and also for the practise of health care.

Medinfo 2010 has been organised and coordinated by the South African Health Informatics Association. A number of governmental organisations, associations and businesses have agreed to be sponsors. Many persons have worked hard and successful for making Medinfo 2010 a great success. Let me here in particular acknowledge the chairpersons of the Organising Committee, Lyn Hanmer (South Africa); of the Scientific Program Committee, Riccardo Bellazzi (Italy) and Johanna Westbrook (Australia); and of the Editorial Committee, Charles Safran (USA).

Reinhold Haux
Peter L. Reichertz Institute for Medical Informatics, Germany
President (2007–2010) of the International Medical Informatics Association

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Chapter 1.

Informatics for the Person

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The Role of Patients in Transiting Personal Health Information: A Field Study

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Abstract

Recent consumer health informatics initiatives advocate individual access and management of personal medical records. However, little is known regarding the impact of personal access of health information on clinical practice. This paper introduces a field study investigating the usage patterns of personal health records in medical consultations. The self-managed records provide patients with a strong sense of ownership and control over their own health information. Personal medical records have been used primarily for transiting information among different providers. This behavior changed patient-provider communication into a records sharing. Doing so effectively eliminated the potential errors in the verbal reporting process. This study indicates that patients can be effective contributors to their own health and suggest the design of health information systems to rethink the role of patients in the healthcare process and shift the responsibility of healthcare to the patients' side.

Keywords:

Medical records, Physician-patient relations, Cooperative behavior, Access to information, Consumer health information, Information management

Introduction

Recent consumer health informatics initiatives encourage individual access and management of medical records using Personal Health Record (PHR) system. PHR has been previously defined as personal notes documenting important medical information such as medical history and current medications [2, 3]. A large-scale survey [1] shows that approximately 40% of people maintain some form of paper medical records, while only 1.5% use computer tools to manage their health information.

Online PHR is therefore "*an electronic application through which individuals can access, manage, and share their health information and that of others for whom they are authorized, in a private, secure and confidential environment* [4]." PHR is believed to be able to improve patient-provider communication and empower patients to engage into their own health [5-7].

While the focus of current PHR study is usually on the patients' side, accessing and managing personal health information also affects the way in which medical consultation is conducted. The information contained in patients' records is crucial for physicians to make correct medical decisions and to apply optimal care. This information, however, is often managed by individual healthcare organizations where a patient previously sought care. It is notable that to date, there is little information as to how personal managed health records manage in actual clinical practice [4].

This paper describes an observational field study that was conducted in urban China, a place where patients are responsible for maintaining their outpatient medical records. We shadowed doctor-patients interactions in consulting rooms in order to understand the usage patterns of paper-based PHR in the medical consultation process. Our observations suggest that for patients, their medical records are transitional artifacts that carry critical information among the multiple physicians they visit. Using personal health records has turned the question-answering mode of clinical interviews into an information-sharing practice. This ensures the accurate medical history is communicated to the providers. It also fosters an effective collaboration between patient and provider where part of the responsibility is shifted to the patients' side. Maintaining their own health records provides a sense of control among patients and encourages them to be more involved in their own health. These findings can be used to direct future PHR system design and to impact chronic disease management.

Methods

This observational study was conducted in an outpatient department of a large hospital located in urban China. The primary reason this field site was chosen is that outpatient (ambulatory) medical records are routinely kept by individual patients in current Chinese medical practice. We obtained IRB approval from the university the researcher is affiliated with, and the approval of the scientific review board of the hospital being studied. All the participants' names are pseudonyms in order to protect their confidentialities.

Participants

The hospital where this study was carried out is well known for its medical expertise in the fields of ophthalmology (eye) and otorhinolaryngology (ENT). Most patients in these two departments are non-locals looking for second opinions or hoping to be treated for diseases that are untreatable elsewhere. By contrast, the other departments consist mainly of local patients. The whole hospital is under resourced due to the large demand of patients care. To observe the medical records usage patterns in both the departments of expertise and non-expertise, we recruited four doctors from the outpatient departments, including two internal medicine physicians, one eye doctor and one ENT doctor. A total of seventy-six patient consultations were observed during the study.

Data Collection and Analysis

The field observations were intended to identify usage patterns of patients' self-maintained medical records during the consultation process. A total of 40 hours of observations were performed in the consulting room. Each observation session lasted for 4-5 hours. Usually, the researcher sat in an unobtrusive location within the consulting room (Figure 1). The research activities included jotting down brief observation notes, asking questions when patients/physicians were available, and tracking down critical incidents during the observations. Detailed observation notes were transcribed after each session. The researcher is a native Mandarin speaker and previously majored in medicine. This ensured proper understandings of the patient-physician interactions in the consulting room. Overall, over 120 observation notes were summarized.

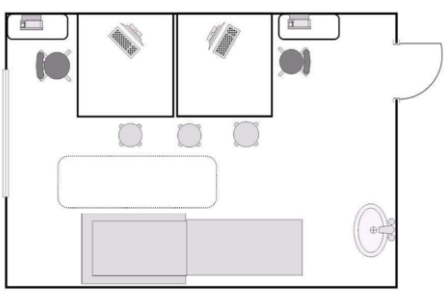

Figure 1- The physical layout of the medical consultation room. The physician sits on the left side at a desk. Student 1 was at the right side desk entering information into the HIS system. The three horizontal chairs were for: patient, student 2, and the observer (from left to right).

The observation notes were coded using an iterative open coding scheme [8] to extract the medical records usage patterns in the consulting room. These findings were verified with participating doctors and other clinicians in the hospital.

Results

In this section, we report medical records usage patterns in the consulting room sequentially following the general clinical workflow in the following three steps: sharing records, checking records and making decisions.

Sharing Records

Keeping one's own outpatient medical records are a predominant phenomenon in Chinese medical practice where patients receive their own records in almost every healthcare organization. Similarly, patients in the current study have full access to their medical records. ***Full access*** means that patients are able to maintain all their medical information generated in healthcare settings, including diagnoses, prescriptions, clinical notes, lab results, and even hardcopies of radiology images. The hospital in urban China is equipped with a Hospital Information System (HIS) where doctors can enter medical orders and diagnoses directly to the HIS system. To ensure that patients have full copies of their medical information, the information typed in the HIS system is always printed out and attached to a medical records book that is used to document their other health information. The records book is used in all healthcare organizations in the region. Patients then keep the records book at home as their own personal health information.

Figure 2- In the Eye consulting room, a family member holding a CT image the patient received from his local hospital – thousands miles away from the study site.

These self-maintained medical records are brought back to the consulting rooms by patients later on. Carrying medical records is a way for patients to share past medical history with current doctors. During observations, patients often came in with a stack of medical record books that they had collected from different healthcare providers or from different time spans, such as from the earliest disease onset to the most recent treatment. In our study, 74 out of 76 patients brought in their own personal medical records.

Xiaoxia is local patient with 20 years of diabetes treatment who also suffers from multiple complications of her illness. She told us why she carries her medical records with her at all times:

> "*I need to go to hospitals frequently. Sometimes when I felt uncomfortable or when I suddenly have a couple of hours free time during work, I just go*

to see a doctor. This small book is easy to carry and I always put it in my purse. That way I don't need to go back home to pick up my records and I can go whenever I want to!"

Later on in the consultation, she took out a couple of medical record books that she recently received from other doctors, including a cardiologist, physician from the community hospital and a Chinese medicine doctor to show her physician. In Xiaoxia's opinion, having medical records is a requisite to seeing her doctors and carrying her records is a convenience that allows her to stay healthy.

Checking Records

Patients have to turn in their most recent medical records to the receptionist with their registration numbers before entering the consulting room. They are allowed to keep with them other medical records, *e.g.* medical records from the past year or smaller pieces of information patients prepared at home, *e.g.* glucose readings in the past two weeks. The medical records the receptionist takes are then put on the physician's desk for review. The physician's work starts with the placement of the records book on the desk. For the first few minutes of the consultation, the patient just sits quietly and waits for their doctor to review their records.

The review process of the medical records starts from the most recent medical visit, then traces back to earlier visits until doctors get an overview of the patients' situation. In the cases of the Eye and ENT departments, where most patients present with relatively severe diseases, the assistant often requests patients hand in all their past medical records along with original radiology images. The Eye/ENT doctors then carefully examined this information and observe the images before the patient begin reporting their symptoms.

After reviewing the recent records, patients start communicating with their doctors verbally about their feeling and symptoms as well as past medical history and history of present illnesses. The interview process generally consists of a series of questions and answers so that doctors can obtain sufficient information to make their judgments. Hence, the ability to effectively communicate personal health information is closely associated with the quality of personal healthcare. Previous studies [9, 10] show that patient-provider communication may be hindered by the ineffective information reported by patients, especially those who have low health literacy. Similar observations happened in our study where patients frequently faltered and had difficulty answering questions, even when the questions were regarding their own experiences. Many of these moments of communication breakdowns were followed by a medical records sharing session where patients took out written documents that helped facilitate the expression of their thoughts. These documents were mostly the medical records that were not turned in at the beginning of the consultation. Xiaoyi is a local patient who came in to see Dr. Yang. During the consultation, Dr. Yang routinely asked what medications and lab tests she had recently. Xiaoyi pondered for a while and started complaining:

"*These pill names are* just *too hard to remember, I think I will never remember them. You know, I have diabetes, hypertension and heart diseases. I need to take more than 10 types of medications everyday. I am 74 years old and I don't have lots of medical knowledge. How could possibly that I can remember these names myself"*

However, after a few seconds of thinking, Xiaoyi took out a small medical records book in which her past medical visits had been documented. She passed this record to Dr. Yang and pointed to a few prescriptions she is now taking. Sharing medical records allows Xiaoyi to report her medical information to the doctors quickly without taking too much effort to remember it. This sharing process is especially beneficial for older patients who might have memory loss and limited medical knowledge. It also saves valuable consulting time in such an under resourced healthcare setting.

Making Decisions

Not only do physicians look to past diagnoses and prescriptions to substitute some oral communication, they also check other information such as radiology images or laboratory tests when it is available to them. To physicians, this information demonstrates a disease's progress from earlier onset to the various treatments already used. It also helps physicians to eliminate their initial hypothesis about an illness. And as physicians almost inevitably request lab and radiology images from patients when reading their basic medical records, medical records help to exclude previously tried medical procedures.

A young man came in with his mother to see Dr. Jiang – a well-known eye specialist. The young man reported a recent loss of vision on his left eye. The loss was getting worse and they suspected that it might be related to an injury that happened seven years ago. Dr. Jiang's first inquiry was about the seven year old injury. The mother took out the records they had received 7 years ago from her purse. Even though the paper records were a bit torn, Dr. Jiang could still get a pretty good sense of what the medical condition was when the injury happened.

After viewing the records, Dr. Jiang did a simple ophthalmoscope check and told the patient:

"Ok, I think you should only take a retinal photograph. You should be able to get results this afternoon. Your precious radiology images seem clear that the lost vision has nothing to do with your injury. You know, it could have cost you weeks to get CT tests here."

Here the personally maintained medical records changed the medical decision making process. Medical decision-making is essentially a hypothetical-deductive process. With more clinical evidence available at the point of care, physicians can eliminate unrelated hypotheses during the initial medical decision-making process. Narrowing down initial hypotheses saves patients from doing unnecessary tests and shortens the overall

diagnosis time. As shown in our observation, for the patients who travel to consult second opinions in the Eye or ENT departments, medical records may save weeks from the waiting time.

Discussion

In this study, we found that personal health records have been used as a means to transmit an individual's professional health information among their various healthcare providers. These medical records are brought to a consulting room and shared with the physician during the consulting process. Patients then add the newly received records to their personal health information repositories. In this section, we discuss the implications of this medical records usage patterns to clinical practice.

Patient-centric Record Keeping

Fragmentation is a term that has often been associated with the current healthcare practice [11, 12]. Fragmentation refers to the fact that an individual's healthcare information may reside in various healthcare organizations that they visited previously. As has been observed in this study, chronic care patients may have routine medical visits with both their primary care physicians and various specialists. Patients who have severe diseases tend to consult multiple experts to pursue the best treatment or obtain second opinions constantly. Many times, past medical records are not accessible at the point of care. Even though we advocate universal Healthcare IT solutions to interoperate different systems in different healthcare organizations, many technical, financial, organizational and political barriers remain in constructing such a universal accessible record-keeping system.

In the current study, the patients' self-maintained medical records shifted record management from provider-centric to patient-centric. The records are no longer kept at a single healthcare organization, but are organized by an individual patient across various healthcare organizations. This individual-based management allows patients to process their life-long medical records and keep information with them conveniently. This concept is much like the integrated online PHR system that incorporates patients' life-long medical records in a safe and secure place [4]. However, the integrated PHR requires huge input from both the providers' side and the patients' side. It requires go-live EMR systems that store patients' information at the providers' side and also Internet access and computer literacy at the patients' side. This study was conducted in an under resourced healthcare settings with many patients who are uninsured and suffering from poverty, yet even in this setting, the patients were capable of managing their own healthcare records. This study proves the values of personal records management from the individual patients' perspective.

Patient-provider Communication

Patient-provider communication is the basis for outpatient practices. In common occasions, patients have to verbally report their symptoms and other medical histories to doctors and continue answering questions that doctors raise. Thus, the quality of the healthcare relies on whether patients can accurately express their needs and answer questions. This, however, may be challenging for those who have low health literacy and educations [9, 10].

Many patients in this study were elderly and suffering from memory loss, and may not have been able to understand what the doctors asked them. In turn, most of times, what they communicated to doctors was generic information about their health. Such as the example showed in the previous section, even though the patient and his mother described the injury incident to the doctor, the information they reported used lay words and may not have satisfied a physician's professional needs. The inaccuracy of self-reported information may be error-prone and lead to medical mistakes.

This verbal communication has been replaced by sharing medical records in this study. Patients always submit their recent medical records book for review before they enter the consulting room. The initial inquiry has changed to a records review session where records from different organizations and time spans are read by doctors. During the medical interview, patients always refer back to their previous records to help answer questions. We have observed many occasions where patients facilitate doctors to locate specific information in the record books, such as one individual lab test result or a particular medical visit. Patients may even bring in records that were obtained many years ago in case it is needed in the consulting process, though this is most often seen when patient present with serious diseases.

This information sharing differs from patients' verbal conversation since medical records are documented by healthcare professionals. In this way, a patient's healthcare information is transmitted among healthcare providers without any alteration. This fosters invisible collaborations among various doctors, across different times and locations. Even though these doctors may never meet, they can use the shared records to collaboratively make their judgment and speculate about earlier disease situations in a way that would otherwise be unavailable to them.

Patient-Provider Collaboration

The shift to a medical records system also affects how physician and patients communicate. Patients often stay passive in the healthcare process. They wait passively for healthcare professionals to collect and review their healthcare information and make their decisions. By managing their own medical records, patients are taking more responsibility since the goal of obtaining good health now requires their involvements. They have to transmit appropriate medical records to their providers in order to guarantee quality healthcare. In this sense, a simple task of carrying medical records to the hospital is participating in one's own health.

By transmitting medical records to healthcare providers, patients start forming a collaborative relationship with their doctors as how they manage their records affects their own health outcomes. Accordingly, the job of organizing pieces of information in the thick medical records is also shifted from the providers' side to patients'. Many patients in our study took the effort to reorganize the scattered information into a mean-

ingful arrangement so that it was easy for physicians to check during the consultation. Patients not only facilitate the timely access to medically relevant information in a time-constrained situation, but also ensure the all the necessary medical information is checked to avoid confusion. These involvements enable patients to be engaged in their own healthcare by supplying medical information at the point of care to ease the information flow in medical interviews.

Control of Personal Health Information

Self-maintained medical records also provide patients with a strong sense of control over their own health information. Patients can choose to show or not show certain records to their physicians. For example, one observation in the study showed that a patient hid some records at the beginning of the consultation and showed it later on. This was because the patient was obtaining a second opinion. He hid previous records so that the doctor could provide him with fresh insight.

Patients also have control over how they keep their records. As some observations described earlier, some patients prefer to have recent records in their purse at all times in the case of impromptu medical visits. Many others keep their records in separate piles, for serious and mild diseases, organizing which records to bring to which providers. Patients also integrate health information that is generated from home with the information they obtain from the hospital, such as organizing home glucose readings with clinics results chronically, or associating lab results with a food diary that account for activities in the same time period. Hence, the full access of medical records enables patients to engage more fully in using their health information, and eventually in their own health.

Conclusion

This paper explores how patients' self-maintained medical records affect clinical practice in consulting rooms. We conducted an observational field study at an urban Chinese hospital to examine how personal health records are shared and used during medical interviews. The observations reveal that self-maintained records are largely used as a transitional tool for patients to share information with healthcare providers. This sharing process allowed patients to integrate their health information in a patient-centric way and provide them with a strong sense of ownership and control over their own health information. Self-managed medical records changed error-prone verbal reports into professional documentations collaborated among providers. Most importantly, this study shows that patients, even those who have low health care literacy in under resourced healthcare settings, can be effective contributors to their own health. Researchers ought to rethink the patient-provider relationship in designing new interactive health systems that force patients to take more responsibilities in the healthcare process.

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Need for a New Care Model - Getting to Grips with Collaborative Home Care

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Abstract

In this paper we discuss the fact that more and more patients are treated in their homes by a set of organizations, sometimes with different ownership, and how this fact places new and severe demands on health care and home service staff to communicate and collaborate. We point to the need for managers in different organizations to agree on ways of communicating and collaborating on the operational level and how this aspect needs to be considered during procurement of home care services. Most importantly, by reasoning around a set of problematic areas, we derive a set of related problems and suggest solutions for dealing with them. The solutions are a mix of organizational/administrative measures and IT support for communication and coordination.

Keywords:

Collaboration, Home care, Home health care, Home service.

Introduction

In Swedish health care more and more patients are treated and taken care of in their own homes instead of in hospitals or nursing homes. This includes severely ill patients who require several different professions to be involved in the care process. The involvement of many different organizational units, often with different owners, complicates the situation even further and creates high demands on collaboration and coordination among the involved care givers in order to achieve high quality care for the patient.

In an earlier paper [1], we described an investigation in two Swedish communities, Stockholm and Umeå. The results indicated problems in inter-organizational communication and cooperation in home care. Most of the problems were due to organizational and social obstacles resulting in a lack of communication among the units and individuals involved. In three subsequent papers [2, 3, 4] we have analyzed the requirements this places on collaboration and coordination. The findings stress the need for improved collaboration among managers and among staff at the operational level. In particular, managers from different organizations need to collaborate more effectively in order to set up goals and routines for collaboration. In addition, our results showed that collaboration has to be considered during procurement of health and social care, and that managers need to follow-up the quality of delivered services. The necessity for substantially enhanced e-services to support coordination and collaboration was also evident. The aim of the present paper is to explore further the needs for collaboration between different health care and home service units and professions, and to suggest organizational and IT-based solutions, based on a patient and process oriented perspective, focusing more on patient related processes than on organizational structures and processes. This focus involves:

- Arguments are grounded in the Understanding, holistically, the forces influencing how collaborative care processes should work;
- Identifying the need for new ways of communicating, and for mobile and immediate access to both medical and administrative information;
- Understanding the need for allocation and acceptance of different types of responsibility among the care givers;
- Suggesting changes in information support, which due to the nature of home care work has to be mobile and based on process-centered information models that support collaboration.

authors' previous research, i.e. on focus group meetings, interviews, questionnaires, observations and analysis of archive data conducted in the projects Intercare [5] SAMS [6, 7], MobiSams [8], VITA Nova [9] and VVP [10]. These studies focused on collaboration within and between organizations involving respondents with a long experience of health care or social care but varied experience regarding IT and IT use. The respondents were doctors and nurses from primary and specialist care, assistance assessors, IT strategists, managers, patients, relatives and representatives of patient organizations. More than 35 in-depth semi-structured interviews were conducted within the projects.

In the following we define how certain terms are used in this paper.

- ***Home health care*** involves:

  basic health care – provided by nurses or nurse auxiliaries, in Sweden the responsibility of municipalities, sometimes outsourced to the county councils' primary care units.

advanced health care – operated by the county councils, led by doctors and provided by multi-professional teams. This care often concerns severely ill children or patients in palliative care.

- ***Social care*** is personal care that involves help with the daily living activities (cleaning, shopping, feeding etc), and care that physically supports the patient (outdoor activities or personal hygiene). In Sweden this is the responsibility of the municipalities and may be provided by their own units, or by a contracted private company.
- ***Home care*** as used in the title of this paper denotes the combination of home health and social care.
- ***Patient care process*** is the sequence of activities carried out for the patient by health care or social care personnel and in which the patient and often his relatives/friends participate. The process can be seen as a project with the aim of producing better quality of life for the patient, while at the same time maintaining patient safety. Each activity in the project should contribute to create this value-based aim.

Collaborative home care

Two or more parties collaborate when they work together in order to achieve a common goal, i.e. perform a task that each one cannot cope with alone or at least not as well or to as low a cost. This implies that the mutual goal must be understood by all parties as well as the basic circumstances, demands and restrictions that the other party faces. Each party must be clear over how tasks are distributed and how ones own tasks contribute to the common goal. Thus, collaboration between organizations is a complex matter. Existing research has focused on a wide variety of aspects. In research concerning collaboration within health care, van Eyk and Baum [11] have studied what they name as interagency collaboration. Hudson [12] has studied joint commissioning across the primary health care-social care boundary in the UK. El-Ansari et al. [13] have focused on public health nurses' perspectives on collaborative partnerships in South Africa. El-Ansari et al. [14] investigated collaboration and partnership and the problems with measuring collaborative outcome. Lichtenstein et al. [15] have studied the effect status difference has on individual members in cross-functional teams. Mash et al. [16] have studied team learning in healthcare that sees the organisation as a living system in which information flows. Participation and the development of team work are key aspects. If managers of the health system wish to enhance organisational change, then their goal may need to shift from optimizing health care delivery in a mechanistic model to optimizing health care workers in a living system.

In the field of mobile work and information processing, Ammenwerth at al. [17] explore how mobile artifacts can be used for information processing in a hospital. Pascoe [18] describes how mobile artifacts increase the amount and speed of data being recorded in everyday work; Najjar et al. [19] describe how wearable computers might increase the performance of quality assurance inspectors. Guerlain et al. [20] describe personal information systems for roving industrial field operators, and Heath and Luff [21] examine the ways in which mobility is critical for collaborative work.

When several parties collaborate it may be difficult to formulate one single objective, since each organization has its own goals. It is, however, important that all involved are aware of the overall purpose of the activities concerning an individual patient and make sure that this is in accordance with their own and with the patient's goals. Cooperation needs to take place both at the top and at the middle management level and among the staff carrying out the care. These levels exist within all health and home service organizations.

Some problems and suggested solutions

There is not much research dealing with the problems of collaboration in home health care, their causes and effects. Apart from works by Winge et al. [3- 5], one example is Åhlfeldt [22] who, based on interviews with health care staff and patients, derive a set of information security related problems in connection with collaborative care. Most of these are related to administrative routines and policies, not to technology. Åhlfeldt and Söderström [23], discuss the need for coordination in collaborative home care. They call for a "coordinator" with an overall responsibility for the patient's care planning. On a more general level, one well-known problem as organizations grow concerns administrative specialization and integration [24]. Health care is also subject to medical specialization, which places special emphasis on the need to coordinate units and professions. Horizontal organizational coordination is, among other areas, addressed in attempts to improve the logistics of Swedish health care (for example national projects to improve accessibility and shorten waiting times), while vertical coordination is a common problem concerning for instance control and feedback systems of work environment, quality and economy. One problem in integrating vertical and horizontal levels can be found in relation to the optimal use of management systems (see for example [25]).

Laws and regulation

Non-existent or inconsistent regulation results in improper routines and policies for cooperation, in poor awareness among those involved and in inadequate compensation systems. This in turn causes inadequate collaboration.

Suggested solution: Revise and re-phrase laws and regulations so they facilitate and insist on real collaboration.

Management and coordination

If managers at different levels do not understand what is required or cannot explain the aim and reasons for collaboration - and clarify which specific collaborative actions that are required - the operational staff will probably be discouraged from performing such actions. Managers of the collaborating units must find ways to explain how the care process as a whole is intended to function and what requirements it imposes on collaboration in order to be both effective and efficient and produce good quality for the patient. If this care model is vague to managers it usually leads to a poor understanding of the way collaboration needs to work on the staff level.

Suggested solution: Managers need to clarify for themselves and others what the holistic organizational mission involves when it comes to collaborative home care; explain what is

required and why; give accurate directions; provide convincing explanations as to why certain coordination and collaboration activities are necessary and provide standards for how they should be conducted. The situation of the patient is the foundation for collaboration between health and social care. A shared plan for the patient process must be produced with the focus on safe and high quality care. The plan should enable a follow-up of the results of the care. In each individual case, the goals of the patient process need to be explicitly formulated and based on the needs of the patient, while the staff has to be trained to always consider the goals of the process.

One of the reasons for poor collaboration is that care staff is not aware of other care staffs' actions and plans. Then activities cannot be coordinated and resources cannot be optimally used. In some cases this may also increase the risks for the patient's safety.

Suggested solution: Information services have to be developed to inform all actors directly of what is relevant for them to know about the patient and the planned and performed activities. This solution needs the clarification of goals and roles. Based on a well functioning care plan, actions can be coordinated so that work distribution will become more optimal.

To bring about collaboration in care is demanding. Health and social care that does not consider requirements for collaboration leads to poor quality and bad utilization of resources.

Suggested solution: Requirements for collaboration and co-ordination must be taken into account during procurement of care services. This includes clear descriptions of services needed to support collaboration for all involved. To achieve this, health care procurement units have to be trained in line with the new care model and in collaborative work. New strategies for follow-up of care are needed, also concerning the process and effects of collaboration.

Concepts and terminology.

The ability to provide the right information when needed, presented in a way that is understandable to all actors, requires well-defined concepts. Unclear or ambiguous concepts lead to a lack of understanding of what information is needed amongst all actors throughout the whole care process. Ambiguously expressed concepts in medical records present risks for the patient. Information requirements cannot be expressed clearly, increasing the risk that information systems will not provide the information needed for coordination and collaboration. Different units and professions offer varying competencies, perform different tasks and see different aspects of the patient. Ambiguous concepts make communication less effective, which in turn obscures coordination and collaboration.

Suggested solution: The concepts have to be identified on the basis of the patient care process. Collaboration has to take place with the patient and his needs in focus and be described on the basis of models involving care and collaboration strategies. The care model needs to define how collaboration should be carried out. The distribution of responsibility must be clearly described. Concepts that are involved in the process should be defined in an information model, and all of this set in a relevant context. It is particularly vital to define concepts that are important for patient safety and for communication between various kinds of care units.

Lack of collaboration may be caused by a poor understanding of what it is that characterizes the collaborative care itself on behalf of the health and social care staff as well as the patient and next of kin. This aspect concerns the situation when it is not clear what the involved units actually should do and how they should take each other into account, e.g. a lack of understanding of the role and responsibility of a unit for "advanced home health care" in relation to hospitals and primary care. Also, the patient and his relatives may sometimes feel that he has been sent home and left abandoned.

Suggested solution: The strategy for collaborative care should be described and clarified on the basis of a common health care and home services process. The need for shared information should be identified and then defined in a common information model for future IT systems. This will clarify responsibility, facilitate planning and collaboration, improve patient safety, and make it possible to monitor the care across organizational borders. The clarification of the collaborative care concept must involve management levels and staff and involve ways to deal with old routines and habits that might be hard to change.

Motivation and inter-organizational team-work

Low motivation due to lack of clear goals and feedback, role ambiguity, fragmentation of tasks etc. on behalf of the operational staff may lead to less commitment to collaboration. Furthermore, care staff may have little knowledge of, or in some cases be less interested in what other units do with the patient. Such awareness is, however, important in order to develop effective and quality-oriented collaboration.

Suggested solution: A new and better reward system for cooperation is needed, allowing for economic compensation and allocating resources for collaboration. Responsibility has to be clearly distributed among actors so that everyone has a basic knowledge of who is doing what. IT services are needed that support the patient process, staff interaction and feed back processes. The staff can be motivated through participation in planning the individual patient process. Doing so they can understand how their own work contributes to better collaboration and fulfillment of patient needs. Organizational responsibility has to be clarified, also concerning managerial decisions. Political and strategic leaders need to realize this and provide means for collaboration. Representatives of care staff from each involved care unit should participate in constructing a joint care plan for individual patients. This will make them understand how other actors' activities contribute, in a coherent set of tasks, to the realization of patient goals. Information support for care staff will provide a better understanding of which actions that lead to particular goals. There is also a need for better coordination of the individual patient process per se. New e-services for care-planning can support this function, optimally a common responsibility of a virtual team. The e-services must include support for quick changes in the patient's care plan.

If goals for the patient process are not clearly formulated it is difficult to coherently provide activities from several care units. There will be no basic ground for adapting and understanding

information concerning what other units do in order to reach the goals of the patient process.

Suggested solution: Formulate a set of goals for each single patient process when new essential needs of the patient occur together with the patient and/or his relatives. State clearly each care provider's responsibility. A well developed IT-based care plan, including coordination support, is an instrument that all cooperating units can access. The organizational members' own responsibility to seek out this information should be clarified and supported from the organization.

Collaboration across organizational borders is a prerequisite for good teamwork among various professions and with the patient and his relatives or friends. Lack of collaboration easily leads to bad care quality, feelings of insecurity and actors being uninformed about the patient's condition. At worst, the patient's health may be at risk. Lack of collaboration and agreement on the management level about the requirements of collaboration may lead to procurement of care that does not take collaborative aspects into account. It may lead to bad utilization of resources, e.g. the same activity is repeated several times or in a less than optimal order.

Suggested solution: Train team members in reading documentation originating from other units (provided that security allows it) so different actors can see patterns and signs at an early stage. Provide an information support for this. This will achieve more timely actions in meeting new needs of the patient and a better anticipation of problems. Collaboration supported by good IT solutions will increase safety for the patient and make him less prone to take unnecessary contacts with the care team. It will also facilitate a good utilization of resources. Routines for measuring and following up provided care should be implemented on the basis of evidence based competency, i.e. ability to judge how care ought to have been conducted according to goals, or if one had realized early what was happening when something went wrong.

Summary

To summarize, improvements are needed among all involved parties, from the top and middle managers to operational staff. The suggested solutions are a mix of development of care and collaboration concepts as well as organizational measures and IT support, and most importantly, the establishment of a new strategy and a new care model for collaborative health and social care. This involves:

- the need for managers in the involved organizations to define and agree on goals, rules and routines for collaboration on all levels,
- the need to include requirements for collaboration already in the care procurement process,
- the recognition of the importance for coordination among care givers and care activities,
- the need for awareness of and clear goals for each individual patient process.
- the need to clarify how care results shall be described, what results to follow up, and how this should be done.

Thus, the presented solutions address and try to improve vertical and horizontal coordination within and between organizations.

How IT may contribute

Unclear or ambiguous concepts are a problem in the entire health care sector. Even the most central terms can be understood differently among different stakeholders. We believe that to a certain extent this is something to accept and learn to live with. In the context discussed in this paper it is, however, desirable at least to agree on terms and concepts that concern collaboration. The models, primarily information models, developed in the projects mentioned initially [5-9] are important contributions to this issue. These models are based on a process that describes important information exchanges around the patient, regardless of which organization that is responsible. The projects also resulted in explicit knowledge on how improved and patient-centered collaboration among care providers can be accomplished, mainly through an enhanced way of working and a utilization of IT support that facilitate collaboration. The new ways of working should be described in process and conceptual models, which also form the basis for building IT support.

The SAMS and MobiSams projects also had the intention of clarifying the patient process, i.e. how it functions today, how the patient experiences it, and how it would appear with the suggested new ways of working and the correct IT tools. The IT support developed in these projects comprises a set of well defined e-services built to support coordination and teamwork. The services presently available concern tools for:

1. Planning and coordinating all work tasks during the entire individual care process, including formulation of mutual goals and objectives for all involved organizations and professions with the best interest of the patient in focus.
2. Definining the planned activities for each unit, in accordance with the agreed goals.
3. Allocation of tasks and resources for the planned activities, assignment of personal responsibility for the goal achievement of each task and definition of a procedure that measure and relate results to goals.
4. Planning and registration of the result of the care activities.
5. Registration of undertaken care activities in such a way that goal fulfillment can be assessed.
6. Conducting follow up and evaluation of the care process from the individual's point of view.

The tools were built in close collaboration with health and social care staff and implemented in a common test-bed where they were tried out together with new ICT techniques, i.e. stationary as well as mobile and handheld devices. The test-bed was set up to facilitate learning while developing collaborative care as a virtual enterprise, including the ways of utilizing IT.

Conclusion

In this paper we have discussed the increasing number of patients treated in their homes by many care givers and the

complex demands this new situation places on communication and collaboration among health care and home service staff. We have further pointed to the need for communication and collaboration on different organizational levels. In particular we have highlighted the need for managers in separate organizations to agree on ways to communicate and collaborate on operational levels, and how the need for collaboration and coordination must be considered during procurement of home care services. Most importantly we have, by reasoning from a set of issues, suggested solutions for how to deal with these demands. The suggested solutions are a mix of organizational and administrative measures, and development of e-services for communication and coordination.

Finally, we would once again like to stress the need for a new collaborative care model for health and social care with the patient's interest in focus and IT-tools as an aid. This model requires managerial awareness and the development of clear goals, against which results focusing on patient needs can be assessed and followed up across organizations. Even so, the challenge of implementing these ideas and changing the involved organizations, processes, routines and key actors will have to be furthered addressed.

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Barriers and facilitators that affect public engagement with eHealth services

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Abstract

It is commonly accepted that public engagement with eHealth is beneficial. However, engagement is also variable. This article presents the findings of a review of published evaluation studies around eHealth services. A targeted search of MEDLINE, CINAHL and EMBASE returned 2622 unique abstracts. 50 articles met the inclusion criteria and were subjected to further analysis. 6 review articles were used for post hoc validation. Four main types of eHealth service or resource were identified: health information on the Internet; custom-built online health information; online support; and telehealth. 5 key themes emerged in terms of facilitators or barriers to engagement: characteristics of users; technological issues; characteristics of eHealth services; content issues; social aspects of use; and eHealth services in use. Recommendations arising from the review include: targeting efforts to engage those underserved by eHealth; maximizing exposure to eHealth across all sections of society; improving access to computers and the internet; appropriate design and delivery; ensuring content is relevant to different audiences; capitalizing on the interest in social computing; and clarifying the role of health workers in the delivery of eHealth.

Keywords:

Consumer health information, Informatics, Internet

Introduction

One commonly cited definition views eHealth as 'an emerging field in the intersection of medical informatics, public health and business, referring to health services and information delivered or enhanced through the Internet and related technologies. In a broader sense, the term characterizes not only a technical development, but also a state-of-mind, a way of thinking, an attitude, and a commitment for networked, global thinking, to improve health care locally, regionally, and worldwide by using information and communication technology' [1]. In common with this definition, other definitions also incorporate aspects of both health and technology. Health is generally represented as a process rather than an outcome, and technology is viewed as a means to augment, rather than replace, human activity. The tendency is towards optimism, with eHealth seen very much as an enabler [2]. It is a commonly held belief that public engagement with eHealth services is beneficial. The Internet facilitates widespread access to up-to-date health information [3, 4] and provides the means to obtain remote support [5, 6]. Telecare applications address an ongoing and increasing demand for care, resulting from an ageing population and a shortage of nurses and other health care workers [7]. However, public engagement with eHealth services remains variable [3]. This review of published literature seeks to formalize the reasons for this variability. This literature review forms part of a larger project 'Including everyone in electronic health information services'. The larger project, commissioned by the National Health service in England seeks to find out what help people need to use eHealth services. The aim of this review is to identify and explore factors (barriers and facilitators) that may influence engagement by the public with those services.

Method

Literature considered in this project included national and international academic and professional (i.e. non-academic) journal articles available from the three bibliographic databases, MEDLINE, CINAHL and EMBASE. The search strategy was developed in stages:

1) An initial targeted text search of MEDLINE (via OVID) using relatively obvious terms such as 'ehealth services', to find 'gold-standard' articles from which to harvest indexing terms i.e. Medical Subject Headings (MeSH) keywords.
2) Allocation of keywords, combined with OR, into three sets:
    a. Application e.g. Internet
    b. Service e.g. Consultation
    c. Evaluation e.g. Patient Satisfaction

    These keyword sets were combined with AND.
3) Fine-tuning of categorized keywords to ensure retrieval of (at least) all exemplar articles
4) Reworking of the strategy for use with CINAHL (via EBSCOhost) and EMBASE (via the National Library for Health, now NHS Evidence).

Searches were conducted in January 2009; they were not restricted by date. Each item (title, abstract, language and type)

from the initial search was reviewed independently by the two members of the project team (NRH, MJG). Items were selected according to the following criteria: an identified eHealth service; intended for use by members of the public; barriers or facilitating factors influencing use; readily and freely available online; and, published in English The following items were excluded: Commentary, book review, conference report, conference paper, conference abstract, editorial, opinion-based.

Review articles were not included in this review but were reserved for validation of the findings. Disagreements were resolved through face-to-face meetings. Agreed included items were obtained, allocated arbitrarily to the two team members and subjected to further analysis. A tailor-made data extraction tool, in the form of a table, was used to analyze articles into a number of categories, such as study design, findings, barriers and facilitators. Emergent themes that were common across different studies were identified via the completed data extraction tool and agreed at further face-to-face meeting.

Results and discussion

Four hundred and forty abstracts were returned via CINAHL, 1226 via EMBASE and 1153 via MEDLINE. After the removal of duplicates, 2622 items were considered in the initial review. Seventy articles were obtained for closer examination. Fifty of these were identified as meeting the inclusion criteria and were subjected to further analysis. The timeframe for included articles was 1999 to 2008. Six additional review articles, spanning 2001 to 2008 were reserved for post-analysis validation.

Type of eHealth service

The first set of themes to emerge from the analysis concerned the type of eHealth service featured in the articles. There were four main types:

1. Health information on the Internet (featured in 27 articles = 54%)
2. Custom-built online health information e.g. CDs, kiosks, portals (7 articles = 14%)
3. Online support e.g. coaching, mailing lists and online communities (12 articles = 24%)
4. Telehealth including remote consultation, monitoring and reporting (4 articles = 8%)

Little appears to have changed over the past several years in terms of types of eHealth service; in an early review of health information on the Internet, Cline and Haynes [3] characterized access to online health information in three ways: searching directly for information (corresponding in the current review with both 'Health information on the Internet' and 'Custom-built online health information'), participating in support groups (corresponding with 'Online support') and consulting with health professionals (corresponding with 'Telehealth').

Barriers and facilitators to use

The second set of themes to emerge from this review concerned barriers and facilitators. One hundred unique themes emerged. These were distilled into twenty seven higher-level themes, from which 5 overarching themes emerged:

1. Characteristics of users
    - Age [8, 9]
    - Educational attainment [9-13]
    - Ethnicity [10, 13, 14]
    - Health status [15-17]
    - Information needs [18]
    - Literacy levels [17, 19-21]
    - Motivation [11, 12, 17, 22-24]
    - Skills and knowledge [16, 25-29]
    - Socio-economic status [10, 11, 13, 26, 29, 30]
    - Trust [9, 17, 31-35]
2. Technological aspects
    - Access to resource [23, 26, 27, 29, 36, 37]
    - Operational issues [28, 38, 39]
    - Security and privacy [36]
    - Technological Issues [18, 40]
3. Characteristics of eHealth services
    - Access to information [32]
    - Content issues [9, 19, 27, 41-45]
    - Physical distance [22, 25, 31, 38, 46-48]
4. Social aspects of use
    - Belonging [31, 38, 46, 49]
    - Interpersonal issues [38, 49]
    - Reassurance [49-51]
    - Shared experience [33, 52]
    - Shared responsibility [39, 49]
    - Social contact [31, 47]
5. eHealth services in use
    - Empowerment [17]
    - Fit with everyday life [18, 23, 25, 26, 53]
    - People as enablers [25, 51, 54]
    - Usability and usefulness [16, 18, 22, 24, 27, 33, 55]

Characteristics of users

The findings suggest that both increasing age and low socio-economic status might be negatively associated with perceptions and use of eHealth services. Non-white ethnicity also appears to be a potential barrier. A literature review by Fogel et al. [4] on online cancer support groups found that African Americans were under-represented. There appear to be higher levels of eHealth service use among people describing themselves as white and among people of higher socio-economic status. Higher levels of educational attainment and literacy appear to be associated with increased awareness and use of eHealth services. Lack of motivation, interest and engagement, both in health in general and in eHealth, appear to be barriers to use. A lack of knowledge and skills around computer or Internet use appears to be barriers to the uptake of eHealth services, as confirmed by Cline and Haynes [3]. However, exposure to these services appears to improve both the perceptions of non-users and the frequency of use. Both health status and information needs play a less predictable role in engagement. For example, poor health status provides an impetus for individuals to seek information. However, poor health status may in itself inhibit an individual's ability and motivation to seek this type of support. Trust also appears to influence users' perceptions of eHealth services - opinion towards 'scientific' sources and researchers appears to be mixed - although it doesn't necessarily affect patterns of use. Trust

was identified as a significant issue also in the literature review by Fogel et al. [4]

Technological issues

Unsurprisingly, lack of access and poor access to computers and/or the Internet are significant barriers to engagement. Simply put, those with better access (particularly at home) are more likely to engage. Cline and Haynes [3] also recognized that access is inequitable. However, having good access does not guarantee use. Perceptions of users are also dependant on operational aspects of the service along with how it handles data security and privacy, as supported by a recent literature review by Botsis and Hartvigsen on telecare for older people [7]. Interestingly, security and privacy concerns did not feature significantly in many of the articles included in the current review.

Characteristics of eHealth services

As might be expected, and as supported by Cline and Haynes [3] the content of eHealth services is an important contributing factor to engagement. Important characteristics include: quantity, relevance (including cultural relevance), comprehensibility (both technical and linguistic), reliability and impartiality, navigability, flexibility and tailoring of content. Cultural relevance was also identified as important by Fogel in a literature review on ethnicity and literacy levels and Internet use for cancer information [6].

Social aspects of use

A decreased sense of isolation is seen by many as an important benefit of eHealth services, along with autonomy and an increased sense of control. Anonymity is also valued, although the impersonal nature of online communication might in some circumstances act as a barrier. Cline and Haynes [3] also acknowledged both a 'shifting balance of informational power' and the potential benefits of anonymity. People are often seen as important adjuncts to certain eHealth services: as gatekeepers, as enablers, as trainers and as coaches. A literature review conducted by McMullan [56] on the impact of Internet use on the patient-health professional relationship suggests three ways in which health professionals may respond to their patients as active consumers of health information: 1) re-assert their role as expert, 2) collaborate in obtaining and analyzing information, 3) guide patients to reliable resources. There appears to still be a place for direct face-to-face communication. To support this, Botsis and Hartvigsen [7] found that 'patients and nurses foresee the need for real nurse home visits along with telemedicine ones'. Social computing (e.g. online discussion and support groups) is generally seen in a positive light, providing a 'safe', flexible and personal environment in which to share experiences and responsibility, foster a sense of belonging, offer empathy and support, and gain reassurance. The review by McMullan makes a similar observation [56]. Active engagement appears to reap the most benefits.

eHealth services in use

Issues affecting engagement with eHealth services arise from their implementation and use. An obvious barrier concerns ease of use. An equally obvious barrier is lack of fit with everyday life, in terms of time, cost and technical or psychological factors e.g. unfamiliarity with the resource. A lack of perceived usefulness or relevance is a significant barrier to engagement with eHealth services. Certain potential users of eHealth services believe that information will make little impact on the status quo and may actually be a burden. Other users find eHealth services empowering, reassuring and supportive.

Conclusion

There are a number of recommendations in light of the findings of this review:

- Capitalize on the continued public interest in social computing and allow users of those services to reap the benefits of online community engagement
- Clarify the role of health workers in the delivery of eHealth services e.g. endorsement, facilitation, etc.
- Continue to focus on the appropriate design and delivery of eHealth services in terms of ease of use and fit with everyday life i.e. time and cost
- Attempts to maximize exposure to eHealth services across all sections of society, in order to increase familiarity and improve perceptions of usefulness and relevance, thereby maximizing potential use
- Make efforts to ensure that the content of eHealth services meets the needs of their target audience. Content should be understandable, relevant and trustworthy to a wide variety of potential users
- Make targeted efforts to engage those who are underserved by eHealth services due to age, ethnicity, educational attainment and socioeconomic status
- Maximizing exposure to eHealth services includes improved access to computers and the Internet

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Barriers of Obtaining Health Information Among Diabetes Patients

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Abstract

While healthcare information plays an essential role in the process of disease management, previous studies have shown that many patients may be unaware of the availability of certain healthcare information, thus leading to the progression of their diseases and deterioration of their health. This study explores the information seeking behaviors among patients with type-2 diabetes and explores the barriers that hinder effective healthcare information usages. 19 semi-structured interviews were carried out with patients and caregivers in various stages of diabetes disease management. Data analysis identified five major barriers for seeking health information: lack of motivation, passiveness, inconsistency of information, generality of information and loss of information. These findings call for the designing of active and personalized information delivery mechanisms.

Keywords:

Information management, Medical records, Access to information, Long-term care.

Introduction

The goal of achieving quality healthcare is a collaborative endeavor that requires input from both healthcare providers and patients [1]. Health information can educate patients to engage in decision-makings processes, understand their own health and actively manage their diseases. Yet, most healthcare information systems are designed primarily for physicians and other healthcare professionals [2]. Recent consumer health informatics initiatives advocate the role of patients in the process of obtaining and managing their own health information [3, 4], yet little is known about what support patient information needs [5].

Studies have found that many patients do not have adequate knowledge about their own diseases [6]. A study found that even for a common disease like diabetes, more than 50% of patients were unaware of potentially serious complications [6]. This raises the interesting question of why patients are not obtaining the vast amount of health information available to them.

Previous studies have looked into the topic of health information management and health information seeking behaviors among patients [7, 8, 9]. However, the focuses of these are mainly on information regarding homecare, such as glucose readings, magazine articles or patients' insurance information**.** Information about patients' encounters in healthcare settings is seldom considered as part of the health information seeking and management process. As various healthcare providers typically operate as separate "silos" without including patients in the healthcare process [10], seeking and obtaining one's own medical records should also be part of the health information seeking process.

In this study, we adopted a boarder view towards personal health information so as to include both the information gathered by patients, e.g. magazine articles, homecare diaries and information produced in healthcare settings, e.g. lab results, diagnoses and other clinical documentations. Since homecare information is produced by patients at home, there was no need to intentionally seek out it any more. Therefore, the scope of information seeking in this study focuses on Medicare information and external educational materials. We chose to study information seeking behaviors among type-2 diabetes patients. There are two reasons for this choice. First, for diabetics, obtaining health information and staying informed is crucial for maintaining self-care, where not only glucose levels, but also diet and exercise have to be controlled by patients themselves. Second, as a common disease, information about diabetes is readily available for patients. This eliminates the possibility of not having enough resources to look for health information. By limiting this study to one disease we avoid the influences of individual disease characteristics in the information seeking process. Due to the space limit, this paper we only introduce the findings regarding health information seeking behaviors and the implications of them for health information system design. The information management behaviors will be presented in our future work later on.

Methodology

We conducted 19 semi-structured interviews with patients with type-2 diabetes and their caregivers, such as family members or friends between June and September 2009. IRB approval was obtained from the university before the research work started. All the participants were recruited at an outpatient clinic located in southern California. One author was stationed in the patients' waiting room during the regular clinic hours and inquired patients if they were willing to participate in our study. We also left flyers in the front desk of the clinic with the researchers' contact information. Each participant was compensated with 40 dollars for their time.

As mentioned in the introduction, for this study we adopted a broader view towards personal health information where both health information generated in healthcare settings and gathered by patients at home are considered personal health information. Interviews often started by asking for the patients' own journeys about their diseases, followed by a series of questions regarding health information needs, information seeking and diabetic management behaviors. Table 1 lists the main categories of the interview questions. Each category of questions was probed further according to patients' responses.

Table 1 – Interview protocol of the study

Interview Questions:
Where do you obtain diabetes related information?
Do you think there's enough health information available?
What are the challenges for you to search for health information?
Do you request of copy of your medical records after medical visits?
What technologies and tools are you using in managing health information and diseases?
Other behaviors about dietary and exercises?

The interviews lasted approximately 60-minutes in length and were audio-recorded for further data analysis. All the interviews were conducted at the patients' homes – presumably an environment where they naturally keep their health information and engage in disease management activities. Since the interviews were conducted at patients' homes, occasionally family members would join the conversation or provide information upon participants' requests. Unless caregivers were interviewed separately as an interviewee, we counted the spondaic discussion with family members as one interview. Digital photos were taken (either during or after the interview) as tools and materials related to disease management, capturing the context and location of the artifacts.

Constant comparative method [11] was used in the study to extract different themes from the interview data. This method allowed the authors to use an iterative open coding strategy to summarize main themes from the data. The authors coded the text to break down, compare, and categorize the data into initial categories, and then further developed these categories into themes.

Results

We interviewed patients in different disease stages, from the recently diagnosed to those who suffer from multiple complications. The number of years the patients had been living with diabetes ranged from 3 to 39. Echoed with what we speculated in the earlier section, most participants believed that health information is radically available for them and that there is generally no difficulty obtaining such information on their own. However, purposely seeking that information seemed rare among the patients. In this section, we describe general information seeking behaviors, and introduce the barriers to information seeking that are identified in our analysis. We will then discuss the implications for designing systems to overcome these barriers. The findings presented in this section are generalized from major participants and represent the common concerns across all the patients we spoke with. Therefore, these findings indicate behaviors and challenges that can be generalized to the broader population of diabetes patients, and perhaps even to other chronic diseases sufferers.

In general, the diabetes patients were satisfied with the amount of health information available to them. No one in the study mentioned any difficulty seeking information on diabetes. 17 out of the 19 participants believed it was fairly easy to obtain health information. In addition, many patients believed they encountered more diabetes related information in their daily lives than in the recent past 5 years. This showed that at least for diabetes, a lack of available health information no longer hinders how patients seek and obtain health information. Healthcare providers are the major information sources for most patients, where they either pick up brochures in the waiting room or receive health information from providers. Other than healthcare providers, social networks are another important information source as a few patients claimed that they obtained information by "*play by ear*". About half of the patients search for health information on the Internet.

Although almost all commented that there is enough health information available for them, many patients admitted that they didn't engage in information seeking and disease management activities. Our analysis identified 5 barriers to understand the breakdowns in the information seeking process.

Motivation Fade Overtime

Interviews indicated that patients' health information needs are maintained largely on a "need to know basis", meaning they seldom look for health information to educate themselves unless they have been diagnosed with new complications – at which time it is impossible to revert to their previous health status. Most patients started collecting health information when they were first diagnosed with diabetes but discontinued the learning efforts shortly after they had a basic understanding about the disease.

> *Ah, well, ah, I think that it was since they told me I had diabetes. Both of my parents are diabetic. I saw them taking pill after pill. I don't want to see myself like that. At the beginning, I did the medications. You know. I did what I had to do. But now, I'm tired. I'll do it tomorrow. I'm at the point where I don't care much about anything.* (U05- line 118)

> *When I was first diagnosed because I want to know exactly what it is and how it affects me.* (U19-line47)

During the motivated information seeking stage, patients actively searched for health information in order to understand what diabetes was and how to manage it in general. Patients' motivation to seek healthcare information gradually faded overtime; many mentioned that they stopped reading and looking for new information after a couple of months.

However, the course of diabetes changes overtime. The health information patients obtain at the early stage of their disease may not be sufficient for the later stages of disease management.

This lack of motivation for health information seeking is partially a result of the misconception that diabetes is a stable illness and that there is no need to continue to learn more. Patients tend to believe that what they have learned should be sufficient for their disease management once they have a pretty good knowledge about diabetes. Lack of motivation also comes from the extremely long disease management process of an illness like diabetes. It is well known that there is no cure for diabetes, and once diagnosed, patients will have to deal with it for their entire lives. It is easy to feel motivated to learn to manage the disease, but it is challenging to continue to engage in information seeking activities. This explains why the patient's feeling of tired and not caring it anymore.

Passively Seeking Information

Many patients use "*accidentally*" to describe the way in which they seek health information. "Accidentally" means they seldom initiate the information seeking process, but pick up sporadic health information that they happen to see or hear. Most patients commented that other than their physicians, they accidentally read a few articles in medical journals placed in patient waiting rooms, or that they happened to get a few flyers about diabetes in the mail or read about it in the newspaper. "*Play by ear*" was also quoted by many patients indicating that the information picked up among their social network was a major source for them to learn diabetes management.

> *[I] Usually get our stuff from the clinic, like the pamphlets lying around. (*U04-line 52*)*

> *Ah, [information seeking is] not too complicated. It depends. You have to talk with your doctor. It depends if you have a good doctor at the time. (*U12-line152*)*

This passiveness reflects on the information sources where the patients obtain the healthcare information. Patients pick up information that happens to be available to them; *Accidentally*, *play by ear* or picking up things *lying around* all indicate the passive nature of patients' information seeking behaviors. They seldom initiate active information searching on their own but passively wait for information that happens to "be there". This passiveness indicates that patients may not obtain a comprehensive understanding about diabetes since they only receive information piece- by-piece from different sources.

Inconsistency of Information

Even though no one in the study thought obtaining information about diabetes was a difficult task, 6 out the 19 patients commented that occasionally the information they saw was conflicting. New information may conflict with what was learned from their providers, articles they read or their own experiences as patients.

> *I'm not real happy about a lot of the diabetic stuff that is out there. The diets and different things that they tell you have things like high fructose corn syrup in them and different things. I'm reading the ingredients and going, "ewhhhh," I would never put that in my body. Even on a regular basis I wouldn't do those things. There are a lot of things out there that I don't agree with at all. (*U08-line 110*)*

This quote shows that even for the small number of patients who are willing to actively seek health information, conflicting information discourages them from continuing seeking it since they don't know whether they can trust the information given to them or which information they should they trust. The quality of health information, therefore, hinders the way patients approach healthcare information and sometimes leads them to turn away from engaging in the active information seeking process.

Generality of Information

"Too general" is another term that was repetitively used by patients during the interviews. When being inquired about how they use healthcare information they picked up, most patients replied that they seldom read or use it. Although information about diabetes is available almost everywhere, it was often too general and only covered things they had already known for years.

> *Most of it I would say is irrelevant to my situation. All of them say don't eat a lot of sugar. You don't have to tell me that. (*U03-Line 73*)*

> *Ah, most of the information we get, we are already aware of at this time. So it's just like a reminder for me…. It's pretty clear and, ah, easy to remember because time and time again it's the same. (*U10-line 89*)*

The flyers and brochures patients collect in waiting rooms usually target newly diagnosed patients, with a hope to educate them about what diabetes is and common complications. However, most of the patients in our study had already gone through the initial learning stage of their illness and often found this information useless for their situation. As shown in the quotes, patients already know not to consume a lot of sugar and already know basic information about the illness and the importance of keeping their glucose in the normal ranges. The heath concerns that bother them currently are more specific, regarding complications they have or questions they have regarding the balance of medications among the multiple diseases they have. None of these issues can be found in brochures in patient waiting rooms or in their social networks.

Loss of Information

One question we explored in the study is whether or not diabetes patients seek the health information generated during their medical visits, *e.g.* information in medical records. 11 out of the 19 patients claimed that they keep a copy of their records at home, indicating a high awareness of owning medical records. However, further probing of this issue found that patients usually only have copies of their lab results rather than their entire medical records. Information such as written diagnoses, prescriptions and clinical notes are almost never pursued by patients at all. Nevertheless, when asked if they were willing to have a copy of their entire medical records, most patients said yes without hesitation. For them, keeping

medical records is way to track the process of their diseases and be more aware of their own health issues.

> *Yes. I would like to know [information in the medical records], uh, to see what it was like. What is was like a year ago. Say, six months ago it was like this and then this happened or this is different. I guess it is just like to compare for myself how is my diabetes going (*U05-line 35*).*

It takes time and effort for patients to request the information that is produced during medical visits and patients often feel frustrated when they don't have control over the information in their records. None of the participants in our study have their entire records with them. Yet, the information in medical records plays an essential role in coordinating patients' healthcare among different providers.

> *I'm a contractor. I move around from state to state so I have to get a new doctor in a new state… They all want to start me over again at 10 units… I usually lose it [medical records]…I always feel unfortunate that they don't have a database that the doctors could feed it in, the web or something (*U03-Line 17*).*

As indicated in the above quote, information loss in transiting from different healthcare settings or from healthcare setting to patients' home may cause serious interruptions in the healthcare process. Some patients mentioned that they don't remember what doctors told them during the medical consolation. During consultation, some patients take notes about what they have been told, more just rely on their memories - a way that is presumably error-prone and easily leads to loss of information.

Discussion

The 5 barriers indentified in our study can be divided within the following categories: 1). passiveness and lack of motivation of the patients 2). non-specific, inconsistent health information and 3). loss of information produced in healthcare settings. In this section, we discuss the implications for designing future healthcare information tools to overcome these barriers.

Designing active information delivery system

Our study found that patients' motivation for seeking health information fades shortly after they obtained a basic understanding of their diseases. Yet, patients are not resistant to the healthcare information that is available to them despite seldom actively searching for it. This information seeking behaviors indicates that the design of health information portal should actively fill in sufficient health information to patients, especially at the very beginning of disease onset stage and then persistently motivate patients with new information. Doing so allow patients to obtain health information effortlessly. The health information sent to patients should be done on a long-term basis to keep them aware of the health risks throughout the course of their disease.

It is notable that online healthcare portal shows great potential in delivering health information actively to patients. A few of the Internet users mentioned that after subscribing to various online diabetes websites, they constantly receive health information. One patient told us: *I get a lot of things on there. I have to screen them quite a bit* (U18-line 39). However, the conveniences of the regular online information delivery are discounted when information are not specific to patients' individual needs. They may also overwhelmed by the amount of information sent to them and choose to ignore it completely.

Designing tailored information delivery system

We also identified factors in the sources of healthcare information that discourage patients from engaging in effective information seeking activities. Patient often encounter repetitive information that is too general for their own health, or they don't know which information they should trust since various information sources conflict with each other. These findings suggest health information should be tailored to fit with patient's personal needs. Personalization holds great promise to transform healthcare from "standard care" to "personalized care."

Compared with generic information, information that addresses individual needs is more likely to be read and have an effect on health behaviors [12, 13]. A survey [14] on available tailoring mechanisms in healthcare found that most tailoring criteria used in previous studies are based only on one health behavior and possible stages of change such as nutrition, exercise and in this study, information about type-2 diabetes. However, what we found has proven that even this level of personalization is still considered generic information. Patients require more specific health information to address information that they do not yet know, such as how to care for certain complications, how to deal with the interplay of multiple chronic cares and new solutions for self-care. Tailored information has to fit with the patients' deepest concerns as well as provide new and trusted information that they have not encountered before. Health information personalization is one goal of future personalized medicine [15].

Integrating medical records with information delivery

Patients in our study seldom seek for health information documented in their medical records and leave this valuable information with providers. This behavior has caused information loss in the transition from hospital visits to self-care at home. Patients do, however, wish to compare their health issues in different time spans or transmit this information among caregivers. Integrating two sources of information will give patients a continued and complete view of their healthcare and keep them informed about their health issues. In addition to this, since most patients have expressed the desire to obtain specific information regarding their recent discomforts or symptoms, a system that matches outside health information with information on patients' medical records would allow patients to receive personalized information particular to the issues they are concerned about in a timely manner. Accordingly, the integrated information delivery would motivate patients in searching for more health related information and engage in disease management process.

Conclusion

This study explores health information seeking behaviors among type-2 diabetes patients and identifies the barriers that

prevent these patients from obtaining the healthcare information that is crucial for their disease management. These barriers fit under the categories of 1). passiveness and lack of motivation on the patients' side, 2). non-specific, inconsistent information available to patients and 3). loss of information produced in healthcare settings. An active and personalized information delivery portal that filters information based on individual needs and initiates information delivery should be able to overcome these barriers. Even though this current study targets diabetes patients, these findings may also be borrowed to direct healthcare information among patients suffering from other chronic diseases. This study is only the first step in an on-going project aimed to understanding patients' healthcare information seeking and management behaviors in the hopes of designing better information delivery systems in the future.

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Pathways Home: Comparing Voluntary IT and Non-IT Users Participating in a Mentored Self-Management Project

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Abstract

This research paper examines the challenges in the development and adoption of an electronic patient diary within the Pathways Home for Respiratory Illness Project. This project supported community-based patients suffering from chronic obstructive pulmonary disease (COPD) to achieve increased levels of self-management and self-efficacy using electronic-monitoring techniques and mentoring by community health nurses. Participants had the option of voluntarily adopting an electronic patient diary to support their self-monitoring, which provided patients, nurses and clinicians with access to symptom and psycho-social data. This aimed to improve the identification, comprehension and initiation of early action in relation to alterations in their conditions. The paper presents data on technology adoption, electronic diary usage and, self-reported data quality, as well as examining the impact of the technology on hospitalisations (frequency and duration). The participants who chose to use the online patient diary continued their involvement with the project for the entire trial period (85% vs 54% completion). Participants were more likely to maintain use of the online patient diary than the paper diary. Both the groups experienced a positive improvement in their self-efficacy to self-manage their condition scores. The data highlight the problems implicit in some of the assumptions underpinning existing information systems models, especially in evaluating impact and the end-points presumed to be relevant in systems development life cycles.

Keywords:

Chronic disease, Self-management, Information technology, Symptom monitoring, Self-efficacy, Technology adoption, Electronic diary.

Introduction

Chronic obstructive pulmonary disease (COPD) is the fifth leading cause of death worldwide [1] and is the third leading cause of 'burden of disease' in Australia [2] with sufferers experiencing multiple co-morbidities [3]. Individuals experience escalating psychosocial changes and functional problems as the disease progresses [4]. These include difficulties with home management, restrictions on recreational activities, loss of independence and feelings of social and emotional isolation [5]. Additionally, people with COPD often have poor quality of life [4,6,7] and low self-efficacy for managing life with COPD, including symptom management [8]. COPD is more prevalent among men in lower socio-economic groups. However, reflecting the increased popularity of smoking by women in the second half of the 20th century, the rates of COPD for women are rising. It is anticipated that over the next 20 years death rates from COPD in women will overtake those in men [9,10,11].

Evidence exists to indicate that the quality of life of people with COPD can be improved and that morbidity and mortality levels can be reduced through a range of interventions including patient education, pulmonary rehabilitation, self-management of exacerbations [10] and a patient-centred approach to care provision [12,13]. These integrated chronic disease management approaches are increasingly focusing on improving methods for engaging and supporting the direct involvement of patients in their own care.

The Pathways Home for Respiratory Illness project is a collaborative project involving researchers from the University of Tasmania's Schools of Medicine, Nursing and Midwifery, and Computing & Information Systems. This project aimed to assist patients with COPD to develop self-management skills, mediated through increased self-efficacy for patient-identified health behaviours (Note: reference to 'self-efficacy' should be taken to mean 'self-efficacy to undertake self-management'). Self-efficacy is a core construct identified in Social Cognitive Theory [14]. This project was also informed by the Trans-theoretical Model of Change [15] through the awareness that individuals may vary over time in their motivation to enact behaviour change.

Bandura defines self-efficacy as: "people's beliefs about their capabilities to produce designated levels of performance that exercise influence over events that affect their lives. Self-efficacy beliefs determine how people feel, think, motivate themselves and behave. Such beliefs produce these diverse effects through four major processes. They include cognitive,

motivational, affective and selection processes" [16:*71*]. Thus, self-efficacy is the belief that one has the capabilities to undertake and complete a course of actions that are necessary to manage a given situation. Self-efficacy, is theorised to be an important predictor of whether one attempts the behaviour [17,18] and has been successfully tested within the domain of chronic disease self-management most notably by Lorig et al., [19] where positive improvements in health outcomes have been demonstrated through supporting self-efficacy.

Methods

Participants in the project were recruited while hospitalised with an acute exacerbation of COPD. They were then randomised into control or intervention groups according to the location of their residence with areas balanced for socio-economic and rurality factors. The quasi-randomisation was by domicile as community health nurses (CHN) performing mentoring were only located in certain areas. Participation was for a period of twelve months, with clinical and quality of life measures being recorded by a research nurse quarterly.

Upon discharge from hospital those participants allocated into the intervention group were linked with a CHN mentor who maintained regular telephone contact and monitored progress over a period of one year. Monitoring and responding to symptoms, a key self-management behaviour [20], occurred primarily via participants keeping a daily diary of their symptoms and any changes in them. The symptom monitoring diary was available to the participants in either paper or electronic format, with voluntary adoption of the electronic diary discussed with participants after an initial six weeks in the project. Participants were assisted with interpretation and understanding of changes in their symptoms by the CHN mentors. It was anticipated this would lead to more rapid and targeted changes in treatment. Mentoring was carried out primarily via the telephone, with electronic diary information made available to mentors via a secure internet site. The role of the mentor has been reported in a previous publication [21]. The inclusion criteria for participants were:

- Age over 45 years;
- Living in the catchment area –(Southern Tasmania);
- Diagnosis of COPD (based on COPDX Australia & New Zealand guidelines incl. use of spirometry [www.copdx.org.au];
- At least one exacerbation of COPD in the last 12 months;
- Passes a cognitive assessment with a mini-mental state examination score >21;
- Able to provide informed consent;
- Has telephone;
- No diagnosis of other active lung disease; and
- Not undergoing palliative care.

The project was approved by the Tasmania Health and Medical Human Research Ethics Committee (H8370).

During the initial stages of the project, information systems researchers utilised the project team's knowledge of COPD to make preliminary technology design decisions. Following ethics approval, a detailed understanding of the potential range of technological experience and expertise of participants was acquired through direct interactions with them. As recruitment progressed it became evident that participants would not utilise the full range of technology options that had originally been considered. All participants with COPD stated at recruitment interviews that they did not use the telephone for banking or similar purposes and they disliked IVR (interactive voice response) systems. Short Message Service (SMS) was also considered but the majority of the COPD participants had limited experience with mobile phones and/or had impaired eyesight and/or dexterity. These factors led to the decision that the only monitoring options would be paper and web-based patient diaries.

It was also considered preferable that the introduction of any IT tool should be phased. Thus participants were commenced with paper-based monitoring systems and migrated to the IT system if and when voluntarily requested. Migration to the IT based diary was implemented by information systems researchers in the team and facilitated by the CHN mentors and other research team members. Each participant's prior experience with computers was evaluated at an initial home visit by the IS team, when the online patient diary was demonstrated and their interest gauged. For each participant, training was provided in participant's homes, commencing with a basic demonstration and explanation, followed by lessons in turning the computer on and off and progressing to using the mouse. Due to the disease process, associated co-morbidities, ageing and underlying educational levels, participant education issues can be pronounced in the COPD population [22]. This was a major challenge for many of the participants and they were encouraged to use the mouse to play electronic card games to improve their confidence and dexterity. All participants were followed up with a telephone call the day after the computer installation to see how they were progressing and to organise a follow-up visit. At the initial visit the home environment was also assessed and the most appropriate location for the computer was discussed with the participants. At the second visit the participants were then taught how to connect to the internet via the dial-up connection and introduced to the project website. Use of the online patient diary and the longitudinal feedback were also demonstrated. A full computer screen-by-screen user manual was provided for the participants to follow when undertaking diary entry. Desktop shortcuts were provided to simplify the processes for the participants. Activities were monitored online by the IS team and further training or support provided as required or requested by telephone or home visit.

Results

A total of 106 participants were enrolled in the project, 51 in the control and 55 in the intervention group. The two groups were well matched and there were no significant differences between groups for baseline demographics, with the exception of gender, there being a greater proportion of females in the intervention group ($p=0.31$ by Chi-squared test). There was a

high attrition rate in both groups with only 68 participants completing the full 12 months, see Table 1.

Table 1- Control and Intervention Groups by Sex and Age

		Control Group			Intervention Group		
	Sex	**M**	**F**	**All**	**M**	**F**	**All**
Enrolment	**Number**	27	24	51	18	37	55
	Mean Age	71.1	68.0	69.7	70.2	64.6	66.5
Completion	**Number**	14	18	32	10	26	36
	Mean Age	70.6	67.2	68.8	71.6	64.3	66.6

In the intervention group, only 20 participants (36%) chose to use the online patient diary. A much larger proportion of those choosing to use online patient diary were female (80%), this was evident even though females predominated in this group. The mean age of those choosing to use the online patient diary in both the male and female groups was lower than those choosing not to use the online patient diary, see Table 2. In the IT Users group all those who did not complete the 12 months participation died prior to completion. In contrast only 27% of the Non-IT Users group died, the remaining (73%) withdrew prior to completion. Possible reasons for this difference are discussed below.

Table 2- IT Users and Non-IT Users by Sex and Age

		IT Users			Non-IT Users		
		M	**F**	**All**	**M**	**F**	**All**
	Number	4	16	20	14	21	35
Enrolment	**Mean Age**	67.8	59.9	61.5	70.9	68.4	68.8
	Number	3	14	17	8	11	19
Completion	**Mean Age**	65.7	61.1	60.2	66.3	66.7	68.0

The symptom monitoring diary was provided to all participants in the intervention group. The intention of the intervention was that the diary would be completed daily. The actual diary use was much lower than anticipated, with a total of 11,477 diary entries being received over the duration of the project from a possible 24,820 entries. As is evident from table 3 the diary usage was unpredictable. Although it is evident (Table 3) that the IT Users group displays a higher mean usage than the Non-IT Users group. Although these data are difficult to interpret due to the fact that people commenced the trial at different times over a two-year period and many of those who commenced did not complete their full twelve-month participation period. Further analysis may be conducted to calculate the number of days the diary was completed for those using paper or web-based entry and to express this as a proportion of the total number of days participants were active in the project. These will then be compared using Chi-squared.

Table 3- Total Symptom Monitoring Diary Usage

	Mean	**Range**	**Total**
IT Users	260.3	59-380	5,206
Non-IT Users	178.7	0-372	6,255

However, the differences between the groups becomes less marked when the analysis is limited to the diaries of those participants completing their 12 months participation (Table 4). The mean usage for the IT Users group equates to approximately 15 more entries than the Non-IT Users group.

Table 4- Completers Symptom Monitoring Diary Usage

	Mean	**Range**	**Total**
IT Users	285.2	83-380	4,849
Non-IT Users	269.9	49-372	5,128

A qualitative examination of the diary entries demonstrated little evidence of differences in the quality of entries between the IT and non-IT users. The hospital utilisation raw data reveals that the IT Users group had more admissions to hospital (Table 5). However, the average length of stay for the IT Users group was 1 day less than the Non-IT Users group.

Table 5- Hospital Utilisation Excluding Initial Admission

	Total days	**Mean length of stay**	**Admission Number**
IT Users	128.5	5.1	25
Non-IT Users	83.1	6.4	13
Total	211.6	5.8	38

Both groups demonstrated increase in mean mini-mental state examination over the period of the project. Essentially the mean MMSE scores were within the normal ranges: scores of 27 and above are considered normal; scores of between 23 and 26 indicate a borderline condition; and scores of 22 and below are abnormal. The minor increases in MMSE scores from enrolment to completion may be due to an initial adverse effect of the participants' exacerbation of their condition and subsequent hospitalization (Table 6). They may also reflect some variability within the measurements themselves.

Table 6- Mini-Mental State Examination Scores

	Enrolment			Completion		
Group	**Mean**	**SD**	**Range**	**Mean**	**SD**	**Range**
IT Users	27.2	1.7	23-29	28.4	1.7	25-30
Non-IT Users	27.1	2.5	22-30	28.0	1.7	24-30

The Stanford Self-efficacy for Managing Chronic Disease 6-Item (Stanford Self-efficacy) Scale is a validated measure of self-efficacy for self-management in people with chronic disease. As the Pathways Home for Respiratory Illness project was aimed at improving participants' self-efficacy for self-management this was a primary outcome measure. A calculated mean of the six items scored is the final Stanford self-efficacy score. Both groups demonstrated an increase in the mean and minimum Stanford self-efficacy scores (Table 7). However, the Non-IT Users group demonstrated a slightly greater increase than the IT Users group.

Table 7- Stanford Self-efficacy Scores

	Enrolment		Completion		Effect Size
Group	**Mean**	**SD**	**Mean**	**SD**	**Cohen's d**
IT Users	5.5	2.5	6.4	1.6	0.36
Non-IT Users	5.5	2.3	6.7	1.8	0.52

Discussion

This study has undertaken a preliminary comparison of the results from IT Users and Non-IT Users within the total intervention group of a clinical trial. The paper has considered outcomes that differentiate these two groups of users. These data will contribute to a forthcoming more comprehensive statistical analysis of the clinical trial and the quantitative impact of the online patient diary within the trial intervention. However, these preliminary results could be interpreted to provide evidence that the use of the online patient diary could be inhibiting the positive impacts of the intervention.

Previous studies, see for example [23] and [24], have indicated that computer use in the elderly is significantly influenced by gender. They found that males have greater computer knowledge, are more confident and less anxious about using computers than females. Interestingly this is not confirmed within this research data where females were much more likely to elect to use the online patient diary option.

In terms of demographic differences between the IT Users and Non-IT Users it appears that amongst the participants within the project the older age group, and particularly older males, were less likely to attempt to use the online patient diary. Those most likely to use the online patient diary are younger females. The participants who chose to use the online patient diary were more likely to continue their involvement with the project for the entire twelve-month period (85% vs 54% completion). All non-completions in this group were deceased. A similar number of Non-IT Users were deceased but 77.95% of those in the Non-IT Users group who failed to complete withdrew from the project. This suggests that participants engaging with the IT aspect of the project may have been more committed to the project although this requires further investigation. The data relating to the actual usage of the online patient diaries and the paper diaries does not provide a clear pattern of behaviour. Participants were more likely to continue to use the online patient diary than the paper diary. There was a marginally higher mean usage in the IT Users group than in the Non-IT Users group.

In relation to the development of self-efficacy to self-manage their condition using the Stanford self-efficacy scale both the groups experienced a positive improvement in their self-efficacy scores. However, the scores for the Non-IT Users demonstrate a greater improvement than the IT User. This appears to indicate that the use of the online patient diary impedes or limits the development of self-efficacy for self-management in people suffering from moderate to severe COPD. Alternatively it may indicate that those who were willing to take on change could adopt the online patient diary and develop self-efficacy but the degree of change was mediated by learning two tasks.

So what are the possible explanations for these findings? The most obvious is that the online patient diary and its use in some way interferes with the process of the mentored self-management. In terms of the Stanford self-efficacy scale the online patient diary appears to have weakened the positive effect of the intervention upon the development of participant's self-efficacy. This is possibly due to the additional learning burden of commencing to use the online patient diary. Alternatively, it is possible that the participants using the online patient diary have more regular interaction with their own symptoms, through the rapid online feedback; this may have raised their awareness of the limits of their self-management skills and as a result enabled them to reflect more critically on their self-efficacy than participants in the Non-IT Users group. In terms of acquiring skills that will assist in self-management behaviours during a life-time it can be argued that the online patient diary may have stimulated a more realistic assessment of participants' actual skills and knowledge.

Significantly, a qualitative analysis of a subgroup of the intervention cohort [25] has demonstrated that the introduction of the online patient diaries had a much broader influence upon the participants than was evident through the analysis above. These influences expanded to include the wider impact of the introduction of computers and the Internet into the participant's lives, the impact of changes in support networks from participation in the trial and the importance and impact of participation issues upon the participant's experiences of the trial [25].

Conclusion

Quality of life for those suffering from a chronic illness is "a product of complex interactions between subjective health, disability and the social environment in which the individual lives" (Anderson & Bury, 1988, p. 249). Thus, it is inadequate to attempt to understand the impact of any intervention in the lives of people with chronic illness solely in terms of generic instrument measurements.

For information system developers, this data highlights the need for more careful consideration of how the evaluation of impact in terms of adoption, usage and benefit is conducted. This paper also provokes the need for more complex analysis of the relationships that exist between clinical, social and technical measures of impact. For health informatics researchers there is also the challenge of the end-points presumed in the development of the technical systems produced to support patients to be able to self-manage – if self-efficacy is to truly be achieved then there is a need to be able to determine when the system is no longer necessary. Otherwise there is a danger of moving from medico-centrism to techno-centrism that artificially replaces one dependency for another amongst those we aim to support being able to self-manage.

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Usage and Effect of a Web-based Intervention for the Prevention of Overweight; a RCT

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Abstract

Web-based interventions can be effective in changing behaviour of people faced with health problems. However, it is unclear whether they are effective in preventing health problems like overweight. The aim of this study was to investigate usage and effectiveness of the Healthy Weight Assistant (HWA), a web-based application to increase healthy behaviour in adults with a healthy weight or slight overweight, by means of a Randomised Controlled Trial (RCT). 297 respondents were randomly assigned to the intervention (n=147) or the waiting list group (n=150). The intervention group received access to the intervention for 12 weeks. At pre- and post-test we measured dietary and physical activity behaviour (primary outcomes) and BMI, knowledge, attitude, self-efficacy, subjective behaviour and insight in behaviour (secondary outcomes). All participants, regardless of group, show improvement in healthy behaviour and subjective assessment of healthy behaviour. People who are older, score higher on dietary behaviour and under-estimate their dietary behaviour are more likely to use the HWA. Using the HWA leads to improvement in physical activity behaviour and insight in physical activity behaviour.

Keywords:

Prevention, RCT, Use, Internet, Intervention Studies.

Introduction

Overweight is a problem in modern society. It is closely related to a number of chronic conditions, including Diabetes Mellitus type II, and places a great burden on the health care system. We all know that losing weight is not as easy as it seems. It might be more (cost)efficient to prevent people from becoming overweight [1-3]. To achieve this goal, interventions aimed at the general public are needed, which must not only inform about the risks of unhealthy dietary and physical activity (PA) habits, but must also stimulate to adopt healthier behaviour. Previous research showed that information only does little to change behaviour, while tailored and interactive interventions are more successful at achieving this goal [1,4,5]. A way to get these interventions to reach the broad target population is through the Internet. Furthermore, by using a web-based application, the content of the intervention can be tailored to the users and the intensity can be varied according to the needs and wishes of these users. Research has already shown the potential of these applications for the achievement of weight loss [6,7] and to some degree weight management [8]. However, most studies are focused on applications aimed at treatment or secondary prevention. Many questions remain on the effectiveness of web-based applications for the prevention of health problems. It is likely that interventions for prevention emphasize different problems than interventions aimed a chronic condition or an urgent health problem. The problem of attrition [9] might pose an even bigger threat to this kind of interventions, considering people who do not experience an urgent health problem, might have less intrinsic motivation to change their behaviour. Therefore, it can be argued that the intervention needs to supply this motivation to a greater extent. Previous research into the user experience of the intervention central in this study, which employed user centred evaluation methods, supports this notion [10]. It showed that improvement of the intervention should be aimed at enhancing motivation to (keep) use(ing) the intervention and to change behaviour. The recommendations acquired from the pilot study were implemented in the application. The goal of the current RCT is to gain insight into the effectiveness, usage and users of the Healthy Weight Assistant (HWA). By gaining insight into the effectiveness we hope to prove that the HWA is a useful tool to be made freely available to the general public in the Netherlands. Furthermore we hope to add to the scientific knowledge base on the requirements for successful web-based interventions in prevention. By gaining insight into usage and users, we hope to clarify the problem of attrition specifically for prevention, when the intrinsic motivation of users might be low. The ultimate goal is to tailor the intervention to user profiles based on the results of this study.

Methods

Intervention

The HWA is a web-based lifestyle intervention developed by the Netherlands Nutrition Centre, which is a government funded organisation aimed at improving healthy dietary habits and preventing weight gain in the general population. The goal

of the HWA is to support people with a healthy weight and people who are slightly overweight (i.e. Body Mass Index (BMI) 18-28 kg/m^2) to achieve and maintain a healthy weight. The aim is not to achieve a given weight loss, but to support the achievement of healthy dietary and PA behaviour. The theoretical basis for behaviour change via the HWA is the Trans-theoretical model [11]. The HWA consists of 4 stages: assessing baseline status; motivation to change behaviour; relapse prevention; goal setting and monitoring achievement of goals.

Design and Recruitment

Participants were recruited through advertisements about an online lifestyle intervention in local newspapers, supermarkets and on health-related websites. 297 respondents were interested in using an online lifestyle intervention and satisfied our inclusion criteria (BMI 18-28 kg/m^2; Dutch speaking). All participants were randomly assigned to either the web-based lifestyle coach or a waiting list. We used block randomization, stratified on age, sex and education with blocks of 4. A total of 150 participants were allocated to the waiting list group and 147 participants were allocated to the intervention group. Online questionnaires were filled out before the intervention period started and after the intervention period of 12 weeks. After this period, respondents in the waiting list group could use the intervention. The flowchart of the study can be found in Figure 1.

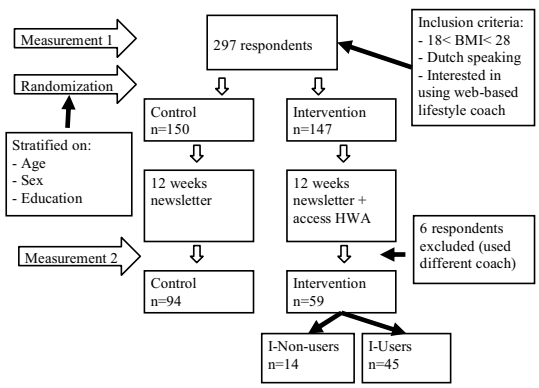

Figure 1 – Flowchart study

Research instruments

BMI was calculated using self-reported weight and length. Dietary behaviour was measured using a 14 item questionnaire [12]. Physical activity behaviour was measured according to the Dutch Standard for Healthy Physical Activity, using a 4 item questionnaire [13]. Self-efficacy for diet and PA were both measured using a 3 item questionnaire with a 5 point Likert-scale [14]. Knowledge was assessed using a 10 item true/false questionnaire based on the Netherlands classification model [15] (diet) and a 10 item true/false questionnaire based on the Dutch Standard for Healthy Physical Activity [16] (PA). Insight in behaviour was calculated by comparing the objective and subjective assessment of dietary and PA behaviour [17]. Questionnaires at baseline and follow-up were identical, except additional items in the follow-up questionnaires: the use of a (e-)coach other than the HWA (both groups); the number of newsletters received and opened (waiting list group); satisfaction with the HWA (intervention group). Satisfaction was measured using 4 items with a 5 point Likert-scale on user friendliness, usefulness, recommending to others and willingness to keep using the HWA [18]. In addition to the online questionnaires, log-files were used to attain the number of times each respondent logged on to the HWA.

Results

Descriptive analyses of baseline variables

As shown in Table 1, most respondents in this study were female (62.2%; n=181) and higher educated (51.9%; n=151). Mean age was 40.9 years (sd=13.8).

Table 1 – Baseline descriptives

	Control group	Intervention group	Total
Age (years)	41.0	40.8	40.9
Sex (% female)	62.7	61.7	62.2
Education (%)			
High	53.3	50.4	51.9
Moderate	31.3	36.9	34.0
Low	15.3	12.8	14.1
BMI (kg/m^2)	23.9	23.9	23.9
Reasons for use*			
Insight in lifestyle	56.6	63.5	59.8
Living healthier	40.7	47.6	43.9
Fun	40.0	44.4	42.1
Lose weight	35.2	42.9	38.7

* Multiple answers possible, so cumulative percentages do not equal 100%

Response rates

Of the 297 enrolled respondents, 159 respondents filled out the post-test questionnaire (response rate = 53.5%). In total the data of 153 respondents were analyzed to measure the effects of the HWA (Figure 1).

Usage and users

55% (n=77) of the respondents in the intervention group used the HWA at least once. Of these respondents, 53% (n=41) used the application only once. Mean satisfaction score was 3.0 (on a scale from 1 tot 5; sd=0.72). There were differences between respondents in the intervention group who used the application (users) and the respondents in this group who did not use the HWA (intervention non-users). Users were significantly older than intervention non-users (respectively 43 and 38; F=4.361; P=0.039). Furthermore, there was a significant difference on dietary behaviour. More users had a healthy diet (34.7%, n=26) than intervention non-users (13.0%, n=6; F=7.912; P=0.019). Lastly, the groups differed on insight in dietary behaviour. Intervention non-users were more often over-estimators (they perceived their behaviour as healthier than it objectively is) (28.3%, n=13) than users (16.0%, n=12; F=7.703; P=0.021).

Effect research

Pre- and post-test scores on outcome variables are shown in Table 2. Independent of group (intervention or waiting list), respondents significantly improved on dietary behaviour (F=7.548; P=0.007) and PA behaviour (F=4.189, P=0.042). Additionally, respondents perceived their behaviour as healthier on the post-test questionnaire (subjective assessment of dietary behaviour: F=8.559; P=0.004; subjective assessment of PA behaviour: F=8.008; P=0.005). Scores on attitude, self-efficacy and knowledge were high at baseline and showed no improvement.

Effect intervention

For the assessment of the effects of the intervention we compared the differences on pre- and post-test scores between different groups (waiting list, intervention non-users, users) as depicted in Table 2.

BMI, knowledge, attitude, self-efficacy, subjective assessment of behaviour

We can show no significant effect of the intervention on these variables.

Behaviour

The significant improvement on dietary behaviour cannot statistically be attributed to the intervention. As seen in Figure 2, both the waiting list group and the users showed improvement in the percentage of respondents who have a healthy diet. Intervention non-users did not show this improvement. There were no significant differences between groups. On PA behaviour, the differences between groups were more pronounced (Figure 2). Both the waiting list group and the users showed significant improvement in the percentage of respondents who showed healthy PA behaviour (waiting list group: Z=-1.964; P=0.050; users: Z=-2.500; P=0.012). This effect was greater for users than for the waiting list group. Intervention non-users did not show this improvement, the percentage of respondents with healthy PA behaviour even declined.

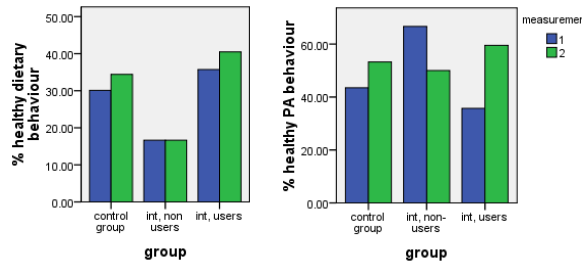

Figure 2 –Healthy dietary and PA behaviour

Insight in behaviour

We can show no significant effect of the intervention on insight in dietary behaviour. However, we did find significant effects on insight in PA behaviour. More users gained a realistic insight in PA behaviour (Z=-2.524; P=0.012). The waiting list group and the intervention non-users did not show a significant change between pre- and post-test. Further analyses of the change in insight of the users showed that the percentage of over-estimators dropped (50.0% pre-test and 23.8% post-test) while the percentage of respondents with a realistic insight increased with the same amount (47.6% and 73.8%). There was no change in percentage of under-estimators.

Conclusion and future work

Conclusions on usage and users

Only little more than half of the participants who received access to the HWA actually used the application. This finding is not unique for this study [see among others: 5,9,19] and stresses an important aspect of web-based interventions. Ostensibly, there is a barrier that prevents almost half of the participants in the intervention group to make use of a web-based intervention to change dietary and PA behaviour. This research sheds some light on the factors that might influence this

Table 2 – Pre- and post-test scores on outcome variables

Variable	Control		Intervention, non-users		Intervention, users		Total	
	Pre-test	Post-test	Pre-test	Post-test	Pre-test	Post-test	Pre-test	Post-test
Diet (mean)	59.1*	60.6	54.7	57.0	60.5	61.7	59.1**	60.6
healthy (%)	30.1	34.4	16.7	16.7	35.7	40.5	30.6	34.7
PA (mean)	5.14	5.38	5.92	5.67	5.05	5.52	5.18*	5.45
healthy (%)	43.5*	53.3	66.7	50.0	35.7*	59.5	43.2	54.8
BMI	24.2	24.2	22.9	23.0	23.9	24.1	23.9	24.1
Knowledge	7.9	7.8	7.6	7.5	8.0	8.1	8.0	7.9
Attitude	4.1	4.1	4.3	4.3	4.1	4.1	4.1	4.1
Self-efficacy	2.1	2.1	1.9	2.0	2.3	2.2	2.1	2.1
Subjective behaviour	6.8**	7.0	7.6	7.9	6.8	7.1	6.9**	7.1
Insight diet (%)								
under-estimator	20.4	18.3	0.0	0.0	23.8	21.4	19.7	17.7
realistic	59.1	61.3	50	58.3	61.9	61.9	59.2	61.2
over-estimator	20.4	20.4	50	41.7	14.3	16.7	21.1	21.1
Insight PA (%)					*			
under-estimator	1.1	1.1	0.0	0.0	2.4	2.4	1.4	1.4
realistic	62.0	66.3	66.7	58.3	47.6	73.8	58.2	67.8
over-estimator	37.0	32.6	33.3	41.7	50.0	23.8	40.4	30.8

* Significant difference between pre- and post-test score at the 0.05 level

** Significant difference between pre- and post-test score at the 0.01 level

barrier. First, it is important to notice that knowledge of healthy diet and healthy PA, attitude towards healthy behaviour and self-efficacy to perform healthy behaviour do not seem to have any influence on the choice to use or do not use the application. Significant differences between users and non-users were found on age, dietary behaviour and insight in dietary behaviour. The finding that the users are older, might seem counterintuitive, but it concurs with recent findings on the motivation to use e-consultation [20], which states that older people are more motivated to use this form of eHealth than younger people. The difference on dietary behaviour shows that the people who need the intervention least are most likely to use the application. These users might not feel they need it least, considering they are more inclined to underestimate their behaviour and therefore feel they should improve substantially to achieve healthy behaviour. The opposite might be true for the non-users. Although objectively they might have a greater need for behaviour change, they are more inclined to overestimate their behaviour, therefore they feel the HWA is of little use to them.

Apart from many potential users who refrain from using the HWA, we saw that the HWA is not used regularly. More than half of the users have used it only once. This might be explained by satisfaction scores which fall in the neutral category. If this is the main reason though, we would expect regular users to express higher satisfaction than occasional users. This, however, cannot be concluded from the data. An alternative explanation might be found in the reasons for use. As shown in Table 1, the most important reason for wanting to use the HWA is to gain insight in one's own behaviour. It might be that this goal is reached after using the HWA once. Participants who feel that their goal is reached, might not need to use the HWA again.

Effects of the intervention

Both the waiting list group and the intervention group show significant improvement on behaviour and subjective assessment of behaviour. Participating in a study on these behaviours in itself may provide some motivation to change behaviour by increasing awareness of current and desired behaviour. In this study we found no significant decrease in mean BMI. This indicates that participating in this study did not lead to weight loss. Although 38.7% of participants do want to lose weight (reasons for use, Table 1), this is not a goal central to the application. Therefore we do not feel that this result exhibits a negative effect of the intervention or study. Interestingly, variables known for their predictive value in behaviour change (knowledge, attitude, self-efficacy) cannot explain differences in behaviour in this study. Participants score very positive on these variables, but they remain stable. It appears that other factors might be of more importance in changing behaviours that are not in urgent need for change, as is the case in a preventive intervention as the HWA where people are more or less healthy and want to become healthier.

We have shown that the intervention has a positive effect on PA behaviour. On dietary behaviour this effect cannot be replicated. This might be due to the fact that users show healthier dietary behaviour at pre-test. This group is less likely to score much higher due to a ceiling effect. The results on insight in behaviour show that the intervention has a positive effect on insight in PA behaviour. Over-estimators who used the application are more likely to gain a realistic insight in their PA behaviour than over-estimators who did not use the HWA (intervention non-users and waiting list group). It seems that the HWA is particularly useful for these over-estimators, although we showed that they are less likely to use the HWA. This contrast poses a challenge to the implementation of the HWA: How to reach the people for whom the HWA is most useful? Returning to the research questions stated in the introduction we can say that:

- Using the HWA leads to improvement in PA behaviour and insight in PA behaviour. All participants, regardless of randomized group, show improvement in healthy behaviour and subjective assessment of healthy behaviour.
- People who are older, score higher on dietary behaviour and under-estimate their dietary behaviour are more likely to use the HWA.

Limitations

A major limitation for this research is that we measure effects for a limited group. Only half of the participants with access to the HWA have used it. We have shown that the intervention has positive effects on these people. But, to increase the efficiency of the HWA it is important to get more people to use the application. Furthermore, it might be that the effects are more pronounced for frequent users. This proposition cannot be proven by this research due to a small group of frequent users, but it holds face value and is supported by other studies in similar fields [21,22]. Therefore a major question for both science and practice is how to get people to keep using applications. A second limitation is the use of self-reported behaviours. Although we used questionnaires from literature, as always, there is a chance of biased results due to self-reported behaviour. Another limitation is related to the participants in this study. Most respondents were female and higher educated. Various studies report overrepresentation of this group [5,23], nevertheless, the question remains whether these results can be generalized to the broader target population of the HWA.

Future work

As mentioned in the previous paragraphs, usage is a major issue in research into the effects of eHealth applications. No matter how effective an application is, when there are few users the effects will only hold for a limited group of people. More research is needed into transforming potential users into actual users and into keeping users engaged with the application and thereby stimulating them to keep using the intervention. Attention should be paid to how technology can motivate users that are willing to change their behaviour. A framework which might be useful is provided by Fogg [24], who states that technology can stimulate the performance of a target behaviour by increasing motivators (pleasure, hope, social acceptance), by simplifying the target behaviour, and by providing triggers to perform the behaviour. Examples are found in serious gaming (pleasure as motivator), automating the collection

of data for monitoring (simplifying) and using mobile text messaging as reminders (trigger). By investigating different methods for motivating a target group to become active users, a large leap in efficiency of eHealth applications can be made.

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The Influence of Crowds on Consumer Health Decisions: An Online Prospective Study

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Abstract

This paper presents an online prospective study investigating whether the strength of social feedback, i.e. the proportion of persons who concur or do not concur with one's own answer to a question, influences the way one answers health-related questions. Two hundred and twenty-seven undergraduate students were recruited to use an online search engine to answer six health-related questions. Subjects recorded their pre- and post-search answers to each question and their level of confidence in these answers. After answering each question post-search, subjects were presented with a summary of post-search answers provided by previous subjects and were asked to answer the question again. There was a statistically significant relationship between the absolute number of others with a different answer (the crowd's opinion volume) and the likelihood of an individual changing an answer ($P < .0001$). Subjects' likelihood of changing answer increased as the percentage of others with a different answer (the crowd's opinion density) increased ($P = 0.047$). Overall, 98.3% of subjects did not change their answer when it concurred with the majority (i.e. >50%) of subjects. When subjects had a post-search answer that did not concur with the majority, they were 24% more likely to change answer than those with answers that concurred ($P < .0001$). This study provides empirical evidence that strength of social feedback influences the way healthcare consumers answer health-related questions.

Keywords:

Consumer decision making, Social feedback, Crowd behaviour, Online information searching

Introduction

Studies reported that people are one of the important sources of information that influences one's actions when confronted with a health-related matter [1-6]. One example is Berkman and Glass's model, which illustrated five ways that social relationships can influence health, such as social influence, social engagement and attachment, access to resources via social ties, social exposure and social support [7].

Social influence refers to how the presence, actions or expectations of others influence the way one behaves [8]. Demonstrated by over eighty years of experimental research, previous studies have examined different classes of social influence, including allelomimetic behaviour, behavioural contagion, conformity, compliance, group pressure, imitation, normative influence, observational learning, social facilitation, suggestion, and vicarious conditioning [8]. In the context of health, the norms of what is considered an acceptable health-related behaviour is often defined by others around you (e.g. smoking), or the controls others impose to achieve adherence (e.g. medication regimens).

With the role of the Internet as a social network, typified by growing interest in sites like Wikipedia, Facebook, and YouTube, more consumers are seeking health-related information and advice from online peer networks. Few studies have evaluated the health impact of social influences that is possible through such websites [9]. Our previous research shows that when consumers search for online information, they experience cognitive biases that influence their health decisions [10] and that such biases are difficult to remove [11]. In particular, pre-existing beliefs are likely to make individuals discount information that is correct [12], where those who lack confidence are 28.5% more likely to change their decision after receiving social feedback online [13].

The aim of this research is to examine whether strength of social feedback, i.e. the proportion of persons who concur or do not concur with one's answer to a question, influences the way one answers health-related questions. We use two measures *opinion volume* (the absolute number of people expressing a view) and *opinion density* (the relative proportion of a group holding a view) to assess the impact of social feedback on consumer health decisions in this study.

Methods

A convenience sample of 227 undergraduate students was recruited from the University of New South Wales (UNSW) to use an online search engine developed at UNSW to answer six consumer health questions. Subjects with Internet access who had previously used an online search engine were recruited by announcements via student email lists, posters, leaflets, weekly student magazines, and a UNSW research news website. The search engine retrieved documents from tested

resources known to have high relevance in answering health-related questions [14], namely PubMed [15], MedlinePlus [16], and HealthInsite [17].

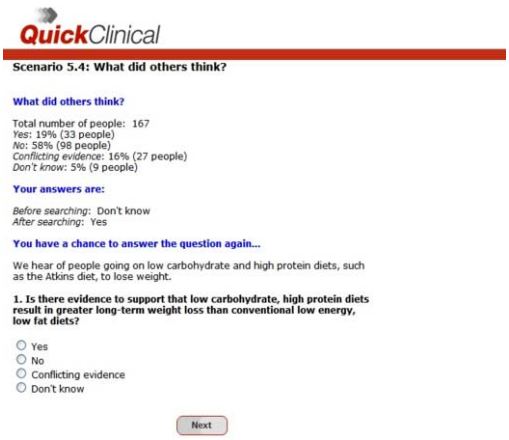

Figure 1- Screen capture of feedback provided to subjects after answering a question post-search

Study protocol

A pre/post protocol was used in this study. Subjects were advised to spend about 10 minutes for each question and to use only the provided search system to answer the questions. To prevent subjects from visiting external websites during the experiment, the navigation bar on the Web browser was hidden once the subject logged on to the study website. Upon completion of the study, subjects were entered into a draw for one of 100 cinema tickets. Ethics approval was obtained from the Human Research Ethics Advisory Panel at UNSW.

Subjects recorded their pre- and post-search answers to each question and their confidence in these answers. After answering each question post-search, subjects were presented with a summary of the post-search answers provided by previous subjects and were asked to answer the question again (Figure 1).

Scenario questions

The consumer health questions and the expected correct answers are shown in Table 1. Each subject was presented with 6 questions, selected at random from the set of 8. There were 4 possible answers to each question: "yes," "no," "conflicting evidence," and "don't know." The questions varied in difficulty and topic in order to cover a spectrum of health care consumer topics. They were developed in consultation with a general practitioner and two academics from the School of Public Health and Community Medicine at UNSW.

Agreement was reached on the "correct" answer and the location of the best evidence sources for each question. A pilot test with 3 members of the general public was used to assess the questions for interest and readability. Two additional pilots, each with 5 subjects, were conducted to confirm that it was possible to locate documentary evidence required to answer the questions correctly.

Table 1- Case scenarios and questions presented to subjects

Scenario question	Correct answer
We hear of people going on low carbohydrate and high protein diets, such as the Atkins diet, to lose weight. Is there evidence to support that low carbohydrate, high protein diets result in greater long-term weight loss than conventional low energy, low fat diets?	No
You can catch infectious diseases such as the flu from inhaling the air into which others have sneezed or coughed, sharing a straw or eating off someone else's fork. The reason is because certain germs reside in saliva, as well as in other bodily fluids. Hepatitis B is an infectious disease. Can you catch Hepatitis B from kissing on the cheek?	No
After having a few alcoholic drinks, we depend on our liver to reduce the Blood Alcohol Concentration (BAC). Drinking coffee, eating, vomiting, sleeping or having a shower will not help reduce your BAC. Are there different recommendations regarding safe alcohol consumption for males and females?	Yes
Sudden infant death syndrome (SIDS), also known as "cot death," is the unexpected death of a baby where there is no apparent cause of death. Studies have shown that sleeping on the stomach increases a baby's risk of SIDS. Is there an increased risk of a baby dying from SIDS if the mother smokes during pregnancy?	Yes
Breast cancer is one of the most common types of cancer found in women. Is there an increased chance of developing breast cancer for women who have a family history of breast cancer?	Yes
Men are encouraged by our culture to be tough. Unfortunately, many men tend to think that asking for help is a sign of weakness. In Australia, do more men die by committing suicide than women?	Yes
Many people use home therapies when they are sick or to keep healthy. Examples of home therapies include drinking chicken soup when sick, drinking milk before bed for a better night's sleep, and taking vitamin C to prevent the common cold. Is there evidence to support the taking of vitamin C supplements to help prevent the common cold?	No
We know that we can catch AIDS from bodily fluids, such as from needle sharing, having unprotected sex, and breast-feeding. We also know that some diseases can be transmitted by mosquito bites. Is it likely that we can get AIDS from a mosquito bite?	No

Table 2- Comparison of changes in answer between subjects who concurred vs. did not concur with the majority (N = 920)

Concurred with >50% of subjects?	Changed answer	Did not change answer
Yes (n=749)	13 (1.7%)	736 (98.3%)
No (n=171)	44 (25.7%)	127 (74.3%)

Results

Of the 1362 potential answers from 227 subjects each answering 6 questions, 338 were excluded from analysis because an answer was not selected, the subject selected "don't know" as the answer, or the subject did not perform a search prior to selecting an answer. The first answer received for each of the 8 scenarios was also excluded, since the first subject to attempt each question could not be given any feedback about other subjects' answers; this left 920 answers for analysis.

Table 2 shows that 98.3% of subjects did not change their answer when it concurred with the majority (>50%) of subjects. Chi-square analysis conducted on data in Table 2 shows that subjects with a post-search answer that did not concur with the majority of subjects were 24% more likely to change their answer than those with answers that concurred (did not concur: 25.7% [95% CI: 19.76-32.77]; concurred: 1.7%, [95% CI: 1.02-2.95]; $\chi^2 = 133.824$, $df = 1$, $P < .0001$).

Subjects were more likely to change their answer when a greater *percentage* of subjects did not concur with their answer – the opinion density (Figure 2). Subjects were also more likely to change their answer when a greater absolute *number* of subjects did not concur with their answer – the opinion volume (Figure 3). There was a statistically significant relationship between the *number* of subjects with a different answer and the likelihood of one changing an answer ($P < .0001$, two-sided Fisher's exact test, Table 3). Chi-square analysis conducted on data in Table 4 showed that amongst subjects whose answer differed to that of >60% of subjects, their likelihood of changing answer *increased* as the percentage of subjects with a different answer increased ($\chi^2=6.10$, $df = 2$, $P = 0.047$).

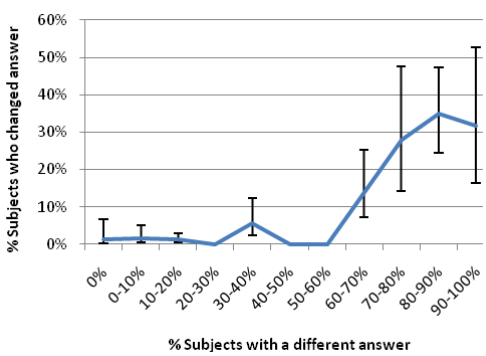

Figure 2- Opinion density effects
(Note: 0-10% means >0% and ≤10%)

Table 3- Comparison of changes in answer amongst subjects whose answer differed to other subjects (N = 920).

No. of subjects with a different answer	Changed answer	Did not change answer
<3 (n=229)	2 (0.9%)	227 (99.1%)
3–9 (n=235)	6 (2.6%)	229 (97.4%)
10–15 (n=225)	6 (2.7%)	219 (97.3%)
>15 (n=231)	43 (18.6%)	188 (81.4%)

Discussion

This study provides empirical evidence that healthcare consumers are more likely to change their answer when a greater number of others do not concur with their answer. It also shows that consumers are more likely to change their answer when their answer is not supported by the majority of consumers. Further, the likelihood of one changing an answer increases as the percentage of subjects not concurring with one's answer increases.

From an empirical perspective, few to no studies have studied the impact of majority influences on how consumers make health decisions. Our previous research showed for the first time that online social interventions can lead consumers to make unsafe decisions about their health. Consumers who are least confident in their decisions are most likely to be swayed by social feedback into making incorrect decisions: those who lack confidence in their answer to a question have been shown to be 28.5% more likely to change their decision after receiving social feedback online [13].

From a theoretical perspective, research on how the majority/minority influences the way individuals process information and alter their attitudes may offer explanations for our findings. One of the earliest and most influential work in this area, Moscovici's *conversion theory* [18-19], proposes that when information is received from the majority, individuals conform to the majority and do not scrutinise the information because they concentrate their attention on "... what others say, so as to fit in with their opinions or judgements" [18]. Whereas, when information is received from the minority, individuals may interpret the information more closely but not as likely to agree with it openly because they fear of being associated with the minority in the public.

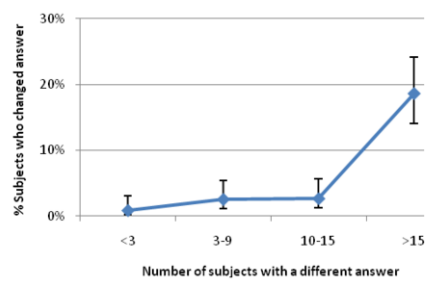

Figure 3- Opinion volume effects

Table 4- Comparison of changes in answer amongst subjects whose answer differed to that of >60% of subjects (N = 167).

% of subjects with a different answer	Changed answer	Did not change answer
60–70% (n=57)	8 (14.0%)	49 (86.0%)
70–80% (n=25)	7 (28.0%)	18 (72.0%)
>80% (n=85)	29 (34.1%)	56 (65.9%)

Note: 60–70% means >60% and ≤70%

Another piece of prominent work in this area, *objective consensus* approach [20], offers several possibilities on why individuals are more likely to systematically process information received from the majority than from the minority. One possibility is that individuals believe their attitudes are similar to those of the majority and are more likely to agree with the majority than the minority [21]. Another possibility is that individuals believe it is more important to process information received from the majority because attitudes held by a majority are more likely to become adopted than those held by a minority [22]. A further possibility is that individuals assume that the majority views reflect reality because "several pairs of eyes are better than one" [20].

Conclusion

The Internet has delivered a glut of information, much of it neither timely nor correct, thus increasing the chances that consumers using the Internet to obtain health information may make the wrong health decision, or experience anxiety about what to do [23]. As consumers play an increasingly active role in managing their health, it is important not to underestimate the extent to which online peer networks can influence the way people manage their healthcare. While the rise of the Social and Semantic Web has facilitated ready access to information about the masses and aggregated behaviours [24], the quality or correctness of aggregated behaviours is often measured by popularity, which does not necessarily relate to accuracy. More investigation should be undertaken to examine whether aggregated behaviours made possible via the Web is a new form of social influence that impacts significantly on consumers' health decision-making.

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Patient web empowerment index (PWEI): An index for assessment of healthcare providers'web strategies. Case study: PWEI application in Italy

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Abstract

The arrival of the Internet contributes to the growth of new areas for patient empowerment. In the presence of a challenge such as this, we nevertheless note that the adequacy and characteristics of the web strategies of healthcare providers have, up to the present, not been subjected to thoroughgoing critical analysis. The aim of this paper is to: (a) provide an analysis of the key factors of an efficient web strategy for healthcare organizations with regard to the issue of patient empowerment (b) build a concise indicator for measuring the degree of empowerment potential of healthcare providers' web sites (Patient Web Empowerment Index –PWEI-). PWEI was calculated in order to assess the web sites of 340 Italian National Health Service healthcare organizations, the aim being the appraisal of the current degree of maturity of their web strategies in relation to potentials for an effective increase in patient empowerment

Keyword:

Patient advocacy, Patient participation, Health promotion, Internet, Medical records, Telemedicine, Social marketing, Italy

Introduction

The arrival of the Internet has deeply impacted relations in terms of the exchange of goods and services in innumerable contexts. We may note that the major impacts of these transformations on relations between 'suppliers' and 'customers' consist in: (a) low-cost availability (or availability even free of charge) to the customer of considerable amounts of information useful for purchasing decision-making; (b) a consequent increase in the degree of transparency of markets; (c) a significant enhancement of the empowerment of citizens/customers in many real life situations and in relations with various (public or private) suppliers. Nowadays, citizens are aware of this historic change and are bearers of a growing demand for the adoption of web services, also within contexts such as healthcare, in which, traditionally, exchanges of information between patient and care provider are significantly 'asymmetric'and formal. Patient empowerment, markedly tied in with the spread of the Internet and of technological resources as a part of our day-to-day lives (in which the Internet is now 'embedded'), represents one of the major challenges healthcare systems face today. Statistical data regarding the use of the leading search engines indicate that questions concerning "health" are decidedly among the most frequently occurring. More broadly speaking, patients are nowadays the bearers also of new demands or desiderata, which we may summarise as follows: (a) access to authoritative, customized and immediately usable health information; (b) greater control over their own personal conditions of health, through personal management of pertaining data, and over the various diagnostic and therapeutic options available; (c) direct and informal relationships with healthcare structures and professionals, also via non-traditional channels; (d) role as 'active player' within the network, also by sharing ones health problems with others and seeking out information on the experiences of others faced with these same problems (web 2.0 rules, the basis of social networks, has considerably amplified this latter development).

In equal measure, in the scientific literature and strategic decision-making processes in the field of healthcare provision systems, the concept of "patient empowerment" therefore constitutes an increasingly significant variable, which is the focus of interest and debate among academics and policy makers alike [1-3]. Within the field of healthcare provision, the concept of empowerment has been adopted on various levels [4]: on the macro level, analysis takes place of the relationship between health and power. A number of studies suggest that empowered people are healthier than non-empowered people; lack of power is therefore a disease risk factor (dependent upon structural factors) [5]. On the micro or individual level, the concept of empowerment has been used to define a particular type of patient. It is here that we arrive at the notion of patient empowerment:

> *"Patients are empowered when they have the knowledge, skills, attitudes and self-awareness necessary to influence their own behaviour and that of others (...) to improve the quality of their lives [6]."*

In the presence of a challenge such as this, we nevertheless note that the adequacy and characteristics of the web strategies

of healthcare providers have, up to the present, not been subjected to thoroughgoing critical analysis. The aim of this paper is to: (a) provide an analysis of the key factors of an efficient web strategy for healthcare organizations with regard to the issue of patient empowerment (b) build a concise indicator for measuring the degree of empowerment potential of healthcare providers' web sites (c) measure the degree of patient web empowerment within the Italian National Health Service (INHS).

Methods

The research project described here aims to engage in a more in-depth study of, and to elaborate upon, the issue of patient empowerment within the context of the introduction of information and communication technologies (ICT). A study has been conducted of the healthcare applications of these technologies, classified according to their impact on the two key dimensions of patient empowerment: information held by the patient and control on the part of the patient with respect to his/her health needs. The baseline research hypothesis is that the information and services provided by Health providers via the web are capable of enhancing patient empowerment regarding both the above mentioned dimensions.

The basic question this research addresses may be summed up as follows: *"To what extent are the web strategies of IHNS organizations aimed at increasing patient empowerment?"*

The various typologies of web information and services were used to develop a succinct indicator by means of which ratings could be given for the web sites of Italian Local Healthcare Units (LHU) and Hospital Trusts (HT). This indicator, termed Patient Web Empowerment Index (PWEI), is the result of aggregation and weighting of 8 sub-indicators, each of which is calculated on the basis of the presence of certain elements characterising the structure of the web site considered[1].

During the period April-June 2009, the indicator was used to assess the web sites of the entire universe of public (and private contracted) INHS healthcare organizations (340 LHUs' and HTs' sites were benchmarked), the aim being the assessments of the current state of maturity of their web strategy in relation to potentials for an increase in patient empowerment.

Analysis and rating of sites were based on two fundamental criteria: (a) the immediacy in finding information or services while navigating the site ("hidden" services were not considered if time-consuming procedures were necessary in order to find them); (b) the official and systematic (as opposed to sporadic or "test only") presence of the information or services in the examined web sites.

Construction of the *PWEI* indicator

PWEI, as pointed out above, is a multidimensional indicator, composed of a series of sub-indicators the objectives of which are measurement of the various aspects of patient empowerment via the web. The typologies of information and services that users can find on the sites of Italian health organizations, in fact, vary greatly. Thus, the capacities of these health organizations to contribute to user empowerment also vary – empowerment ranging from access to knowledge, to control of data concerning ones personal conditions of health via the electronic medical record and telemedicine.

Figure 1 illustrates how the main *PWEI* sub-indicators are linked to the main ambits of influence of ICT on the web sites of LHU and HT and the impact of these ambits on the two elements defining patient empowerment: information and control.

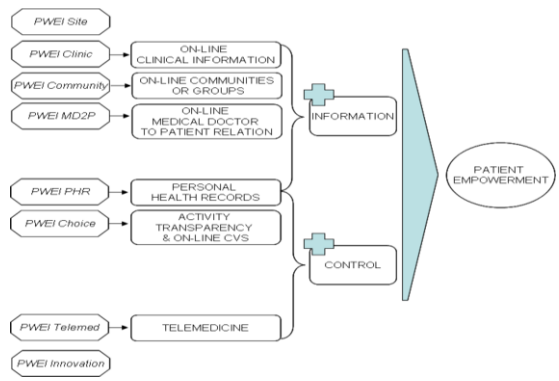

Figure 1 - The main influences of ICT on patient empowerment

The first element making up the overall index of patient empowerment has been termed ***PWEI Site*** **(P1)**. It relates to certain structural characteristics of the site which enable user-friendly navigation and which, above all, respond efficiently to the primary information needs of the patient. Assessment was conducted of a number of these characteristics: accessibility (e.g. the option of graphics changes, including font size, for patients with eyesight problems, or to facilitate handheld computer or mobile phone site access) and immediate usability of the content and services provided by the examined healthcare provider. Site structure was examined, including rating of sites enabling the life events model for navigation (i.e. navigation starting out from events which may characterise the life, in health terms, of the patient, such as "giving birth", "growing" or "life as a senior citizen"), or which provide clear segmentation of patients by cluster (the elderly, women, children, foreigners etc.). Menus constructed according to these approaches may aid consultation by patients presenting specific problems, who thus receive immediate answers targeting their specific needs. Lastly, an exhaustive description of the health organizations and their departments may aid the patients in that the description can be used as a map for orientation among the services provided: clear presentation of the organisational structure of the health unit was therefore also assessed.

[1] During the stage of quantitative determination, the value 1 was ascribed to the presence of the service or of the information considered, value 0 to absence, and value 0.5 to incompletely structured presence.

The second component of the indicator consists in the clinical information that may be obtained by patients from the site. To construct sub-indicator ***PWEI Clinic (P2)***, various elements relative to health information present on the site were considered, ranging from simple leaflets or fact files to tests for assessment of the clinical risks of individuals or information for self-diagnosis. Investigation was conducted of the presence of: i) leaflets or fact files on specific pathological states; ii) files dealing with prevention and for promoting correct lifestyles; iii) files to aid understanding of laboratory examinations; iv) healthcare provider magazines or newsletters with information regarding health and healthcare issues; v) back-up with guidance for self-diagnosis; vi) questionnaires and clinical risk assessment tests. Use of each of the first four elements can generally be enabled by file downloading or – in rare instances – by video, links to internal resources (web pages maintained by professionals from the health unit) or links to external resources (the resources of the Health Ministry, the sites of Regional government authorities or regional health agencies, on-line libraries).

The third component of the indicator is termed ***PWEI Community (P3)***. This sub-indicator assesses web site presence of on-line communities or of groups which ensure clinical back-up in the form of information, psychological support or a service consisting in accompanying patients with special health problems. The following entities were noted: i) institutional communities: counselling; on-line support centres (e.g. stop-smoking, dietary health problems, etc.); health organization linked voluntary associations; ii) bookmarks for Internet support group resources, i.e. direct links to medical sites or sites run by voluntary players or by patients; iii) lists of, and references to, non-web community and support group resources (generally, address directory mode).

A further indicator factor – contributing to significant enhancement of the quality and quantity of clinical information available to users – consists in direct on-line medical doctor-patient communication (***PWEI MD2P – Medical Doctor To Patient – P4***): patients can directly contact professionals for health information or advice. In this context, the prospect of adoption of a multi-channel approach on the part of health organizations was also considered (telephony or digital terrestrial television communication resources, alongside the Internet). Thus, the systematic presence of the following elements was assessed: i) telephone line for counselling or general healthcare orientation purposes, ii) telephone line for health counselling on specific issues (e.g. influenza, contraception, AIDS, etc.), iii) use of personal email communication on the part of the organisation's medical doctors, iv) moderated institutional forums for communication among patients, v) blogs, forums or live sessions for communication between patients and medical doctors, vi) FAQ service on health issues providing medical doctors' answers to users' questions.

A further key aspect considered for an assessment of empowerment consists in access to ones own ***Personal Health Record (PHR – P5)***, generally understood as an electronic format record with information on the health conditions of the individual, alongside a record providing the full medical history of the person in question, directly accessible via web. *PHR* is therefore an important instrument in terms both of information and control of ones own personal health data. Sub-indicator *PWEI PHR* analyses openings for examining and downloading ones own electronic format record directly from the health unit's site or by other means (e.g. via electronic card or access on the part of the patient's general practitioner or specialist).

The expectations of many users have grown, and these users display greater awareness of the importance of selecting professionals and the most appropriate structure (safety, specialisation, available technologies and methods, etc.) for healthcare provision and optimal responses to their health problems.

This aspect was processed by means of a further component of the index, i.e. ***PWEI Choice (P6)***. This sub-indicator accounts for a number of the most important elements which, if present on the site, may provide patients with orientation in selecting the most appropriate health unit and professionals for the required service. These elements, in any case, are auspicious in terms of transparency of health unit during dealings with users, namely by provision of user-friendly access to: i) medical doctors' curriculum vitae data, ii) information on the typology and quantity of treated cases by pathological condition, iii) waiting lists for diagnostic services, specialist examinations and emergency room admissions.

The need to meet increasingly complex demands brings with it the need to re-configure the manners in which certain health services are provided, this latter aim receiving a significant stimulus from progress in the ICT field. In this context we note the potentials of telemedicine, which generally enables virtual mode clinical diagnosis without physical contact between patient and medical doctor. For the purposes of analysis, a search was made for unequivocal provision of the following services on the sites of health units: i) specialist tele-counselling, ii) telehomecare iii) emergency telecare. Assessments relative to these elements were pooled in sub-indicator ***PWEI Telemed (P7)***. The availability of services provided by telemedicine system enables greater control by the user of personal conditions of health.

Lastly – for individual cases – the presence on sites of certain ancillary ICT-based services was surveyed, such as webcam or photo albums for newborns (provided by maternity departments or by intensive treatment departments). These innovations were translated into the last of the index elements: ***PWEI Innovation (P8)***, gauging the presence of particular innovations (including innovations which are exceptional in nature and which go beyond the impacts, in terms of information and control, investigated during the research under discussion here).

Each sub-indicator was weighted according to its significance for the enhancement of patient empowerment[2]; weights were determined on the basis of scientific literature on patient empowerment and then validated with the involvement of a pool

[2] A sensitivity analysys of the adopted weights is available upon request

of experts. The total value is reached by means of equation (1). The maximum theoretical value of the weighted PWEI is 10.

PWEI = 0,5 P1+ 2 P2 + 0,5 P3+ 1.5 P4 + 2 P5 + 2 P6 + 1 P7 + 0.5 P8 **(1)**

Results

From analysis of the single *Patient Web Empowerment Index* indicators we learn that, as yet, few health organizations have developed web-based strategies oriented toward information and user control of clinical data. Although, nationally speaking, the presence of best practices was noted (above all, in Lombardy and Emilia Romagna regions), it was observed that none of the local health units surveyed had reached an overall PWEI rating approaching the maximum theoretical value of 10.

The overall *PWEI* results can be assessed by geographic area (Table 1). Here, the health units of Northeastern and Northwestern Italy rated higher than the national average. The data reveal a nationwide gap situation with regard to patient empowerment via web sites. While Northern Italy's average *PWEI* values were not particularly high, the area does seem to be gradually coming round to the idea of paying more attention to web strategies targeting the users of its health units. The health units of the Regions of Central and Southern Italy still display an inability to implement the openings provided by the web for responding to patient needs.

Table 1 – Average PWEI by regional cluster (min 0- max 10)

	PWEI by regional cluster
Northwestern Italy	2.20
Northeastern Italy	1.85
Italy	**1.50**
Central Italy	1.07
Southern Italy	0.98
Islands	0.78

Particularly worthy of note is the prospect of *PWEI* sub-indicators analysis. The average national values for *PWEI* sub-indicators are listed in Table 2 (on a 0-10 scale).

Table 2 – National average values for each PWEI sub-indicator (min 0- max 10)

	Average Px value
PWEI Site (P1)	3.55
PWEI Clinic (P2)	1.10
PWEI Community (P3)	2.13
PWEI MD2P (P4)	0.94
PWEI PHR (P5)	2.79
PWEI Choice (P6)	0.32
PWEI Telemed (P7)	1.06
PWEI Innovation (P8)	0.46

The data indicate the greater significance of the *PWEI Site*, *PWEI Community* and *PWEI PHR* sub-indicators. For *PWEI Site*, the value is directly ascribable to the existence at least of an institutional web site. For *PWEI Community* and *PWEI PHR*, the result is owing to the positive outcomes noted in a number of the major health units.

Discussion

The analysis offered a number of interesting results regarding each of the surveyed ambits and a number of best practices, where these could be found.

With regard to the ***PWEI Site*** component, research revealed that very few health organizations had enabled a system for web site use of information based on a life event approach. Other health providers selected visitor-type clusters (e.g. the elderly, special-needs patients, foreigners, etc.) as a means of orienting information users. While taken up by a greater number of health organizations (compared to the life event system), this latter option remains infrequent within the entire surveyed sample. Indeed, this was the choice made by most health organizations in Emilia Romagna Region and by a considerable number of organizations in Lombardia Region. In the other Regions, however, this type of segmentation of visitors was sporadic, the menus bring based instead on the organisational structure of the concern (e.g. districts, departments, hospitals etc.).

Analysis of P**WEI *Clinic*** elements revealed that there are practically no guided support resources for self-diagnosis or assessment of personal clinical risks (the two exceptions regard diagnosis of cardiovascular and melanoma risks). The LHU generally provide downloadable leaflets dealing with prevention, above all for tumour screening and for promoting healthful lifestyles. Information files on specific pathological states are more frequently to be found on the sites of HT than on those of LHU concerns.

Turning to communities aspects (***PWEI Community***), only a few health organizations host institutional support groups (in most cases, voluntary associations for specific patient types). Sites hosting bookmarks or lists of pertaining associations are more frequently found. This information was systematically included in the sites of the health organizations of specific regions.

In terms of medical doctor-patient relations (***PWEI MD2P***), few health organizations have, as yet, made provisions for an interactive approach to exchanges between the two players. Indeed, there are few telephone lines for patient orientation on health concerns, both with regard to general services and specific areas of specialisation. On their sites, the health units of Emilia Romagna refer to a dedicated AIDS telephone line (*Helpaids*): the project was actually started up by the Regional authority, and not by LHU. Generally speaking, medical doctors' personal email addresses are not hosted by sites, with some exceptions (while cases are to be found, this service does not generally regard all medical doctors of the organisation). Only on some sites are user-accessible forums and blogs to be

found. Managed by counselling centres, they target adolescents and women. Solutions enabling medical doctors to respond to user questions via the FAQ function are slightly more frequently to be found.

For *Personal Health Record* (***PWEI PHR***), we must distinguish between two differing operational ambits: i) single health organizations which independently decide to acquire systems for counselling and for patient downloads of electronic format health files; ii) *PHR* systems finalised within the ambit of regional projects. In the former case, there are, as yet, few health organizations which have made provisions for such instruments. Only in the Lombardia and Emilia Romagna regions have solutions been devised for clinical data management on a regional level (the CRS-SISS[3] project for Lombardia and the SOLE[4] project for Emilia Romagna). These regional projects were considered when assessing the sites for the health organizations of these two regions, and the presence of *PHR* was duly taken note of, although at present the projects have not been fully implemented in terms of the prospect of direct *PHR* use on the part of patients [7] [8].

Performance for telemedicine (***PWEI Telemed***) among health units is still unimpressive. A number of LHU especially in the Veneto, Emilia Romagna and Toscana regions, do have pilot projects, ranging from emergency telecare for infarcted patients to telehomecare for the elderly.

With regard to ***PWEI Choice***, we note that, with the exception of certain organizations, the sites do not systematically include curriculum vitae data for their professionals and there is practically no information at all on case-mix treated by health organizations or professionals. Managers' CV publication is foreseen by law at a national level as an admnistrative pro-transparency measure; real-time waiting lists data are available only on approximately fifty sites (at times, data are provided only for specific services).

Conclusions

A number of preliminary conclusions may be reached on the basis of this study. Three general points may be considered:

- health units' awareness of the potentials of web instruments for curbing 'asymmetric information' situations (a typical characteristic of relations between medical doctor and patient) is only partial. Indeed, few organised resources have been made available such as provide solutions capable of responding to a broad range of health needs displayed by the citizenry;
- we find considerable resistance to the idea of using the web as a means of truly and significantly enhancing transparency, this aim being frustrated to a considerable extent. This situation is evident for all areas and all 'critical' services, i.e. "real views" (of waiting lists for services) or online CVs of professionals. While we are aware that the degree of cultural resistance to such innovations is significant, we believe that this ambit may represent a natural line of development of some interest for web strategies;
- the web strategies of health organizations basically reflect a state of immaturity. The strategies still display a tendency to modulate their approach with the accent all too frequently placed on the structures and responsibilities of the organisation itself, rather than on the needs and demands of citizens-patients. While site design seems to be well executed from the graphics angle and the information content is updated in a satisfactory manner, the logic behind design is still based on considerations regarding the concrete organisation of the structure. Patients may well not be familiar with such organisational aspects. By adopting this approach, transparency may be impeded with respect to specific needs.

Overcoming these three highly significant limits may turn out to be a prerequisite for concrete development of the provision of "healthcare 2.0" – a concept for innovation which healthcare systems are beginning to discuss.

[3] The CRS-SISS (Regional electronic card for access to health data and public services) project of the Lombardia regional authority aims to plan, develop and manage the information system enabling telematic links in the region.

[4] The SOLE (Sanità On-line), or on-line health care, project consists in a computer network with links between 3,800 general practitioners and paediatricians and all the medical structures and specialists of the health units of the Emilia Romagna region.

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Development and Implementation of an Integrated EHR for Homecare Service: A South American Experience

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Abstract

This paper describes the development and implementation of a web based electronic health record for the Homecare Service program in the Hospital Italiano de Buenos Aires. It reviews the process of the integration of the new electronic health record to the hospital information system, allowing physicians to access the clinical data repository from their Pc's at home and with the capability of consulting past and present history of the patient health care, order, tests, and referrals with others professionals trough the new Electronic Health Record. We also discuss how workflow processes were changed and improved for the physicians, nurses, and administrative personnel of the Homecare Services and the educational methods used to improve acceptance and adoption of these new technologies. We also briefly describe the validation of physicians and their field work with electronic signatures.

Keywords:

Hospital information systems, Homecare services, Clinical data repository, Electronic signatures.

Introduction

Patient care in the home setting is a complex task. There are ongoing and intricate interactions between patients, medical, and administrative staff. Physicians and health care professionals, such as those in ancillary services, may be impeded in giving prompt care without access to real time clinical data or if they are unable to share knowledge efficiently. Communication can fail and when these elements are not properly coordinated, errors can occur. [1]

Compared with other levels of health care, homecare service involves a substantial flow of information. Delivery of services requires coordination of geographically distributed patients and professionals by central administrative personnel who usually have little access to vital medical workflow decisions.

For the personal that works on homecare services, to have restricted access to some of the right information in real time and in an not optimal format makes it difficult to make the decisions in their work. [2]

Much of the clinical and technical orientation in Home Care Service (HCS) is on telemedicine; previous works described how to improve the care of special patients with specific diseases or how to extend the telehealth to the home.[3, 4].Or even, describe technical support for close care and consistent information flow between different health care providers.[5]

Because Hospital Italiano de Buenos Aires (HIBA) wished to integrate all levels of care in the Hospital Information System (HIS), we decided that HCS should have the same interface as the existing applications. To create and put in place a platform that supports such complex model was not a trivial task: it required a carefully planned design.

The objective of this paper is to describe the experience of the development, integration, and implementation of an Electronic Health Record for HCS into the HIS of the HIBA. Our first planning phase and our first results involved two target populations in HCS, “"Homecare"” and “Follow up care”.

Materials and Methods

The Hospital Italiano de Buenos Aires (HIBA) is a non-profit health care academic center founded in 1853, with over 1,500 physicians and 3,500 employees.[6] HIBA has a network of two hospitals with 750 beds (200 for intensive care), 500 "Homecare" patients under care, and 23 clinics. It has an insurance plan that covers approximately 150,000 people and also coordinates insurance for another 1,500,000 people who are covered by affiliated insurers. Each year over 38,000 inpatients (pediatric and adult) are admitted to its hospitals that are located in Buenos Aires and its suburban area. HIBA has more than 2,200,000 outpatient visits annually from patients from across the country and Latin America.

HIBA, a well-developed teaching hospital, offers both graduate medical education and residency training for 35 medical subspecialties and 34 fellowships programs. There are currently 400 residents and fellows in training.

In 1998 HIBA began the implementation of a Healthcare Information System (HIS) by integrating clinical information with administrative applications that were already in use. This in-house project currently handles all clinical and administrative

health care information from data capture through to analysis. It is now a fully implemented web-based, problem-oriented and patient centered EHR system.[7, 8] The system includes computerized provider order entry (CPOE) which is available to physicians throughout the HIBA network.

Early in 2008 we decided to start the design and in 2009 implementing the EHR into the HCS. We involved staff from admission, physician, billing for the process of design.

HCS Overview

The Homecare Service is different from all other clinical areas at HIBA; geographically HCS provides services over an area of approximately 350 square km (City of Buenos Aires). Has an average count of 350 to 400 admitted patients and is divided into two different areas according to the level of the patient care.

- 80 to 100 are allocated in Follow up care" (FC). Under Follow up care are those patient whose disease is not that acute and needs one physician and nurse visit per month, e.g. follow up to medication for deep venous thrombosis,
- 270 a 300 are allocated in "Homecare" (HC). Under Homecare is denominated for those patients whose disease only needs one home physician or nurse visit per week, e.g. surgical wound infection.

HCS is provided by 61 physicians : 49 internal medicine physicians, 12 physicians from others specialties (Cardiology, Psychiatry, Trauma, General Surgery, Infectious Diseases, Neurology, Palliative Care, Urology) and 4 physician-auditors that coordinate the service. 32 nurses that administer medications, draw blood samples, monitor and provide daily physical care and 6 Administrative personnel that coordinate the ratio patient/physician by location.

The Homecare Service Pre-Implementation

Pre-implementation administrative processes

The admission consists in the classification of patients and the determination of the priority of needs and the scope of treatment: homecare or follow-up care. Most of cases administrative workflow starts with an inpatient being admitted in HIBA. Each patient selected to be admitted to HCS from HIBA was assigned a physician who performed the first evaluation. This evaluation defined the scope of admission into HCS (FC or HC). The admission was done by an administrator by adding patient data to a spreadsheet. Then manually they admitted to the HCS, and added medication and oxygen if it was needed. Once the admission was confirmed in HCS office, the administrator opened another spreadsheet where all physicians were listed and then assigned a physician whose address most closely matched the patient address. Finally the administrator called or sent an e mail to this physician informing of the patient admission and assignment. The same process was followed in nursing.

All information related to the admission was manually added and shared trough a spreadsheet, with the exception of email notification. Another spreadsheet included the number of patients admitted with the personal contact information.

Pre-implementation Clinical workflow

A patient's case history was accessed from the HIBA EHR through a Virtual Private Network (VPN); this also displayed the levels of care that patient had received. If a laboratory or radiology test was requested, the physician needed to call or to send e mail to the administrator for coordination with the nurse. This process had an average delay of 5 days. The laboratory nurse then took the administrator's call and had to update the patient information in the spreadsheets; this increased the possibility of clerical error. Results were seen in the Ambulatory EHR through VPN connection. Also if a patient needed to be readmitted to HIBA because of a complication, the HCS physician was infrequently informed in real time of this re-admission.

Design of the Homecare Services EHR

The design consisted on meetings and analysis of HCS needs based on pre-implementation evaluation on 2008. This initial design was for defining obligatory applications and functionalities of the HCS EHR should have similar to the EHR already running at HIBA so the integration was more equal. In this meeting, personal of the technician service were present too, and the basis of module was developed. Then in a second phase, the 4 physician-auditors of HCS were invited to review the HCS EHR prototype. Few changes where asked, but the most important need was for physician validation, authentication and certification, so electronic signature was adopted as a form of authentification.

Implementation Plan

Training in the use of the Admission Discharge Transfer (ADT) Application

ADT training of full time HCS administrative staff was done one month prior to the implementation. The ADT system for inpatient has been a part of HIBA for more than 8 years. ADT interacts with the EHR for many patient admissions, discharges and transfers. ADT workflow process was modified with patients leaving the HCS "domain" to the HIBA emergency room and either return to HCS or is admitted to HIBA administrative staff from both HCS and other services were informed and trained in order to avoid compromising patient care.

Training in the use of the "Homecare" Service EHR

Training in the use of HCS EHR was given one month prior to implementation. Physicians who were to use the application on a daily basis attended a workshop, and were given face to face instruction. All instruction manuals were provided on HIBA's "virtual campus". A more detailed course was created for newly registered physicians. They were required to take an exam, after which they were given access to the EHR.

The implementation of the Electronic signature

HCS EHR physicians received virtual and face to face instruction on how to install the software and the hardware. All HCS physicians were required to sign a legal agreement that was validated by the legal department of HIBA. This agreement is an informed consent that validates the physician signature on electronic documents; it provides security, privacy, confidentiality and authorship of the information entered on the EHR.

Results

Informatization of the Homecare Services

ADT system functionalities

Once HCS is integrated into ADT system an admission to this service precedes as follows: First the medical team of the HIBA decides to admit the patient to HCS. Second, an email is sent or a call is made to the HCS physician-auditors. Third, when the patient is physically admitted into the HCS system the auditors' physicians call the HIBA medical team to request the HIBA discharge via the EHR.

The administrative inpatient personal of HCS receive an email alarm with the data of the patient to be admitted. They re-check the data with the physician-auditors and then confirm the incoming ADT message. The clerk creates the episode and all the personal data of the patient is loaded automatically from the Master Patient Index. At this point if the patient is not discharge from inpatient episode through the EHR, the clerk has an option that is called "PRE DISCHARGE". This state allows to virtually admitting the patient for 48 hours waiting for the medical team of HIBA discharge. The ADT system interacts with the Geographical Information System (GIS) so the patient address can be located.

The Homecare Service EHR

Access to the Homecare Service Electronic Health Record (HCS EHR)

Because of the geographic distribution of physicians the HCS EHR is through web access. Homecare Services physicians can access to the EHR from any PC with Internet connection. Physicians log into the HIBA web page and then to HCS through an icon on the intranet web page. There though a SSL certification and two servers that make web application between the Data Base and the web. The web app server 1 include web applications without logic and the web app server 2 with the logic. You can only access the Data Base server by IP assigned by web app 2, then Physicians are sheltered from the Data Base web server thought the web app 1 that can not get to the Data base server. Thought this way all data is preserved. Information flows safely and encrypted.

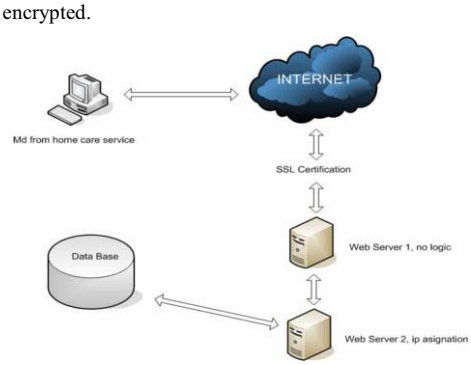

Figure 1- Network & data flow diagram

The Homecare Service Electronic Health Record

The first screen a physician views shows lists of patients, clinical practice guidelines, and a messaging system. This intermediate level default display presents a preferential way of visualization.

Patients' records can be retrieved through a search function. After the physician retrieves the correct patient he/she is presented with a modular, problem oriented and patient centered EHR.

The modules available are:

- Overview: The initial view where all modules are summarized.
- History and Problem lists: This module allows for the visualization of the clinical history. It also provides for the addition of new problems or change in of level of care which had been entered into the Problem Manager by other clinical staff.
- Progress Notes: This is a critical view for physicians. Patient co morbidities and, clinical history is integrated into the record which physicians can easily navigate. The physician can access laboratories results, additional studies, current and historic medications prescribed, and write progress notes (Figure 2)

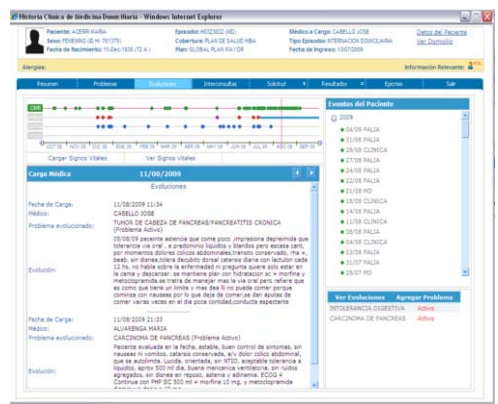

Figure 2- Progress notes module of the "Homecare" Service

- Referrals: The physician can request consults for their patient with any HCS specialist through the EHR. This request automatically generates two e mails -- one to the specialist and the other to administration as an advance notice for billing purposes.
- Clinical or lab studies: the physician can electronically order new studies and lab tests. In addition when if the lab test requires a blood sample to be drawn an email is sent to the nurse where they coordinate the draw example.
- Results: All historic and current studies can be accessed and reviewed. In some instances visualization tools have been created for improved longitudinal result views.

- Episode data: This module enables the physician to close the episode and discharge the patient. The discharge summary includes a principal diagnosis, if necessary a second, comorbilities, and an episode; and with the epicrisis.

Patient discharge of Homecare Service

The finalization of the episode is complete; as said before, by the discharge summary. When it is determined that a patient can be discharged; also to other areas of HCS such as "Follow-up Care" if patient was on "Homecare" and vice versa. When the patient is finally discharged by the physician through the EHR, ADT sends an automated alarm and email to the HCS administrator and they can then finalize the episode.

The more complex situation occurs when the patient experiences an exacerbation of his or her disease(s), is admitted to the ER and needs admission to HIBA for higher level care. When in the emergency room physician admits the patient an ADT automated alarm is sent to the HCS physician and the other to the HCS administrative staff. HCS administration gives the patient a "PRE DISCHARGE" notation in ADT\ which allows the HCS physician 48 hrs to complete the discharge in the electronic medical record of HCS EHR.

Electronic signature

Since authentification is done by electronic signature, a digital photo is taken and printed in a chip card with personal data (private key and certificates), which is given to each physician with an USB card reader to install on their PC or Notebook (Figure 3). A paper instruction manual and a face to face tutorial on electronic signatures were provided. In addition we replicated this information in our"Campus Virtual del HIBA (www.campus.hospitalitaliano.org.ar)"; here they could download the manual and see the instruction at their convenience or for knowledge reinforcement. The documents to sign were the new clinical notes, the discharges and discharge summaries.

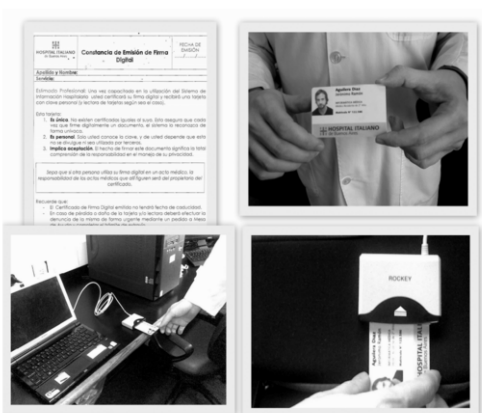

Figure 3 - Agreement-Card-USB card reader

Post-Implementation Data Analysis

During the period from January 2009 August 2009, the HCS admitted a total of 10,836 patients, 82% of "Homecare" and 18% of "Follow-up".

There is an average of 26 days of hospitalization for "Homecare" and 38 days for "Follow- Up care".

32 % of the patients admitted on ER where from HCS because of exacerbation of their disease.

The ten most frequently input clinical disease were taken from ICD 9 classification. During the same period, the four most frequent were: Essential hypertension (27%), Dementia (12%), cognitive deficit (11%), Urinary tract infection (8%).

The remainder was further classification of factors influencing health status, infections and diseases of the nervous system and sensory organs, injuries and diseases of the circulatory system, musculoskeletal and connective tissue, and the genitourinary system.

Clinical information captured will enable research, audits to improve care and better clinical management. Improved patient monitoring identifies deficiencies in the process and assists management in the HCS [9].

Workflow can be monitored online and patient's relatives can be better informed. The initial stages were overcome, but one of the critical was the transition from the administrative work in paper to the electronic form. Also to select the proper technology and way of implementation so the work flow is not interrupted.

Other critical task was not to add unnecessary complexity or increase the cognitive effort required for interaction with devices. If information technology is not implemented or not well integrated into the work often result in duplication or suboptimal division of tasks. [10]

The limitations of our work were that we didn't measure any outcome or any test of usability yet. Another limitation of the system that is being developed and nearly implemented, the possibility that nurses can write notes and physician can prescribe the patient's chronic medications.

Conclusion

The design and implementation allowed, personal previously excluded (medical, administrative, and nursery) now included in the Health Information System of the Hospital Italiano. Strikingly improved the staff communication of the HCS with the rest of the Services and between themselves too. Now there is information into Clinical Data Repository and also to manage and audit for future. Now all patients are correctly located in the city with georreference. All clinical notes of physicians are complete and more organized.

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We thank the physicians, nurses and administrators of the Homecare Service of HIBA.

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A Home-centered ICT Architecture for Health-enabling Technologies

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Abstract

Population ageing needs health-enabling technologies for delivering pervasive health care. Home care plays an import role in pervasive health care. In this paper, we aim to construct a home-centered health information system architecture which can efficiently manage multi sensors, actuators and decision support systems. Open Services Gateway initiative (OSGI) was used for constructing the service oriented architecture. HL 7 Arden Syntax for medical logic module (MLM) was used to describe the medical knowledge; An Arden compiler was used to interpret the MLMs. The Arden compiler was packed in an OSGI bundle. All of the knowledge bases can share the compiler within the OSGI platform. System within the OSGI-based architecture can change their behaviors during runtime. The proposed prototype architecture was deployed in a case study.

Keywords:

Health-enabling technologies, Home care, Information system architecture, Decision support system.

Introduction

With the improvement of living standards and medical quality, people have rising life expectancy. A United Nations population division report shows the changes of the age structure [1]. The global potential support ratio (the number of people age 15-64 per one older person aged 65 or older) has decreased from 12 in 1950 to 9 for today and is estimated to 4 in 2050. The number of persons aged 80 or older is 1.6% of the population worldwide for today and is estimated to be 4.4% in 2050. Every country is facing or will face population ageing and the issues that come along with it. Older people have a significantly greater probability of having multiple chronic diseases than younger people [2]. An estimated 14% of the world's older persons live alone, who might need outside assistance in the case of illness or disability and are at greater risk of social isolation and poverty [3]. Population ageing is an unprecedented challenge for human societies.

With the development of information and communication technology (ICT), pervasive health care, which contributes for the independent life of ageing people, keeping up quality of life and self-sufficiency of ageing people, might be one solution for the ageing society. According to Jakob Bardram, one of the important pervasive health care aspects is home care [4, 5]. Many researchers try to develop home care system for monitoring of vital signs and for improving life quality. Rogers et al have developed a home-based monitoring system for measuring blood pressure [6]. Using of the home monitoring system, detection of essential hypertension has significantly improved. Angius et al have developed a home care system exploiting the DVB-T technology [7]. Using of the set-top box enables untrained or even elderly people can easily use the system. A low-cost base station for the acquisition of 1-lead ECG signal has been connected to the system. Jakkula et al have created a smart home which can perform automated health monitoring and detect anomalies [8]. Based on the context information of interactions with electronic devices, models of resident behavior in the smart home were analyzed.

Decision support system (DSS) is an effective method to improve the price-performance ratio of patient care and reduce medical error [9]. DSS has also been used in home care system for dealing with vital signs and for assisted living. Marschollek et al have developed a home care DSS which can merge smart home and vital signs [10]. Using data from different sauces enables individualized, more personal decision support. Song et al have developed a DSS for home-based rehabilitation of patients affected by chronic obstructive pulmonary disease [11]. This DSS can observe and control physical ergometer training sessions autonomously.

A home care information system contains some key elements: people especially old people, sensor for measuring data, DSS for processing data, and actuator for the implementation of the action. These four elements can form a loop (figure 1), this loop enables people have an assisted living. In order to fully care the elderly, multi sensors, DSSs, and actuators should be used in the home care information system. To efficiently manage the multi sensors, DSSs, and actuators, a high-quality information architecture is very important.

Objective

The aim of our research is to construct a home-centered health information system architecture which can efficiently manage multi sensors, actuators and DSSs.

Methods

Open Services Gateway initiative (OSGI)

OSGI is a service-oriented architecture and has been used in building automation [12]. We use OSGI framework to build up the home-centered health information system architecture. The so-called bundles within the OSGI framework are services. The bundles can be remotely installed, started, stopped, updated and uninstalled during runtime. This means, it is possible to connect or disconnect new services without having to reboot the system. We embedded the sensors, actuators and DSSs in the bundle so that they could work as service and could be controlled individually during run time.

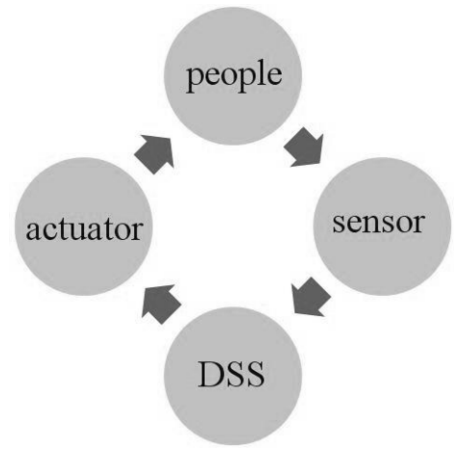

Figure 1- loop in home care information system (decision support system (DSS))

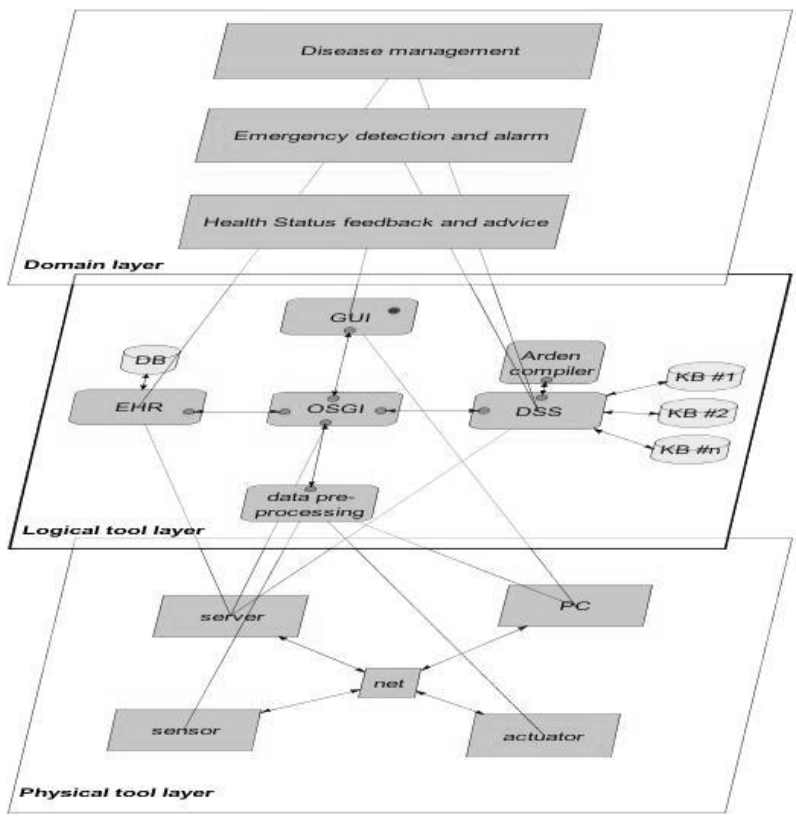

Figure 2- Three-layer Graph-based meta model (3LGM^2) of the proposed home-centered health information system architecture (electronic health record (EHR), graphic user interface (GUI), decision support system (DSS), knowledge base (KB), data base (DB), Open Services Gateway initiative (OSGI), personal computer (PC))

Arden Syntax for medical logical module (MLM)

Health level 7 (HL7) Arden Syntax for MLM is a language to encode medical knowledge for delivering decision support [13]. The medical knowledge is organized into MLM by Arden Syntax. We propose to use Arden Syntax for MLM in the home-centered health information system, because it facilitates knowledge sharing among health care providers. The knowledge base (KB) standardized by Arden Syntax for MLM can provide interoperability with other heath information system (e.g. hospital information system).

We utilized the commercial software "Medexter" [14] to interpret the Arden Syntax. "Medexter" contains an Arden compiler and an interface to connect to other host systems. The Arden compiler supports the Arden Syntax version 2.7.

Results

A service-oriented architecture

We use Three-layer Graph-based meta model ($3LGM^2$) [15] to describe the proposed home-centered health information system architecture (figure2). The three basic tasks of home care: disease management, emergency detection and alarm, as well as health status feedback and advice [16], proposed by Haux et al are shown at the domain layer. In the logical tool layer, OSGI framework is used to construct the service-oriented architecture, electronic health record (EHR), data pre-processing module, DSS and graphic user interface (GUI) are connected as bundles in the framework. The data pre-processing module is connected to sensors (or actuators) and used to provide preliminary data treatment. The meaningful data gathered from sensors are recorded into the EHR. The EHR is connected with DSSs which are used for emergency detection and alarm, disease management, as well as daily assistant. Delivering decision support for people especially old people in home environment contains many aspects, e.g.: fall detection, training controlling, appointment scheduling, etc. Each aspect should have a corresponding DSS. Managing of multi DSSs is a challenge in the architecture; the solution is reported in the next section. The GUI is used for the feedback of the health related information to people who live at home. In the physical tool layer, sensors, actuators and computers are connected by wireless or wired network. Sensors measure people's vital parameters, actuators enable an assisted living.

Managing of multi DSSs

As expressed in the previous section, multi DSSs including KBs should be used in the home-centered health information system. We used Arden Syntax for MLM to standardize the knowledge and packed the Arden compiler into an independent OSGI bundle for sharing of the compiler. This compiler bundle exports all of the packages which are used by other bundles for interpreting MLMs. The MLMs in each KB were connected with the compiler bundle through an interface bundle. MLMs in the same KB can be linked directly according to the logic; MLMs in different KBs are not allowed to fire each other directly. The compiler bundle can be started or stopped. If the compiler bundle is stopped, the MLMs cannot be interpreted. This design is demonstrated in Figure 3.

Case study

We have built a smart home equipped with environment sensors and on body sensors to deploy our home-centered health information system architecture. This smart home is designed for old people who have multiple chronic diseases and live alone. OSGI-framework is used in the smart home to build up the architecture. Some sensors are embedded into OSGI bundles, so they could be controlled during run time. Figure 4 shows most of the sensors in the smart home.

We have constructed two DSSs which were embedded in the OSGI-framework. One DSS is used for rehabilitation training of patients suffering from COPD; the other is used for fall detection. The two DSSs shared one knowledge engine, but the two KBs in the two DSSs were stored and managed separately. MLMs which are stored in the same KB can call each other directly. The knowledge engine can find and fire the MLM through a unique routing.

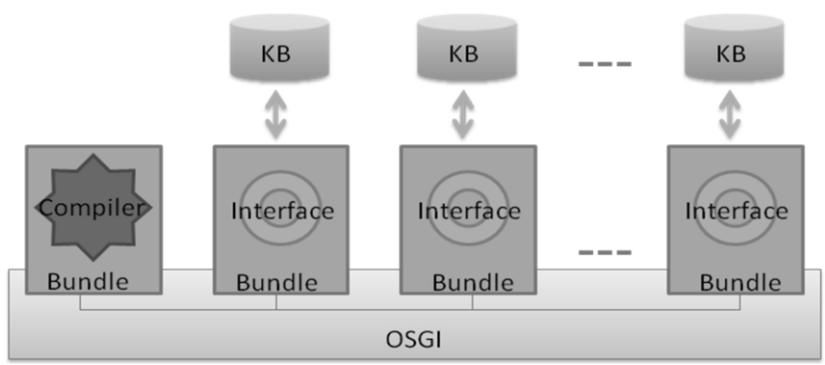

Figure 3- sharing of Arden compiler within Open Services Gateway initiative (OSGI) framework (knowledge base (KB))

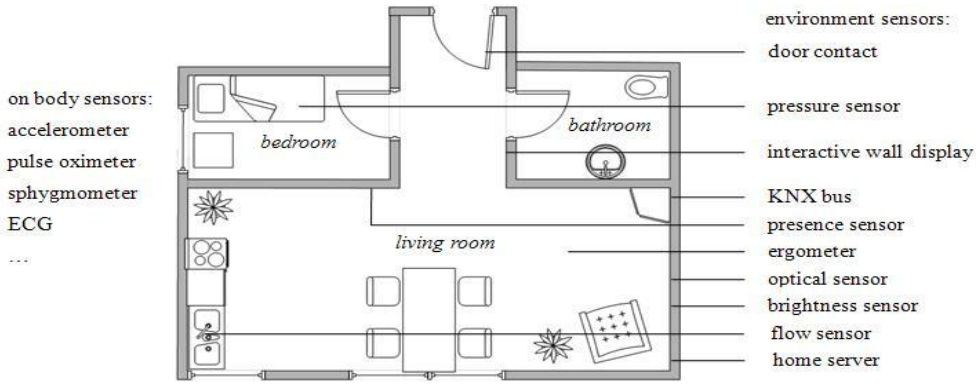

Figure 4- The smart home equipped by environment sensors and on body sensors (Electrocardiography (ECG))

The triaxial accelerometer is one of the on body sensors, it is used for activity detection (e.g.: fall, step, etc) [17]. We take the triaxial accelerometer as an example to follow a work flow of the smart home. An old person takes the triaxial accelerometer and lives in the smart home, once the DSS detects an emergency situation (e.g.: the person fell and cannot stand up alone), the DSS will automatically fire the rules and call for outside assistance. The related information about the fall gathered by the triaxial accelerometer and other sensors will be recorded into the EHR for further treatment and investment.

Discussion

Health-enabling technologies have the potential to significantly improve quality of life and efficiency of health care in aging societies [18, 19]. Sensor-enhanced information system plays an important role in Health-enabling technologies for delivering pervasive health [20]. Haux et al identified four major paradigms of ICT architectures for health-enabling technologies: [16]

- person-centered ICT architectures,
- home-centered ICT architectures,
- telehealth service-centered ICT architectures,
- health care institution-centered ICT architectures.

In this paper, we propose a service-oriented home-centered ICT architecture. This architecture contains sensors, actuators, data pre-processing module, DSSs, EHR, GUI, etc. Our architecture is based on the OSGI framework and can thus change system behavior on the fly. Using health-enabling technologies in home environment for improving life quality of older people has not only technical issues but also social issues. Sensors might not be accepted for various reasons [21], privacy can be a barrier for people's adoption [22]. E.g.: although a camera can detect an unexpected fall, people don't want to install a camera in their own bathroom. The OSGI framework based architecture enables people choice services on demand during run time.

There are also some other related works about using OSGI in home care information system. The SAPHIRE project tries to develop an intelligent healthcare monitoring and DSS on a platform integrating medical sensor data [23]. OSGI was used to build up the multi-services home care platform which communicates between clinic and the patient's home. In addition, this platform manages the execution of the individualized guideline which is modeled by Guideline Interchange Format (GLIF). The Gator Tech Smart House project aims to create assistive home environments that can sense themselves and resident and enables the communication with outside services [24]. To create the Gator Tech Smart House, a generic reference architecture which contains five layers (physical, sensor platform, service, knowledge, context management, and application layers) was built up. In the service layer, OSGI was used to maintain leases of activated services. In the knowledge layer, ontology was connected to the system.

Comparing with architectures in the SAPHIRE project and the Gator Tech Smart House project, our architecture has not only similarity but also difference. The similarity is that all of the three architecture use OSGI framework. The difference is that we use Arden Syntax for MLM to represent the knowledge in the DSSs (SAPHIRE uses GLIF, Gator uses ontology). Knowledge could also be represented in other formats, e.g.: Drools. We use Arden Syntax for MLM because it has been standardized by HL 7 since 1999 and it facilitates knowledge sharing among health care providers. To the authors' knowledge, this is the first integration of Arden Syntax for MLM into OSGI framework.

To deliver decision support for people especially old people in home environment, multi DSSs including multi KBs should be used. Ng et al have developed an architecture for managing multi DSSs [25]. In this architecture, each DSS has its own KB and knowledge inference engine. We think that sharing the knowledge inference engine among the multi KBs could improve its reusability and reduce the system redundancy. The precondition of sharing knowledge inference is that the knowledge in different KBs should have a unified representation form. The KBs which are standardized by Arden Syntax for MLM in our proposed architecture fulfill the precondition. We

packed the knowledge inference engine (Arden compiler) into an independent OSGI bundle. This Arden compiler bundle is responsible for interpreting MLMs in all of the KBs. We evaluated this design with two KBs in a prototype-like laboratory implementation; a formal evaluation with multi DSSs will be done in the further.

Conclusion

In this paper we have introduced a home-centered ICT architecture for delivering pervasive health care. Systems in this OSGI framework based architecture can change their behaviors on the fly. To deliver decision support, HL 7 Arden Syntax for MLM was integrated into the architecture. This architecture could be used in a home environment for improving life quality of people especially old people.

Acknowledgements

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Information Needs in Home Based Healthcare in South Africa

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Abstract

Home based health care (HBHC) is advocated by the WHO "to ensure better accessibility to effective and efficient health care in community and home-settings to improve health and well-being, and contribute to morbidity and mortality reduction". In South Africa the government and many other role players see an increasingly important role for HBHC. Many researchers believe that the evolution of HBHC will follow the socio-technical network evolution. There can be no doubt that the focus is on using information and communication technologies (ICT) to implement HBHC solutions. The objective of this paper is to provide a rich picture of the current situation and needs for improvement in HBHC in South Africa today through descriptive research in one specific case. The longer-term purpose is to identify pain-points that require socio-technical solutions, including but not exclusively ICT-supported solutions.

Keywords:

Home nursing, Home-based healthcare, Socio-technical systems, Landscape modeling.

Introduction

A few decades ago house calls by general practitioners, midwives and certain other medical professionals were far from uncommon. Indeed, in developed countries they were considered the norm. As the burden of illness increased globally, and put increasing pressure on health professionals to speed up their patient throughput, the time (and later expense) of visiting patients at home became prohibitive. For instance Meyer and Gibbons [1] reported that even a decade ago in America house calls were on the decline.

Comprehensive community and home based health care (CCHBHC) is defined by the WHO as "…an integrated system of care designed to meet the health needs of individuals, families and communities in their local settings" [2]. Such care includes physical, psychosocial, palliative and spiritual activities. The goal of HBHC is "…to ensure better accessibility to effective and efficient health care in community and home-settings to improve health and well-being, and contribute to morbidity and mortality reduction" [2].

The report further states that many of the recent efforts to establish home based health care (HBHC) initiatives have been driven by specific emergencies, in particular the HIV/AIDS pandemic [3]. Other major drivers of HBHC are maternal health care and geriatrics, and specific outbreaks of illnesses such as TB and cholera, although poverty driven interventions such as famine and drought relief tend not to fall under the same banner as HBHC. The WHO [2] also report that very often HBHC efforts are not derived from government controlled medical efforts, but rather from various NGOs, religious groups, international donors and even from the communities themselves.

As the burden on health services increases, these services will be pressurized to re-invent themselves [4]. Many researchers (e.g. [4-6] and others) believe that the evolution of HBHC will follow the socio-technical network evolution, as originally outlined by Kling and Lamb [7]. Coiera [4] proposes four "rules" to help guide the design of new socio-technical systems in health services, namely "(1) Technical systems have social consequences; (2) Social systems have technical consequences; (3) We don't design technology, we design socio-technical systems; (4) To design socio-technical systems, we must understand how people and technologies interact". This reinvention is not just limited to under-developed environments. Even such prestigious institutions as the Johns Hopkins Home Care Group (part of the Johns Hopkins University) are having to rethink their approach to this issue [8].

Bentur [9] states that different health care systems have different objectives with respect to the extension of health care service to the home. Amongst these are "providing services to small populations dispersed over large geographical areas, improving access, easing the burden of hospitals and responding to patient preferences." Cost containment without loss of quality of care remains a priority, however.

Although much work has been done in America and Europe on home based health care, it is clear that much benefit will be felt by applying these principles to under-developed countries, where resources of all kinds are stretched the thinnest. Epping-Jordan et al. [10] cite problems identified in the Caribbean, India and South Africa in this respect. Lehoux et al. [6] raise the issue of "information infrastructures" (II), and countries such as South Africa, being on the wrong side of the "digital divide", are particularly susceptible to the issues of scalability.

A number of models for addressing HBHC have already been documented. Ncama [3] cites cases from Malawi, Botswana,

Zimbabwe and South Africa concerning HBHC for families living with HIV/AIDS. She mentions some of the many role players in HBHC, and the confusion amongst them as to what their various roles are, or should be. The Department of Health, NGOs, "concerned citizens", religious bodies, and communities themselves have all, in various places and at various times, started HBHC initiatives.

Technology usage has also come under scrutiny. Although Shaibu [11] documents a non-technology driven HBHC situation in Botswana, there can be no doubt that the focus is on using information and communication technologies (ICT) to implement HBHC solutions. Kling and Lamb [7] describe research into the use and acceptance of medical technology in home care settings. Their findings indicate that, whilst such technology can prove to be useful, it isn't necessarily so, and can have a negative impact of raising false, or at least dubious, hopes amongst the recipients. Lehoux et al.'s issue around scalability is largely reliant on the implementation and availability of ICTs [6].

Access to technology is not the only limiting factor in a South African context. Given that most HBHC will be implemented in the most chronically poor areas, concern will have to be given to the physical security of the technology. Anything requiring the use of a standard PC or mobile phone is likely to suffer from problems of theft. Anything requiring stable power will be subject to the country's continuing national power crisis, and any attempt to overcome this using battery or generator backed equipment will run into the aforementioned security problems.

Research objective of the paper

The objective of this paper is to provide a rich picture of the current situation and needs for improvement in HBHC in South Africa today through one specific case. Within the socio-technological paradigm [4] [7], we must start by developing an in-depth understanding of the social context of HBHC in the case. Thus at this stage the emphasis is on descriptive research. However, the longer-term purpose is to identify pain-points that require socio-technical solutions, including but not exclusively ICT-supported solutions.

Materials and Methods

The Socio-Tech SA project

The study was conducted within the *Socio-Tech SA* project (Made-in-South Africa socio-technical methods and education for local software industry to contribute to socio-economic development) funded by the South Africa – Finland Knowledge Partnership programme (SAFIPA). The purpose of the project is to develop socio-technical information systems development methods for South African software practitioners to contribute to socio-economic and human development in South African communities. Home cased healthcare was selected as the case environment where existing methods will be tried and further developed according to local needs.

The data collection process

Several unstructured interviews were conducted, initially with HBHC coordinators and managers, to obtain an understanding of the HBHC landscape in this specific context. This was followed up with interviewing care givers (providing the home-care service) and nursing sisters (who are assessing and managing the patient's care process). At the same time relevant literature was reviewed to establish what was found in other similar studies. A video recording was made of a care giver visiting patients at their homes to observe the entire care process. This allowed us to observe many other activities that the care giver performs that may not have been mentioned in the interviews. The relevant documentation, such as the care plan and care reports, was also studied.

The emphasis for this study and therefore for the data collection, is on the care service path but from the specific perspective of the care giver, patient and primary supporter. The roles of the professional healthcare professional, facility and authority are all to support the care giver, patient and supporter, i.e., those in the communities.

Results

In this section the results of an initial exploratory HBHC study are given. In order to obtain an understanding of home-based healthcare in South Africa a community in the Western Cape was selected. This community suffers from many negative socio-economic factors that impact the well-being of citizens in such communities. They rely on HBHC to deal with many conditions that are beyond the care service provision of public healthcare. NGOs, NPOs and other interested organisations have taken the responsibility for providing home-care services. These organisations rely on funding organisations or otherwise have to raise their own funds to support an ongoing care service. They report to the Depart of Health, their governing bodies, (in this case the South African Hospice Board) and the respective funding organizations.

The NGO investigated is responsible for the home-based care service to a number of communities around Stellenbosch, a town in the Western Cape province of South Africa. They employ qualified nursing sisters as the healthcare professionals responsible for supervising the care givers; assessing the patients/clients who need home-based care by managing the care plan; and finally taking the responsibility for summarizing the data about the care service for reporting purposes. Healthcare professionals are important stakeholders in these communities serviced by the NGO and are responsible for the care plans of the patients/clients and are familiar with the condition of the community in general. They for example know what are the major problems experienced in the communities and are the first to pick up trends. They rely heavily on information about the care visits and spend too much time processing the data which is still collected from paper patient/client folders, daily and monthly care reports.

The care givers themselves are generally from the respective communities and have only a basic training in home-based healthcare. They are responsible for the ongoing daily care

provision to patients/clients according to a schedule compiled by the responsible sister. Their training is of a very elementary level and they can only provide a basic care service. They often have to provide this service in unfavourable conditions where both their safety and comfort is often compromised. Their commitment and dedication is extraordinary but they feel that the recording of data is taking up too much of their time and that this takes their attention away from their patients.

The actual care service at the home of the patient/client is often attended by many family members and other supporters involved with the patient/client and it is clear that they are actively involved in not only the visit but also taking care of the patient/client on an ongoing basis. The care givers also observe the condition of the home, the availability of food and other supplies, and whether children are looked after. Care givers are well respected and accepted in the communities although in some cases they are refused entry to homes where patients/clients fear that they may be stigmatized, e.g. HIV/AIDS is still a very sensitive issue in many communities where much folklore about this condition still exists. This also applies to some psychiatric conditions. It is therefore clear that the primary care giver, family members, friends and neighbours are important and active participants in a home-based care service. Many of these supporters are ill informed about the condition of the patient and as a result are ill-equipped to care for the patient.

Patients are often referred to as clients since their home care needs may not result from a medical condition, e.g., malnutrition through poverty. In poorer communities their only access to a care service is overcrowded public health facilities which are often at a far distance from their home. The condition of their homes is often inadequate and they do not have the basic necessities and are often not protected from the outside elements. The home-based care service is an absolute necessity for the patients/clients in the poorer communities to provide them with access to a much needed healthcare service. They are often not well informed about their condition and may not be able to assist with administering their own care. Many are illiterate and cannot read the instructions for their medication.

Following from the above findings the landscape model was used as a basis to depict the home-based healthcare service path and the different stakeholders' involvement. The main emphasis of this study is on the needs of the care giver, the patient/client and supporters from the community. Specific research questions were derived from the above to direct further studies to incorporate ICT into an improved home-based healthcare service model to address the information needs. In order to ensure that the different stakeholders' needs are met any design and development of systems with ICT components need to be done with the active collaboration of the stakeholders. The landscape model is an important aid to unpack the complexities around home-based healthcare. It is important to consider the context of home-based healthcare because the different communities are affected by factors that related to their contexts. The context of the HBHC case is depicted in the canvas part of the landscape model illustrated in Figure 1.

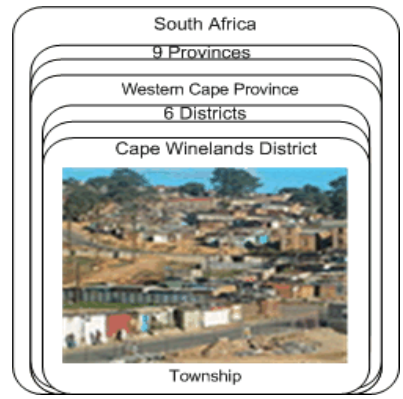

Figure 1 – Context of the Township

In Figure 2 HBHC from the patient's perspective is depicted. Most organizations providing a HBHC service prefer to refer to clients rather than to patients. Although clients sometimes live alone, they live mostly in dwellings with many other relatives or other citizens. In order to address the information needs of the patient the indicated questions need to be answered.

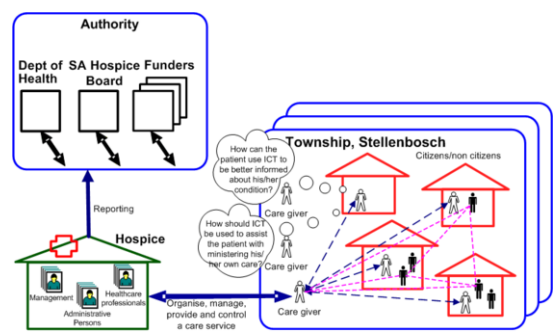

Figure 2 – HBHC from a patient/client perspective

Although the individual members in a community can be referred to as citizens it is also the case that in many communities citizens from other countries also find a home. In some cases the presence of these refugees causes tension in the community where resources are already stretched to a limit. Although there is already a sense of caring for each other present in the community this often is without sufficiently being informed about the condition of the person being cared for and also without knowing who else experience a similar situation. An example is when a person is diagnosed with TB and receives care for it; the supporters of that person may want to know more about TB in order to deal with their perplexities about the condition. Persons fulfilling the role of supporter can gain tremendously from being part of a supporting network where information and experiences can be shared amongst persons dealing with similar situations. In Figure 3, the shaded persons represent the supporters and the dotted

lines indicate how such a network can be formed aligned an interest in a particular condition or issue. The information needs for the primary care giver are to support them when caring for the patient or for interacting with each other and the care giver.

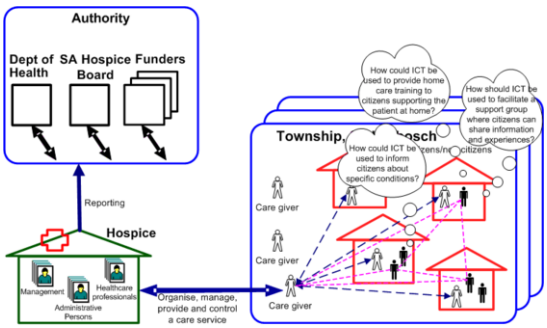

Figure 3 – HBHC from a primary care giver perspective

The care giver's information needs are indicated next as illustrated by Figure 4. They obtain the details for the patient/client's care from the care plan which is kept at the home of the patient. The care plan is compiled by the healthcare professional who does the initial assessment of the patient/client and based on the care needs devise a suitable care plan. They record the details of what they have done to the care plan and write the visit details on the daily care visit report. The patient/client has to sign the report and in the case of illiterate persons to make an "X". The care givers communicate with healthcare professionals to ask for advice when the care plan is not specific enough or the patient has developed another problem. This is not always possible since not all care givers have access to a mobile phone. They meet once a month to give feedback to the NGO and discuss common problems. Care givers not only rely and information to care for the patient but at this stage the manual recording and summarising of data waste much of their time.

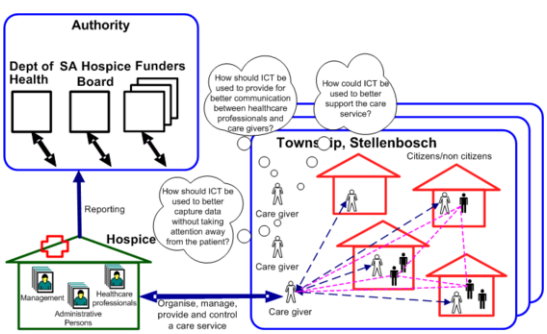

Figure 4 – HBHC from a care giver perspective

Facilities rely on data of good quality in order to manage the home-based care service. They need to know who are the patients and care givers; details about the location of the patients/clients and their care needs as well as availability of care givers are important to assign care givers and to schedule care visits. They need to know how many patients they have in the different areas; what types of care are required; any trends; etc. The paper care plan folders are collected from the homes and brought to the NGO every three months to be updated before being taken back to the homes. A copy is also kept at the facility which means that data is duplicated.

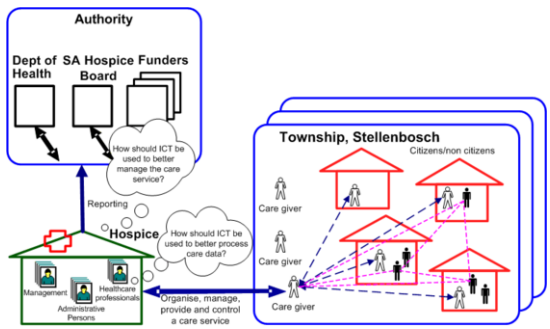

Figure 5 – HBHC from a facility perspective

Not only are organisaions, e.g., NGOs, hospices, etc., responsible for the home-based care service in the communities but are they also accountable to the different authorities. They need data of good quality to report to HBHC situation to the different authorities and each wants it in a different format. Many hours are used to capture, transfer, process, aggregate and summarise data. The primary data is manually collected from the different paper reports and entered into the computer which currently uses spreadsheets to manipulate the data. Little of this manipulation is automatic and the administrator has to still transfer data to the different sheets. Stats are not compiled from the individual source data but instead the aggregated figures are calculated manually and then these are entered in the computer. There is currently no electronic patient record system in use.

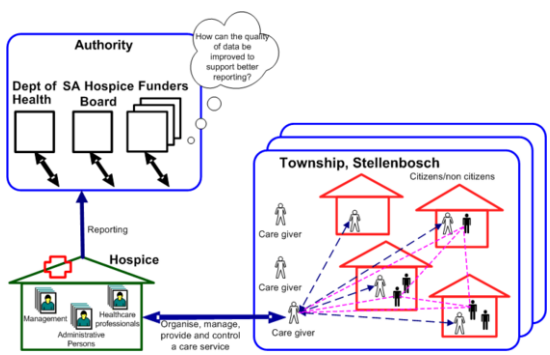

Figure 6 – HBHC from a authority perspective

The current focus of this study is not on the authority's information needs but it already follows from the other perspectives that if their information needs are addressed then ultimately the authorities could also gain. Data of a better quality will improve reporting of home-base care cases, issues, etc. which ultimately enable authorities to better respond to specific community needs. It will also be possible to identify trends in time to cater for a specific condition, e.g., the number of swine flue cases will indicate whether there is an urgent need for inoculation and to put other preventative measures in place.

Discussion

It follows from the above that HBHC is an important and necessary service to citizens in communities that have a need for a healthcare service for citizens not having easy access to public healthcare facilities. It is also clear that often NGOs take the responsibility for delivering such a service. The five landscape models depicting the main perspectives show the care service paths and questions that represent the stakeholders' information needs. The HBHC landscape is even more complex than anticipated and the introduction of technology solutions will add to the complexity. The results confirm that a comprehensive community and home based healthcare (CCHBHC) system is required that will have social and technical components [2]. Any design for such a system will have to follow the four rules [4] for socio-technical design, accepting that social and technical systems have consequences for each and that it is important to understand how people and technology interact. The CCHBHC system should provide for a care service that addresses the needs of the entire care path. In order to obtain a better understanding of how stakeholders interact with technology this interaction where the social and technical worlds overlap need to investigated.

The proposed socio-technical approach provides for close collaboration between the users and developers of a system with both social and technical components. It is also necessary to consider all the other social aspects in addition to where the users interact with technology to cater for an improved care service provision.

Conclusion

The importance of HBHC is not only confirmed but in fact emphasized. In countries where there is severe pressure on an over-burdened healthcare system such a service is crucial and necessary. This may be in contrast with affluent countries where the emphasis is more on comfort for care at home. The stakeholders involved in HBHC are already committed and therefore the only possibility to improve the care service is to consider technology solutions to address their information needs. Further research should be directed to address these needs.

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Integration of Cognitive and Physical Training in a Smart Home Environment for the Elderly People

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Abstract

Our research work is towards a service that can support senior citizens towards their independent living and active ageing. As it is suggested, physical and cognitive exercise training can contribute to a significant prolongation of personal autonomy and participation in society across prevailing age-related impairments such as cognitive decline. In the current paper, the approach of combination of both physical and cognitive training - adopted by LLM project - is discussed related to other similar projects that have taken place in the area of elderly home care and training. The aim of this work is to describe the technical design details of the integration process of the LLM service, which is based on a Web service architecture and to discuss alternative interface elements to be included in the LLM platform in terms of enabling user accessibility and acceptance.

Keywords:

Cognitive, Training, Elderly, Assisted, Independent, Mild cognitive impairment

Introduction

Substantial advances have been made over recent years in applying technology to meet the needs of older people. In parallel and in accordance with e-Health solutions, the field of Ambient-Assisted Living (AAL) has been developed, aiming on alleviating the difficulties of everyday life for the elderly or people with disabilities in general [1]. Taking into account the increasing number of elderly population in Europe and the identification of its subsequent social and financial consequences, national and European research efforts have focused on such independent living solutions, trying to make an edge on this quickly arising and expanding market [1]. Condition monitoring of the senior and notification in case of an emergency, comprise the most common features of such systems. This offers a sense of safety and reassurance to the elders themselves and their relatives that they will receive the care required in a time of need, without having to be succumbed to intensive care.

On the contrary, the adoption of technology to elderly healthcare systems is doomed to encounter major problems since the vast majority of this population category is unfamiliarized with the available communication and interaction services [2]. Hence, further attention must be paid to the accessibility and understandability of ICT platforms targeted to seniors, which will provide an innovative solution validated and fitted under realistic scenarios [3].

In the last few years several scientific projects have been conducted concerning the amelioration of senior citizens' overall well being. More recently, a number of solutions have been proposed that make use of sensor networks, from audio and movement to micro- and nano- sensors hand, to detect undesirable situations for elderly, like falls. Projects Netcarity [4], INHOME [5], EMERGE [6] and OLDES [7] fall under this category. AttentiaNet [8] and Seniority comprise two already completed projects which aim at improving the quality of assistance and hence quality of life of elder people in Europe by utilizing advanced technologies for telemonitoring and telecommunications. An alternative framework of tele-assistance services which aims to enhance the security of elderly not only in their home as the previous case, is introduced by the MobilAlarm project, where older people are enabled to initiate an alarm call whenever and wherever they need to do so (using GPS; mobile telephony; body-worn alarm devices; service centres; geographic localisation and alerting software). Another, more recently proposed perspective for a solution to the same problem is offered by Confidence [9] and SMILING projects that utilize wearable tags and non-invasive systems to detect mobility patterns and provide a sense of security in the Third Age.

Apart from improving the physical status of senior citizens, several European projects have been focused on the mental health of elderly people attempting to alleviate the difficulties from certain deficits which are common among this population. In accordance with mainstream e-Inclusion targets, this approach's objective is to retain elderly people socially active and more self-reliant for a wider period of time. An example of such projects is the FP7 HERMES [10] project which aims at providing an integrated approach to cognitive care, based on assistive technology that reduces age-related decline of cogni-

tive capabilities. HERMES offers cognitive training through games, while also supporting them in indoor as well as outdoor environments, when necessary. On the other hand, VM (Vital Mind), provides cognitive training by using related psychology, a TV-set and advanced ICT. The reasoning of VM is to enable elders to exercise actively and autonomously in front of the familiar to them television medium. Support for elderly people with cognitive disabilities, and especially mild dementia or Alzheimer's disease, is provided by COGKNOW [11], which aims to develop a cognitive prosthetic device which will help elder "navigate through their day". Functionalities like reminders and support for communication and anomaly detections are planned to deliver this promise. Finally, the Elder-Games project [12] offers the ability to elderly to train themselves through a series of mixed reality games, whose design is specially adapted to their needs, with particular emphasis on the maintenance of their cognitive skills.

Furthermore, several programs have focused on the improvement of elderly people physical condition and especially target to the training of their balance, endurance, flexibility and coordination. Through the use of interactive technology and virtual reality technology, physical interventions have been successfully applied to seniors. An example of this kind of training is a program called TheraWii. It incorporates the use of Wii Balance Board (four accelerometers are embedded at the four corners of the board and record each step (x, y, z coordinates) of the user), a Bluetooth adapter connected to a PC and a game-like interface, with which seniors are interacting. TheraWii offers seniors the chance to combine exercise and entertainment in order to improve their physical health and quality of life.

Though several other categories for applications for the elderly can be identified like mobility aids or medical implants, the aforementioned ones are those more closely related to the Long Lasting Memories (LLM) project [13]. By enforcing the unprecedented approach of simultaneously inducing neural and corporal stimulation in a safe and controlled environment, this platform will deliver an effective countermeasure against age-related cognitive decline, thus significantly reducing chances of mild dementia or Alzheimer's disease appearance. Moreover, the service will utilize a number of remotely operated screens, which will be embedded in the independent living environment and connected to training equipment (like recumbent bikes, ergometers or treadmills). Light exercise will be combined with a targeted set of cognitive exercises, while the environment's sensors will ensure the safe and enduring application of this training, adjusting, intervening or providing motivation according to each person and situation. The aim of this paper is:

i. to describe the technical design details of the integration process of the LLM service
ii. to describe alternative interface design scenarios to be incorporated in the LLM system

Materials and Methods

As already mentioned, the heart of the LLM service is an integrated ICT platform which combines state-of-the-art cognitive exercises against cognitive decline with physical activity in the framework of an advanced ambient assisted living environment.

Thus, the main service is comprised of three independent components:

- CTC, Cognitive Training Component
- PTC, Physical Training Component
- ILC, Independent Living Component

These three independent components will meet the proposed service by means of a server side system, which is comprised of a database and a web service and a decision making system called Central Management System (CMS). The main aim of the LLM system is to offer support not only to elderly people but also to their relatives and families.

Web Service Architecture

The integration aspects of the system are tackled on the basis of a web service and a database. The web service is responsible for providing all methods and functions in order to support the three independent components' and CMS's functions as it is depicted in Figure 1. Moreover, the web service is responsible for the authentication of the system's users according to their role. A database accompanies and supports the web service's procedures. Each of the three components accomplishes a different scope of application and provides heterogeneous data and semantic sources. According to these requirements the proposed architecture must support the integration of the data and the co-ordination of the components' functionalities. One of the major features that the proposed architecture should accomplish is flexibility. The web service's architecture and functionality will be open in order to allow new developments to be integrated and supported by the proposed service in the future developed components (CTC, PTC, ILC). The only prerequisite for the candidate applications to be integrated into the proposed service is to be compatible with the general framework of the service.

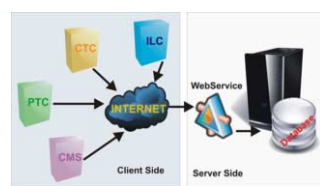

Figure 1- The web service supports the three independent components

The Web Service provides programmatic access to the system's features and services. Developers can build custom applications, tools, and services that correspond to the same services. Typical applications include add/edit and searching for registered seniors, add senior's progress to cognitive or physical training and add information about senior falling or alarms. The Web Service includes the Simple Object Access Protocol (SOAP), Web Services Definition Language (WSDL), and the XML Schema Definition language (XSD). These standards are

supported by a wide range of development tools on a variety of platforms.

The web service provides structures (an example is given in Table 1) as inputs and outputs to all supported methods. All structures and methods are well described by a human readable document which is publicly available. Moreover, each structure is accompanied by an "error" structure in order to facilitate appropriate message exchange with the components.

Table 1 – Structure for senior's demographic data example

```
<s:complexType name="senior">
   <s:sequence>
      <s:element minOccurs="1" maxOccurs="1"
name="senior_id" type="s:int"/>
      <s:element minOccurs="0" maxOc-
curs="1" name="lname" type="s:string"/>
      <s:element minOccurs="1" maxOc-
curs="1" name="birthdate"
type="s:dateTime"/>
……..
   </s:sequence>
</s:complexType>
```

For example, in order to add an activity performed by a senior we use the method shown in Table 2. It behaves as a log file of the senior's progress and activities. The required attributes that must be provided are:

- senior_id: The senior that performs the activity
- ctcactivityid: The CTC Activity that is performed by the Senior
- ctcid: The CTC Component that is used by the senior in order to perform the Activity
- datetimestart: The date and time that the activity started
- datetimeend: The date and time that the activity ended
- score: The score that is achieved by the Senior
- level: The level of difficulty of the performed CTC Activity

Table 2 –C# example using LLM web service method to record user's performance to a certain CTC activity

```
ctcactx = new CTCSeniorActivity();
ctcactx.ID = 0;
ctcactx.senior_id = 16;
ctcactx.ctcactivityid = 1;
ctcactx.ctcid = 1;
ctcactx.datetimestart = new Date-
Time(2009, 6, 21, 10, 00, 00);
ctcactx.score = "16";
ctcactx.level = 8;
ctcsac = AddCTCSeniorActivity(ctcactx,
"username", "password");
if (ctcsac.error.ErrorCode == 0)
ctcactx =
ctcsac.CTCSeniorActivityList[0];
```

A senior has the privilege to use this method only for himself, the Therapist for all of his/her Seniors and the Administrator for all the Seniors. The common scenario is the senior to provide his activities (by LogIn to the LLM system).

Scenarios of Use - Interfaces

Each component, like ILC, CTC and PTC, supports a finite predefined number of activities. These well-described (by the component's providers) activities behave as the elementary entities of the Seniors Interaction. For example, the movement activity in the kitchen may be named "KitchenActivity1", the movement activity in the bedroom may be named "BedroomActivity1". These two activities are different entities. Another example may include the procedure of software that displays 3 screens to the senior (with different multimedia material each time). This may be a CTC Activity. In conclusion, activity is a set of exercises that is treated by LLM system as an Activity. The activity is performed by a Senior and a score for this activity is generated. The proposed system supports a finite number of activities. This number stems from the activities that are supported by the CTC, the ILC and the PTC. These activities are defined by the providers of the components and added to the system once. If a new Activity is available, the administrator is responsible for adding it as a supported activity of the system. Moreover, the term Component is used in order to describe the system that is used by the ILC, CTC and PTC. For example, the Components of the PTC may be a treadmill model1, a treadmill model2, a Wii Balance Board, a Wiimote, etc. Each of the above activities may be available to more than one Component. For example, the "walking" activity may take place at the treadmill model1 or the Wii balance board. If a new Component is available, the administrator is responsible for adding it as a supported Component of the system.

Independent Living Component

The ILC component is based on the eHome system [14], which is comprised of a network of wirelessly distributed operating sensors connected to an embedded system (the e-Home central unit). It includes features such as intelligent learning of normal and exceptional patterns of behavior (dangerous situations or indicators for emerging health or social problems), raising of alarms and controlling of elements which are typical for a smart-home environment. Falls constitute one of the major safety and health risks in older people. For this reason the detection of possible falls plays an essential role in the concept of the sensor technology to be used.

Cognitive Training Component

The CTC is designed to support the cognitive exercising procedure. Any software that is compliant with the web service can be used for this process. Several applications (commercial or not) will participate in the early stages of the service development so as to validate the integration of the system and its usability. The cognitive training procedure contains several kind of exercises that target to specific brain functions, such as memory, attention, etc.

Physical Training Component

The system is completed by the Physical Training Component (PTC) which is comprised by custom training equipment. The only prerequisite for this equipment is to be able to provide exercise performance output. Sub parts of PTC should offer a variety of physical exercising possibilities according to needs and disabilities of each individual. The system will monitor the user's performance progress and will provide feedback using motivation messages and performance indicators. Possible physical training equipment options are: Ergometer Bikes, Treadmills and Wii Balance Board and Wii Remote

Central Management System (CMS)

CMS offers the end user an intuitive, simple to use graphical interface for interaction with the cognitive training system, the physical training system and the independent living component. Besides this, the CMS will be responsible for providing the appropriate feedback to the interacting senior:

- A humanoid avatar, like in Figure 2, will accompany the individual during his/her activity
- Scheduling daily form activities and plan based on previous data (overall performance, physical training, cognitive training)
- Making use of current and previous performance indicators, avatar acts not only as an instructor but also as a supporter, by motivating the individual to achieve expected targets
- Recognizes individual's presence (ILC) and makes a reception call

A television or a touch screen will host the main graphic user interface (GUI) of the system, thus providing elderly a more user-friendly mean of communication with the LLM system. Although touch screens concerned as user friendly input devices, voice recognition and remote controls (wii remote) may be used as the interaction layer between the senior and the system. Apart from providing an abstract schedule for the senior's daily activities, CMS is responsible for displaying the appropriate GUI of the three components, based on the current activity.

Figure 2- Avatar accompanies senior during exercise

User Roles

The system is able to deal with 4 Member Roles. The Role with the most limited access rights is the Relative (User) who is able to get information about his/her relative (senior). More privileges are attached to the Senior (Senior) who has not only the right to see his/hers progress but also to add information about it (through his/her LogIn action to the ILC, CTC and PTC). The Therapist has the authority to add/edit, delete and get results about all seniors that are under his/her supervision (Seniors that are attached to the Therapist). Finally, the administrator has all the available rights [15].

Prototype testing

For the prototype testing a scenario of home installation was selected, as it is shown in Figure 3.The proposed system and especially the web service were tested by contributions of the components' providers. The system testing concerned the efficiency, efficacy, data encryption, data integration and fusion, versatility, code re-usage and cost savings. During evaluation of the web service development, substitute took place in order to provide us with more conclusions concerning the testing. Moreover, some of the methods were redesigned and redeveloped according to the contributors' comments and ideas. As a result, the proposed system is able to support the components; as it was designed for (ILC, CTC and PTC). Although the data semantic information derived from different data source is different from one component to the other, the proposed integration technique seems to be promising for giving a more enhanced meaning to this kind of data fusion providing CMS with information needed for its decision – support system. Last but not least, data encryption techniques provide protection from privacy vioaltion and preserve anonymity of each senior user across the Internet.

Figure 3- Trial site. At Home installation scenario

Furthermore, the combination of the proposed methods and structures may provide a standard on the integration of different components targeting to elderly people ambient assisted living [16].

Discussion

As discussed in the introduction of this paper, an ICT platform which integrates physical, cognitive training and independent living components may be promising for the improvement of elderly people quality of life. Moreover, continuous brain and fitness exercise are considered as one of the most important methods of prevention in elderly dementia and more specific in Mild Cognitive Impairment – MCI (early stages of dementia) [17]. Although seniors with MCI are able to stay at their home, they often visit day care centers. A system as the one proposed to this paper should be able to be applied in both situations. Furthermore, the LLM system due to its open and flexible architecture design, can meet the needs of a wide

range of elderly population, as it is able to integrate any application or device, which complies with the LLM infrastructure. Therefore installation and implementation costs per home can be dramatically reduced and suit to each end user's financial affordability. Future steps include testing of the proposed system not only to senior's homes but also to day care centers. Moreover, trials to different European countries will contribute not only to the further evaluation of the system, but also to the extrapolation of conclusions concerning the benefits of concurrent usage of CTC and PTC by seniors with MCI.

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A Configurable Home Care Platform for Monitoring Patients with Reminder Messaging and Compliance Tracking Services

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Abstract

This paper illustrates a platform based on a general architecture for implementing home care services for chronic patients composed of a Remote Care Unit located at a patient's home and a Health Care Center Unit located at the treating center. The Remote Care Unit may be deployed on multiple platforms including PCs, mobile phones and even embedded devices not equipped with monitor, and may be configured to support many interoperability issues occurring among the parties involved in a health care delivery process. The platform may be tailored to match the specific issues of any chronic disease supporting either data acquisition as well as customized reminders and notifications from the center. Remote Care Unit platforms are also able to exploit multiple channels for acquiring data, including wireless links with medical devices, speech interaction and graphical user interaction. In this paper a couple of applications addressing the needs of diabetic and nephropatic patients developed on top of that platform are also introduced.

Keywords:

Telemedicine, Reminder systems, Outpatient monitoring

Introduction

All the western countries are concerned about the ever increasing trend of their health care budgets. As pointed out in [1] those expenses are now growing much faster than GNP on a world-wide basis, with an expected trend of 5% per year which may render them rapidly unaffordable even on a short term. Most efforts are thus being directed at finding new and effective ways to cope with this problem, and there is a common belief that a generalized adoption of the Information and Communication Technologies (ICT), despite some initial hardships, might help in streamlining the health care delivery process thus saving costs at the organizational context while preserving or even increasing the overall quality and effectiveness of health services [2, 3]. This is also witnessed by the increasing efforts addressing research projects in the telemedicine and e-health related areas aimed at preserving a close contact of patients with health care providers [4] while not at clinical settings. Furthermore, encouraging treatment of patients at their homes besides saving costs may also reduce the stress they suffer during a hospital stay [5]. However special care should be undertaken in developing those applications since a patient is inherently forced into the role of an application user.

This paper introduces our approach to the problem illustrating the telemedicine platform we have developed. The platform is based on a general telemedicine architecture addressing the interoperability issues of chronic outpatients, and makes use of mobile network devices such as cellular phones, palmtops and PDA's in addition to PC's in order to provide an advanced framework for remote clinical monitoring while also facilitating interaction among patients and their families as well as with the health care staff.

Materials and Methods

Addressing communication issues for chronic patients

There is a long-standing debate about the compatibility of ICT solutions with physicians' clinical routines. While at the beginning telemedicine mainly addressed the live transmission of images and biological signals to support *on-line* remote consultations with questionable success, recent achievements in computing, networking and data storage now account for new scenarios modeled on the so called *store-and-forward* paradigm. This approach seems to be more useful in capturing and facilitating data acquisition and interoperability issues for patients who aren't in critical conditions [6]. Networked mobile devices are particularly useful in that case since their inability to guarantee an immediate delivery of data or messages, due to transient coverage, becomes a stronghold in addressing the needs of people on the move.

Such a paradigm turns out to be very useful also for chronic patients who are required to manage a disease by themselves while also being busy with their daily activities [7]. In fact an otherwise normal lifestyle often results in lessening the tie with the clinical settings in charge for the treatments which eventually become unable to promptly notice any situation calling for attention and fail to issue the corrective actions.

The architecture we devised is highly configurable in order to easily adapt to virtually any chronic disease domain. As shown

in Figure 1 it is partitioned into two main interconnected hubs around which several satellite components can be plugged in as spokes. On the left side of the figure the Remote Care Unit (RCU) is located which is centered on the specific monitoring needs of a chronic patient. The RCU exploits mobile devices such as smartphones, PDAs, regular PCs or even plug-computers not equipped with monitors as *gateways* towards the Health Care Center Unit (HCCU) which is shown on the right part of that figure. The information exchanged by the RCU encompasses chunks of the Electronic Health Record (EHR) and log messages about activities to be accomplished on the patient side. The HCCU provides instead reminders about important tasks for a patient concerning his treatment as well as notifications for him about the effectiveness of his/her actions.

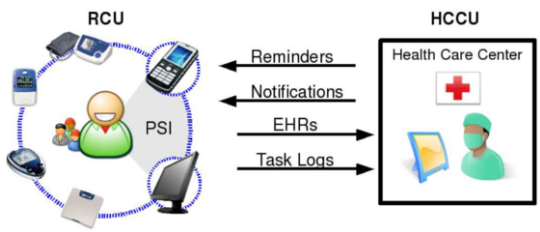

Figure 1 - The functional architecture of the platform.

On the RCU side mobile phones, PDAs and PCs may be interchangeably used as hubs depending on the skills and nomadic habits of a patient. One of their primary purposes is to act as collectors for clinical information required to build up the EHR, which may be acquired through multiple channels in order to guarantee the widest customization possibilities. Among the channels provided by the RCU, the basic one is based on a graphical user interaction. As shown in the figure this requires an explicit interaction of a user with the Personal Service Interfaces (PSI) available on the hub. Since mobile phones, PDAs and PCs greatly differ in terms of the graphical user experience and usability, their selection may be based on the patient profile.

Nevertheless, even though a patient profile may account for successfully adopting PSI for data acquisition, our personal experience has shown that this is definitely prone to errors or cheats especially when young patients are involved. Thus as far as possible we are also supporting automatic data acquisition directly from medical devices towards the RCU gateway exploiting wireless links.

To this aim we use primarily the Bluetooth™ standard which is available on almost every mobile phone and PDAs as well as on a large and ever growing number of medical devices such as scales, blood pressure monitors, heartbeat detectors, pulse oxymeters, glucometers etc. Specific wireless connectivity solutions such as Infrared or ZigBee™ require instead a PC to be used as a gateway.

Finally, we are also supporting data acquisition using the patient's own voice through regular phone calls placed to a dedicated service located at the HCCU. That service is able to model voice dialogues exploiting speech recognition and synthesis capabilities [8]. The possibility of acquiring clinical data with an automated dialogue interview effectively adds voice interaction as a new PSI to the phone gateway and is very important in order to provide a comprehensive PSI suite. This is particularly useful in addressing the needs of those patients whose profiles prevent the use of a graphical interface and no wireless solutions are available as alternatives.

Besides acting as a source of data, the RCU provides reminders and notifications to the patient. Thus a careful tailoring of those functionalities makes it also useful as a monitoring station for a patient's significant person requiring to keep in touch and be always aware of the patient state. Finally the RCU may be endowed with domain specific knowledge for issuing alerts or performing other actions locally without the need to wait for the complete loop involving the HCCU to be accomplished.

The HCCU is responsible for transferring any information acquired into the Hospital Information System, so that it may become available for inspection by the medical personnel. A host of services for monitoring trends in patient data and promptly raising alerts on the physician desktop have already been implemented although they will not be described here since they don't represent the main focus to the paper.

The platform architecture

From an architectural point of view the platform implements a general hardware/software platform which is almost independent from any domain specific data. In that way a particular telemedicine service for monitoring a chronic disease (i.e. diabetes, nephropaties, heart failure, stroke or pulmonary diseases) could be easily implemented on top of our platform exploiting the full power provided by its services with just minor case-by-case customizations required to match domain specific requirements.

The platform is based on the client-server computational paradigm in order to make it available remotely on the territory while at the same time collecting all data at the health care center. The communication between client applications and the server takes place on the internet. In order to enforce the ubiquity of the service, client applications have been mainly developed on mobile platforms with enough computational power and embedding networking capabilities either on a short range (i.e. Bluetooth) as well as on a long range (i.e. GPRS/UMTS and Wifi).

As shown in Figure 2(a) the RCU platform includes a unique pluggable component encapsulating all the Application Logic (AL). This is the only component where domain specific knowledge has been confined, which allows the implementation and configuration of a desired telemedicine service. Any other component shown in the figure and located around AL is totally domain independent. Those additional components constitute the foundation upon which the application relies to exploit local connectivity with personal medical devices (i.e. blood pressure monitors, scales, glucometers, etc.), remote data synchronization with the health care center as well as

scheduling and tracking task execution. The Bluetooth Communication Module (BTC) takes the burden of the connection with personal medical devices thereby allowing us to distribute system intelligence and create clusters of local devices directly managed by the AL running on the mobile [8]. The right protocol for communicating with a specific device is hardcoded into it and automatically selected by the Device Driver Recognizer (DDR) so that AL may be totally agnostic about the syntax and the semantics of communication. A Local Database is set in order to contain a personal copy of the patient Electronic Health Records (EHRs) created with all the measurements collected from local devices and patient task reminders (REM) remotely placed by physicians. Finally, within the RCU a Scheduler Agent (Sched) notifies the AL each time a task is hit during the day, storing back into the Local Database any information about its completion status and outcome.

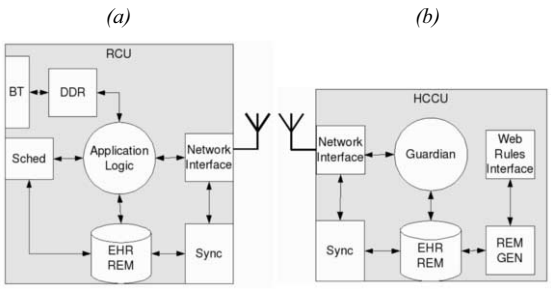

Figure 2 – (a) Remote Care Unit (RCU) architecture. (b) Health Care Center Unit (HCCU) architecture.

A key feature of the architecture allowing RCUs to consistently exchange data with the HCCU is represented by the Synchronizer module (Sync). That module implements a synchronization engine and a protocol based on XML transaction messages for updating, deleting, creating and resolving conflicts within records [9]. Its purpose is to guarantee a regular alignment concerning EHR and REM records stored on the patient side within those available at the treating centre. Finally, a Network Interface module is available for managing communication over the internet. That module, in gateways based on mobile platforms, provides everytime the most convenient channel between GPRS/UMTS or Wifi, while, on gateways based on PCs or plug-computers, it is used to discriminate between ADSL or Wifi connections.

The HCCU architecture is represented in Figure 2(b). Patients' EHRs and REMs are stored on a Local Database which is regularly updated with contributions coming from all remote databases through the Synchronization Agent (Sync) that implements a protocol matching the one available on RCUs. Through the server platform a physician can monitor his patients' health state keeping track of the associated EHRs acquired at their homes according to a personal measurement agenda. The agenda is a task schedule built by the physician through the server Task Definition Interface, a module allowing him to assign the duration and the frequency of a measurement (task) in a human-like way. Once acquired tasks are translated into reminders by a module called Reminder Generator that processes agenda entries and stores the reminders into the database. The server will later exploit this knowledge for monitoring the patients' compliancy to their assigned calendars of tasks through the Guardian. This module analyzes once a day all the EHRs and REMs and rises notifications of value non-compliance or time non-compliance if a patient has taken a measurement whose value falls out of the target range or misses to take the measure altogether. Notifications about non-compliance events are sent to both the physician and the patient through SMS or Email by a Notifier Agent that periodically spools the notifications generated by the Guardian. For those patients being overlooked by a significant other person, notifications may also be sent to that person through an additional RCU acting just as a monitoring station.

The reminder service

Compliance with self-management regimens is often poor, particularly with elderly patients. Nevertheless, since chronic patients play an active role in their treatment, they should carefully take measurements according to the expected time frame mandated by the protocol and avoid missing them altogether [7]. Furthermore chances that patients may forget to take their measurements increases even further for those who are still involved with their daily business.

To overcome the problem a reminder facility has been embedded in our architecture aimed at issuing appropriate warnings to a patient when the due time for a measurement is approaching. The facility is split among RCU and HCCU with different and complementary functionalities. On the HCCU the health care staff responsible for treating a patient may define some rules concerning tasks to be accomplished by the patient. This is based on the rationale that a generic task can be abstracted and applied to any measurement or action to be taken by patients with no concern about which specific chronic disease affects them.

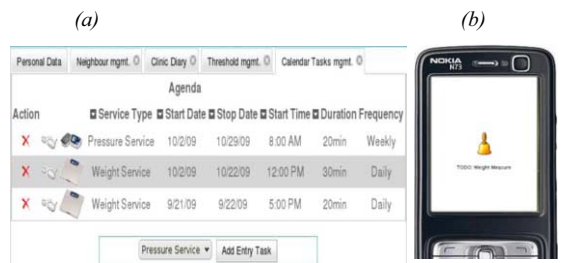

Figure 3 – (a) Task Rule definition interface. (b) A Task Reminder fired up.

As shown in Figure 3 a task rule concerns a specific measurement or action, provides information about its duration (i.e. validity days), its frequency (i.e. daily, weekly, etc..), the time window (i.e. start time and span), and the number of subsequent warnings to be issued within that window if the patient fails to immediately accomplish the tasks. After a rule is ac-

quired, the system starts generating task instances based on it which are then periodically exchanged upon subsequent synchronizations.

The RCU has the burden of tracking tasks by issuing all the expected warnings on approaching due times depending on the platform functionality. Mobile phones and PDAs will do so by emulating an incoming virtual call, while the PC will use loudspeakers and popup alert screens. The RCU monitors if the patient fulfills the request and eventually records the completion status for each task, so that HCCU may be informed about it.

The compliance monitoring service

Monitoring compliance has always been a key issue for chronic diseases, since the better a patient is able to follow a prescribed treatment, the slower the evolution of his disease will be. This becomes an even more important issue in outpatient contexts when patient-staff interactions occur less frequently and the risk of overlooking or missing some important evidence increases. Therefore an explicit service has been embedded within the HCCU with the aim of helping physicians in promptly identifying those patients whose data suggest a critical situation. The information provided by the service may thus be regarded as a fast discriminating mean, so that patients with missing or remarkably abnormal readings can be immediately raised to the physician's attention.

The service is based on warning events which may be triggered by two different information sources. Complying with a given treatment entails first a proper accomplishment by the patient of all the assigned tasks. Since the RCUs inform HCCU about the completion status of each assigned task, rules may be easily provided for generating events concerning missing or missplaced task accomplishments. More warnings may be raised by generic rules checking if any single measurement falls beyond its allowed range or by specialized rules checking some combination of values. The inherent specialization of knowledge required for generating alarms prevented us from building a comprehensive modeling of the whole process for acquiring rules through an easy-to-use graphical interface. Thus while events and their subsequent notifications have been standardized in the system, medical knowledge for raising events must still be represented in terms of small code chunks into the system. This leaves to the interface just the option of enabling/disabling every single rule.

The notification service

After an event has been raised, in order to be effective, it must be notified to the health care staff for proper handling. The first time a physician will connect into the system he will be notified about any pending alarm directly through the graphical interface. Nevertheless requiring physicians to connect it's not an option since even before the availability of a home care system they were accustomed to schedule regular visits for chronic patients just every one or two months with no other contact in between. Thus in order for the system to be really effective we realized that it should proactively send notifications about significant events rather than wait for connections to occur. In order to generalize the solution, the capability of sending notifications has been factored out and encapsulated into a separate module which is dynamically fed up with events raised by the compliance monitor. The physician configures the module by indicating how and when (i.e. preferred time) to be notified about those event. The module collects any notification occurring since the last submission, and forwards them to the physician using the preferred mean (i.e. SMS, E-Mail, etc.) If requested, the same notifications could also be sent to the patient by forwarding them to the RCU.

Results

The platform developed has been used to implement two separate prototypes, one supporting young patients affected by Type 1 Diabetes Mellitus (IDDM) and the other one addressing uremic patients undergoing Peritoneal Dialysis (PD). In the first case young patients are required to measure their glycemia levels several times a day, usually before meals or snacks, in order to adjust the insulin therapy which is administered either through a pump (continuous infusion) or injections (boluses). In this case we have been unable to acquire readings automatically since glucometers are classified as medical devices and to date there is no approval by the Health Ministry for wireless ones. Measurements are thus inserted into the RCU by the patient using the GUI which also offers the opportunity to annotate data with additional information concerning meals and personal notes. Periodical synchronization with HCCU ensures that physicians may have those data promptly available for inspection.

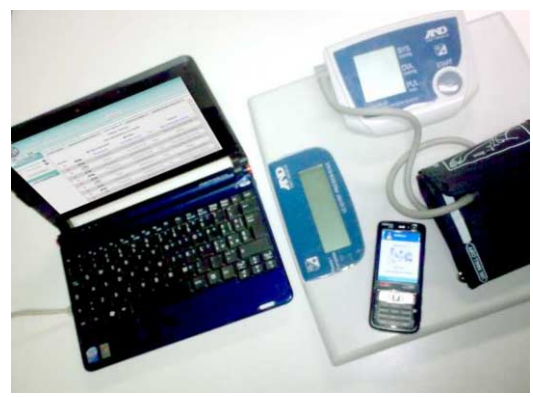

Figure 4 – The Remote Care Unit for the peritoneal dialysis application.

Patients undergoing PD instead of being treated with external hemodialysis at a hospital setting, fill their abdominal cavity regularly at home with a suitable solution cleaning their blood by osmosis. For them it is mandatory to keep pressure and weight under strict control since that information acts as a clue for potential cardiac failure and helps in controlling daily urine volume preventing overhydration. The RCU in that case has been configured for automatic data acquisition since both a scale and a blood pressure monitor equipped with Bluetooth

were found on the market, as shown in Figure 4. Given that the dynamics of body hydration is very rapid, according to the protocol it is mandatory to take frequent measurements always at the same time. Thus reminders were used to alert patients when time for the next schedule approaches. This application is currently undergoing an evaluation phase at a major hospital located in northern Italy. Four patients previously accustomed to write down blood pressure and weight measurements regularly were enrolled into the trial. The physician summoned all of them in a single day at the beginning of which he held a short preliminary statement illustrating the benefits of the trial. A short demonstration session was held and at the end each patient has been provided with a personal package including a complete RCU and an operating instruction booklet. Separate session training were then held in order to make sure that at the end of the day each patient was fully convinced to take part in the trial and be able to successfully operate the RCU. The trial is expected to last for at least 6 months with the aim of comparing the decrease in the physician workloads ensuing the reduction of face-to-face encounters with the quality of service delivered to patients.

Discussion

The scientific literature illustrates several implementations of telecare applications addressing the needs of chronic patients. Nevertheless each one of them seems to target a specific problem instance which restricts its applicability to the very same domain for which it was designed despite the potential demand for similar applications. Our efforts have been directed exactly in the opposite direction since they try to address the problem at a higher level by providing a sound architecture and an implementation platform which may be easily configured for building applications in different domains, each one with its own distinguishing features.

In addressing IDDM we configured the patient RCU with a GUI for acquiring data, notifications were adopted just for text messages issued by physicians and no reminders at all were used. Nevertheless, since the application is meant for young patients it has been almost mandatory that parents stay informed about the state of their kids. Within our platform the problem has been solved quite easily introducing additional RCUs for the parents configured with notifications as their only service. In that case notifications include either messages issued by physicians as well as readings so that parents can be informed about their kids even when they are away from home (e.g. at school).

In designing the uremic patient application the wireless module has been exploited for acquiring data on the RCU given the availability of suitable devices. This greatly simplifies data acquisition for elderly patients who are not proficient with the use of PCs or mobiles. Furthermore, since it is important to take measures at fixed times and the application is meant for elderly patients, the reminder service has been extensively used. Finally in both applications, once data become available to the HCCU, additional services have been implemented to help physicians in promptly identifying critical situations.

Conclusions

This paper illustrates a configurable platform for delivering home care services to chronic patients. The platform represents a solid foundation providing several common facilities which may be exploited out-of-the box in order to rapidly assemble and configure specific applications in different medical domains. The platform is composed of several Remote Care Unit stations located at the patients' homes and a Health Care Center Station located at the treating center. Both have been designed in a highly modular fashion in order to keep any issue concerning the representation of medical knowledge and its related processes separate from technological and networking issues. Configuring the platform we were able to implement two prototypes addressing separate medical domains and exploiting different input capabilities. In both cases we were able to provide patients and their family caregivers with proper advice concerning the therapies by embedding separate chunks of medical knowledge on remote stations and at the health care center.

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Daily activities and fall risk – A follow-up study to identify relevant activities for sensor-based fall risk assessment

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Abstract

The demographic change will lead to an increase in the incidence of falls in the elderly. Technological progress allows for unobtrusive physical activity measurement with miniature sensors, e.g. accelerometers. Yet it is unclear which activities or activity patterns are associated with an increased fall risk. The aim of the research for this paper is to identify daily physical activities associated with a high fall risk. A one-year follow-up study was conducted with n=50 geriatric patients who took part in a telephone interview to assess fall events, their consequences and a set of daily physical activities. Descriptive analysis of the data shows that there are marked differences between fallers (n=21) and non-fallers (n=29) in the overall activity level, the amount of shopping activity and associated locomotion, and in the intensity of light household work. The results confirm that there are differences in typical daily activities between fallers and non-fallers that may be used as parameters to enhance fall prediction models.

Keywords:

Accidental falls, Motor activity, Assisted living facilities, Sensors

Introduction

It is a well-known fact that the future demographic development will lead to an increase in the elderly population, both in absolute and relative numbers [1]. This change in population composition will lead to a rise in the prevalence of chronic diseases and in multi-morbidity. Physical activity is an important and independent factor in the etiology of many chronic diseases, including diabetes mellitus, cardiovascular diseases, musculoskeletal diseases, certain types of carcinomas and even affective diseases (e.g. [2, 3]). Along with the recent development of wellness and exercise support systems, this has led to a rush in sensor-based activity recognition/analysis projects in the last decade, because automated assessment even during long-term periods in daily life has become feasible due to the rapid development in sensor technology and mobile computing power.

With regards to the demographics, however, falls are a predominant problem. It is estimated that the annual cost of falls and their consequences amounts to $20 billion in the U.S. [4]. Furthermore, falls are associated with a high risk to retain functional limitations as well as the so-called 'post-fall syndrome' that comes along with an increased fear of falling, leading to a vicious circle of ever-decreasing activity leading to a loss of muscle mass (sarcopenia) and so on [5]. Individual fall risk is associated with gait parameters that can be measured with miniature accelerometers [6-8]. There is also evidence showing that persons with a high risk of fall-related fractures risk tend to be less active in their daily lives than those with a low risk [9].

One of the most relevant applications of activity measurement could be to identify persons with a high fall risk by identifying gradual changes in daily activity patterns. Thus, persons with an increasing risk may be prompted to get timely intervention to reduce individual fall risk [10]. It remains unclear, however, what types of activities and activity patterns are correlated with a high fall risk.

Therefore the aim of our research for this paper was to identify those daily physical activities which are the most relevant for identifying persons with a high fall risk.

Materials and Methods

Study population

The basic population for this study are all elderly persons, the selection population were all patients that received in-patient treatment at the Department for Geriatric Medicine of the Braunschweig Medical Center, Germany, between April 24th and October 18th, 2007. These patients were enrolled in a previous study that investigated the use of sensor-based gait parameters to identify persons with a high fall risk [11]. Altogether n=119 subjects with a mean age of 80 years participated.

For the study at hand these 119 persons were contacted by mail and asked to participate in a one-year follow-up study to assess their fall history and their daily activity profile. 50

subjects agreed to participate in our study and gave written consent.

Telephone interviews

In order to identify an adequate telephone assessment tool to record daily activities, the first author conducted a search for suitable questionnaires on the Internet and in corresponding scientific journals. To the authors' knowledge, the only activity questionnaire that has been designed and validated for elderly people is the questionnaire presented by Voorips et al. [12], containing ten questions concerning the amount of light and heavy household work, the number of persons, rooms and floors taken care of in the household, meal preparation, number of stairs walked daily, shopping, and mode of transportation when moving in one's hometown and for shopping. Each answer is scored on a scale from 0 (low activity) to 4 points (high activity).

Within the interviews, fall history was assessed following the criteria proposed in the *Prevention of Falls Network Europe* consensus [13]. A 'faller' was defined as a person having sustained at least one "unexpected event in which the participants come to rest on the ground, floor, or lower level" ([13], p.1619).

The interviews were conducted by co-author AR, a registered nurse and diploma student at the Peter L. Reichertz Institute for Medical Informatics.

Data analysis

We chose two different approaches for data analysis. The first method was a descriptive analysis of the point values for all ten questions. As the answers are scored on an ordinal scale, we chose to calculate rank sums for each score and to present the results in a bar diagram (Figure 1).

The second approach was an exploratory analysis of the relevance of each activity score. We chose to calculate the *information gain* and to rank the parameters accordingly. In information theory, the information gain is defined as the amount by which a parameter is able to decrease total entropy. It is measured in *bits* and used by several pattern classification algorithms to choose a parameter to split a dataset, e.g. by the C4.5 algorithm [14].

Results

Descriptive analysis of rank sums

Figure 1 shows a bar diagram with the rank sums for each activity sub-score and the sum of all scores. While differences between the two groups of fallers (n=21) and non-fallers (n=29) can be seen in the rank sums of all activity parameters, the largest differences can be observed for the mode of locomotion when shopping, the overall amount of shopping activity, engagement in light household activities such as washing the dishes or dusting. The smallest rank sum differences are found for the number of stairs walked daily and – correspondingly – the number of floors in a person's living surroundings. Finally, the overall activity sum score also shows an obvious difference between fallers and non-fallers.

Information gain analysis

The calculation of the parameters' information gain yielded only three activity sub-scores with a positive gain value. These are shown in Table 1. All other sub-scores were not applicable to split the given dataset into fallers and non-fallers.

Table 1 – Information gain value ranking of activity sub-scores

activity parameter	information gain [bits]
shopping – mode of locomotion	0.155
amount of shopping activity	0.127
amount of light household work	0.119

Discussion

First of all, it can be observed that – despite the limited sample size – there is marked difference in overall activity between the two groups, indicating that persons with a high fall risk have a low activity intensity. This can be observed in the activity sum score, but also in all sub-scores. This confirms results of Stevens et al. who report a higher activity in patients who do not sustain a fall-related fracture, provided that they do not suffer from any limitations in terms of an ADL-score ≥ 0 [9]. For patients with such limitations, the odds ratio is reported as 3.2 to sustain a fall-related fracture.

Among the different daily activities that have been measured by our questionnaire, the largest differences between the two groups can be observed in the intensity of shopping activity on the one hand and in the mode of transportation or locomotion when going shopping on the other hand (Figure 1). This result is confirmed by the highest ranks of these two items in the information gain calculation (Table 1). It may be concluded that persons who have a high fall risk either do not or less often go shopping on their own or – if they do so – rather use a means of transportation (car, public transportation) that does not require advanced motor skills such as bicycling or walking – possibly with shopping bags. The reasons for this may be manifold. Firstly, as fall risk is related to functional limitations in performing demanding motor activities such as repeated sit-to-stand transitions or alternate steps [15], shopping may be regarded as a demanding task requiring multiple physical skills, and – as such – changes in this activity might be regarded as an early indicator for the onset of motor functional limitations. Secondly, falls often lead to the 'post-fall syndrome' [5], leading to a vicious circle of increasing fear of falling, subsequent limitation of personal and social activities, leading to a further increase of fall risk, and so on. In our sample, 61.9% (13 out of 21) of the persons who fell within the study year had at least one fall event before. The post-fall syndrome therefore might be one of the reasons for shopping

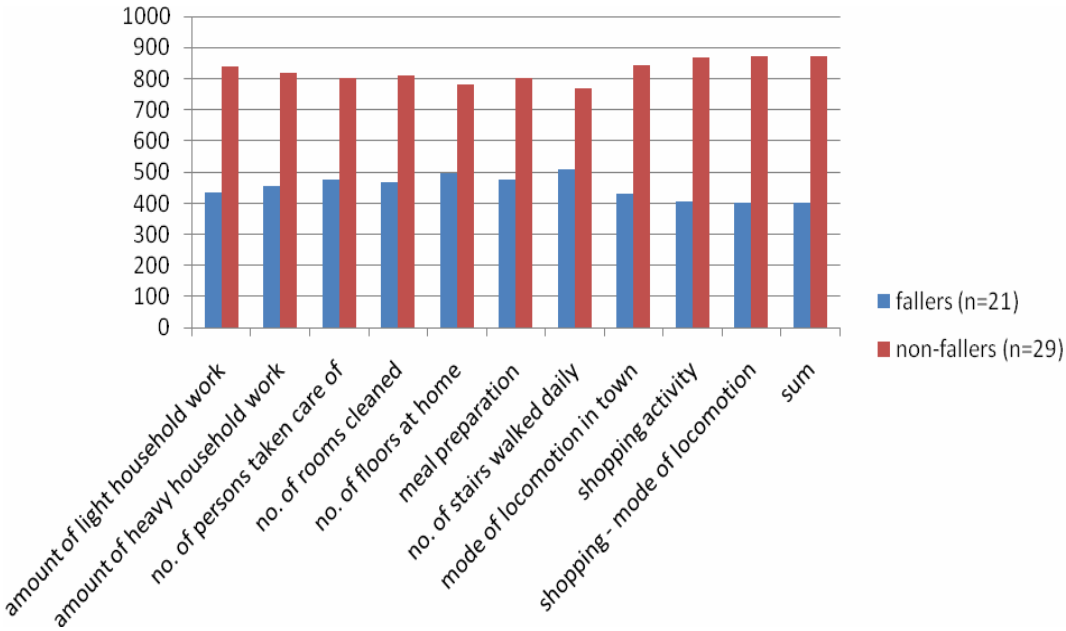

Figure 1- Rank sums for ten different daily activities and the sum score for fallers (n=21, blue) and non-fallers (n=29, red) in the one-year follow-up study

activity differences. It might be noted that shopping is regarded as one important social activity for elderly persons, so that these limitations may have severe consequences for social participation and integration.

From a technical perspective, the sensor-based assessment of shopping activity is possible if a mobile sensor system is used. In a previous study with five elderly persons wearing a multi-sensor system, the authors were able to identify shopping activity with an accuracy of 79.9% [16]. In another study it has been shown that activities such as driving a car (90.4%), riding a train (86.4%) and riding in a car (64.0%) can also be identified with a moderate to good correctness, if a classification is trained on individual sensor-based movement data [17]. Thus, it can be concluded that the two most important daily activities that were identified by our study setup can be assessed automatically and therefore can be used to enhance fall prediction models.

Apart from shopping activity, group differences have also been shown for the amount of light household work. This indicates that these activities. however 'light' they are, tend to be more difficult for persons with a high fall risk. This, again, may be interpreted as a consequence of the progressive loss of functional motor ability on the one hand [18], and of the post-fall syndrome on the other hand [5]. The activities explicitly mentioned in the validated questionnaire are washing the dishes, sewing and dusting. It might be argued that these require heterogeneous motor and cognitive skills that cannot be distinguished by just one question. Nevertheless, this item seems to be a further indicator for an increased individual fall risk.

It may be argued why the authors have not chosen to use established scores such as the *Katz Index of Independence in Activities of Daily Living* (ADL) [19], the *Barthel Index* [20] or the *Instrumental Activities of Daily Living* (iADL) [21]. These are clinical scores that help to assess functional limitations, and they are scored by external reviewers. The crucial factor, however, is that they do not allow to quantify physical activity and therefore were deemed inappropriate for our purpose.

Limitations

First of all, the sample is not very large (n=50). Only 42% of the persons contacted agreed to participate in our follow-up study. Apart from declining due to personal reasons that were not specified any further, several persons had moved to unknown locations and quite a few had died already. This sample therefore should not be regarded as being representative.

Secondly, the authors have chosen a descriptive analysis instead of a confirmatory analysis of the data in order to avoid the problem of multiple testing. The authors believe that this

kind of analysis using the rank sums is rather appropriate for the task at hand.

Finally, it may be argued that the set of activities that is assessed by the questionnaire only provides a rough approximation of daily activities, and that it lacks the granularity necessary for an all-encompassing activity assessment. The authors agree with that, but – as stated above – are not aware of another, more detailed questionnaire that has been validated for use with elderly people.

Conclusion

This is the first study that has assessed the relationship between the amount of different daily activities of elderly people in their home environment and their fall risk with regard to the potential of sensor-based activity measurement. A low amount of or no shopping activity, a passive way of individual locomotion when going shopping and the inability to perform even light housework could be identified as indicators of a high fall risk in our follow-up study. Our future work will be directed towards the sensor-based, long-term assessment of these activities to provide a further, valid source of information to be integrated in automated fall prediction models.

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Can Multilingual Machine Translation Help Make Medical Record Content More Comprehensible to Patients?

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Abstract

With the development of electronic personal health records, more patients are gaining access to their own medical records. However, comprehension of medical record content remains difficult for many patients. Because each record is unique, it is also prohibitively costly to employ human translators to solve this problem. In this study, we investigated whether multilingual machine translation could help make medical record content more comprehensible to patients who lack proficiency in the language of the records. We used a popular general-purpose machine translation tool called Babel Fish to translate 213 medical record sentences from English into Spanish, Chinese, Russian and Korean. We evaluated the comprehensibility and accuracy of the translation. The text characteristics of the incorrectly translated sentences were also analyzed. In each language, the majority of the translations were incomprehensible (76% to 92%) and/or incorrect (77% to 89%). The main causes of the translation are vocabulary difficulty and syntactical complexity. A general-purpose machine translation tool like the Babel Fish is not adequate for the translation of medical records; however, a machine translation tool can potentially be improved significantly, if it is trained to target certain narrow domains in medicine.

Keywords:

Comprehension, Translating, Consumer health information, Medical records.

Introduction

Providing patients access to their own health records is key to the new patient-centric health care paradigm, in which patients take charge of their own health by becoming active participants in their health care decisions [1]. In line with this new paradigm, in many countries, including the US, patients have the legal rights to access their own medical records. The recent development of electronic personal health record (PHR) systems holds the promise to significantly improve patients' access to their own records.

While PHR is helping more patients gain access to their records, comprehension remains an obstacle if PHR is to fulfill its full potential to motivate and empower patients to better their health [2]. Medical records typically contain complex information intended for healthcare professionals, not consumers. The challenge posed by the comprehension of health-related material is even greater for patients who are not fluent in the language in which the records are written. According to a 2004 US Census Bureau report, there are 33.5 million foreign-born residents in the US, representing 11.7% of the total population. Undoubtedly, while many foreign-born residents may well be fluent in English, many others cannot speak, read or write in English, or may never reach an acceptable level of proficiency in that language.

With respect to PHR applications in the US, foreign-born patients' lack of English proficiency may well place them in the "hard-to-reach" category, similar to low-literacy English-speaking patients. It has been argued that we particularly need to reach out to such patient population, since low literacy has been associated with poor self-care and poor health outcomes, including increased mortality and hospitalization [3, 4] and, ultimately, increased social and health-care costs. If consumer applications such as PHR do not address the needs of the "hard-to-reach" populations, we run the risk of widening the existing health disparity gap.

One way to minimize this gap for the non-English-speaking segment and to allow them to benefit from the PHR availability is by providing translations into the patients' native languages. Many US hospitals provide on-site translation services for patients (timely point-of-care services). Further, an increasing amount of patient education materials are available in languages such as Spanish. A number of studies have been conducted on the needs, methods, barriers, and benefits to providing human multilingual translation services [5, 6]. However, within the context of medical records, resorting to human translators is not feasible, since each record is unique. Thus, anticipating the need for record-specific, accurate translations, machine translation emerges as the next best option. We believe machine translation is worth exploring in this context. The goal of this pilot study was to test the efficacy of a popular general-purpose freely-available machine translation tools on patient medical records. English was the source language and the target languages were Spanish, Russian, Korean, and Chinese. Even though this study was meant as a proof-of-concept endeavor, our general goal is the development of machine translation tools

specifically devised to render accurate and understandable medical record information.

Background

Machine Translation can be defined as an automated system that takes a given text as input (source language) and produces as output the translation of that text into a target language. The translation process as such is performed using special computational programs, dictionaries, vocabularies, glossaries, and different sets of linguistic rules [7].

Although the concept of machine translation (MT) has been around since the 30's and 40's, it gained popularity only in the 60's and 70's, when it was touted as the perfect solution for text translation, capable of rendering translated text of human translation quality [8]. However, MT lost much of its appeal when it became evident that those were unrealistic expectations. With the expansion and application of natural language processing (NLP) techniques and stochastic methods to MT in the mid to late 80's, there was a renewed interest given that these techniques produced superior results. Further, despite its potential for numerous errors and disjointed narrative, people became aware that raw, unedited MT output could be used to obtain the gist of a document. More recently, the widespread use of MT in the Internet opened the door to other novel uses and applications, such as cross-language information retrieval [9] and multilingual communication [10].

While it is still true that post-editing is unavoidable for first-rate translation quality, the use of controlled language and vocabularies can go a long way towards reducing the need for intense revisions, especially when restricted to specific domains or to particular types of documents, as in the case of meteorological reports. This is also the setting for electronic health records: they are contextually restricted to the medical field and the narrative can be quite formulaic. An MT system specifically tailored to medical texts could potentially be used on English electronic health records to make them understandable to speakers of other languages.

One such system, engineered by the Pan American Health Organization [11], has several micro-glossaries with domain-specific vocabularies, two of which are geared to the medical field: *Super Medical* and *Patient Information*, with consumer health vocabulary. The fact that the Pan American Health Organization Machine Translation System (PAHOMTS®) is limited to three languages (English/Spanish/Portuguese), however, made it unsuitable for our project, as we were also evaluating the application of MT to other languages not included in this system, namely, Russian, Chinese, and Korean.

Another system, the open source medical speech translation system (MedSLT), has been described in the literature. The prototype of MedSLT translates spoken questions from English into French, Japanese and Finnish in three medical subdomains (headache, chest pain and abdominal pain) using a vocabulary of about 250-400 words per sub-domain [12]. Since the goal of this project was not to evaluate how well or how appropriately different MT systems perform, but rather, whether the use of unedited MT output represents a viable option for translating electronic health records, it was important that the same software be used for all languages involved. This consideration, along with the wide availability offered by the Internet translation tools, pointed to Altavista for this experiment.

Methods

Materials and Reviewers

We retrieved 11 publicly available sample medical records from two websites as testing materials:

- MedLEE demo site (http://zellig.cpmc.columbia.edu/medlee/demo/)
- MT (Medical Transcript) resources (http://www.mt-resources.com/index.html)

They include discharge summaries, surgical notes, admission notes, and radiology reports. For a translation tool, we selected the freely available Babel Fish by AltaVista (http://babelfish.altavista.com/), as it is one of the most easily accessible and widely known online translating tools.

A total of five reviewers participated in the study. All reviewers were proficient in English and a native speaker of either Chinese, Korean, Spanish, or Russian. All were medical informatics researchers with graduate school level of education or higher.

Procedure

Identifying the testing variables

In order to identify operational variables that measure the quality of the translation, we first translated one record using Babel Fish from English into each of the four different languages mentioned in the introduction. In order to review the quality of the translated text, we used two testing variables which had also been identified as important evaluation criteria for MT by other studies [13, 14]: understandability and correctness of the translated sentence. Regardless of the language in which they are written, medical records are difficult to understand because they are fairly technical documents that require a certain level of expertise to understand. Moreover, they often contain abbreviations and grammatically incorrect phrases and expressions. In order to control for such intrinsic confounding factors we added a third variable: understandability of the original sentence.

Establishing the evaluation rules

We divided each text into its component sentences, to assess the translation quality of each sentence via a 3-point Likert scales. We considered each sentence to be a self-contained chunk of information. In order to promote consistency in using the scale and set uniform parameters, an initial detailed instruction sheet with examples were developed and distributed to the reviewers. First, four reviewers coded 39 sentences collected from 2 records. The coding results were shared and discussed in a group meeting, and the rules and instructions were further refined. For example, when the translator failed to translate certain terms the reviewers were instructed to replace the untranslated terms with blank spaces

and determine the understandability and correctness as if the untranslated terms were missing.

Coding the translation

The specific coding steps were similar to those described in (13). They were as follows:

1) Rate the understandability of the translated sentence first without seeing the original sentence in the source language (English) and without consulting any dictionary.
2) Rate the understandability of the original sentence in English without consulting any dictionary.
3) Rate the correctness of the translated sentence in terms of accuracy, by comparing the translated sentence to the original sentence. Dictionaries may be consulted in this step.

Reviewers then rated 213 sentences collected from 8 records, following the finalized evaluation rules and instructions.

Reliability of the translation evaluation

In order to test the reliability of the human evaluation results, we trained a second native Spanish speaker (the fifth reviewer) in the use of the same evaluation rules just described, and then assessed the level of agreement between the two reviewers. After practicing with the evaluation rules on 15 sentences, the second Spanish reviewer independently rated the quality of the Spanish translation of 65 sentences which were randomly selected from the 213 sentences. We observed the percentage of agreement in each variable. In addition, the level of agreement in each variable was tested with a McNemar test. In the McNemar test, the categories of "partial" and "no" were merged as one.

Analysis of the sentence characteristics

In order to identify factors that affect the accuracy and comprehensibility of the translation, we investigated the characteristics of the original sentences. We extracted three kinds of text features using an in-house built Natural Language Processing (NLP) tool: HITEx (Health Information Text Extraction) [15]. We also measured the overall readability of each sentence using the readability analysis tool called HIReA (Health Information Readability Analyzer) which assesses the text readability based on three types of text characteristics [16].

Results

Translation quality

Reviewers found the translation to be understandable only between 11.27% and 31.46% of the time (Table 1). In other words, for each language tested, reviewers found that the vast majority of translations were either incomprehensible or partially comprehensible. In contrast, the majority (65.73% to 85.73%) of the original English sentences were deemed comprehensible by all reviewers.

When examining the correctness of the translations, we found that only a small percentage (7.98% to 11.74%) of the Chinese, Russian, and Korean translations were deemed correct by the coders. Spanish translations did comparatively better, with 33.80% deemed correct. Nevertheless, for all languages involved, the majority of the translations we not totally correct. Due to the nature of medical records, which contain critical information, the lack of accuracy in translations is very problematic.

Table 1 - Understandability of the original and translated sentences and correctness of the translated sentences

		Spanish	Chinese	Russian	Korean
Translation understand-able?	Yes	31.46%	11.27%	14.55%	19.25%
	Part.	43.19%	26.29%	20.19%	28.64%
	No	25.35%	62.44%	65.26%	52.11%
Original Sent. Understand-able?	Yes	88.73%	66.67%	80.28%	65.73%
	Part.	10.33%	25.35%	13.62%	26.76%
	No	0.94%	7.98%	6.10%	7.51%
Translation Correct?	Yes	33.80%	7.98%	11.74%	9.39%
	Part.	44.60%	7.51%	10.33%	24.88%
	No	21.60%	84.51%	77.93%	65.73%

Reliability of the translation evaluation

When comparing the results of the two Spanish coders on the 65 test sentences, we found that they agreed with each other 71.31% to 80.00% of the time on the three parameters. This agreement rate is acceptable considering that the two reviewers spoke somewhat different Spanish dialects, as they came from two different Spanish-speaking countries. When applying the McNemar's test, statistically significant differences ($p<=0.01$) were found in their judgment of comprehensibility and correctness of each sentence, but not in the comprehensibility of the original sentences.

Analysis of the sentence characteristics

The correlation analysis (Table 2) shows that the sentence length is a significant feature that negatively affects the understandability of the original sentence and the translation quality. In other words, longer sentences were less likely to be understood or yield a correct translation. Both vocabulary features (vocabulary familiarity score and out of dictionary word ratio) were significantly correlated with the understandability and correctness variables. The use of familiar terms showed positive correlations whereas the use of out-of dictionary terms showed negative correlations. No part-of-speech categories consistently and significantly correlated with understandability and correctness. The readability score (how difficult a sentence is) was positively correlated with understandability and correctness.

Table 2 – Correlation analysis: sentence characteristics and translation quality

	Sentence length	Vocab. familiarity score	Out of dictionary word ratio	Readability score
Understand-ability of original sentence	-0.2722*	0.2949*	-0.4267*	0.3554*
Correctness of translation	-0.4393*	0.1201†	-0.2502*	0.2664*
Understand-ability of translated sentence	-0.3625*	0.1996*	-0.2702*	0.2588*

* *correlation coefficients are significant at 95% significance level,*

† *correlation coefficient is significant at 90% significance level.*

The mean values of text features that showed significant correlations with translation quality and the understandability of the original sentences are presented in Table 3. "Yes" answers received a weight of 2, "no" answers a weight of 0, and "partial" a weight of 1. The average original and translation understandability and translation correctness were categorized into two groups: incomprehensible or incorrect (=<1) and comprehensible or correct (>1).

Table 3 - Mean values of text features that had significant correlations with translation quality and vocabulary familiarity score

		Number of words per sentence	Vocabulary familiarity score	Out of dictionary word ratio	Readability score
Original	Incompr.	17.6920	0.6784	0.2427	-0.6450
	Compreh.	12.9700	0.6737	0.0904	-0.4740
Transl.	Incorrect	14.4670	0.6774	0.1024	-0.5010
	Correct	8.6136	0.6612	0.0894	-0.4180
Transl.	Incompr.	15.2540	0.6684	0.1087	-0.5260
	Compreh.	9.2670	0.6854	0.0817	-0.4010

As suggested by the text feature analysis, the main cause of incomprehensible and incorrect translations appears to be the technical domain-related medical vocabulary on one hand, and irregular or complex syntax used by the original English sentences on the other. Longer sentences tend to have more complex syntax and a higher chance of containing difficult words. To a lesser extent, the vocabulary and syntax also made the original English sentences fully incomprehensible or partially comprehensible at times.

Upon closer examination, ambiguous and out-of-dictionary terms are the two main vocabulary problems for MT. Take the example of the sentence "Patient has had small to moderate amounts of serous drainage at site". The word "moderate" has several dictionary definitions and different parts of speech. In the original sentence, it is used as an adjective with the meaning "of medium or average quantity or extent." However, it could also be used as a verb to mean "to lessen the violence, severity, or extremeness of," which apparently was how the word was wrongly interpreted by the MT system when converting the sentence to Chinese, Korean, and Spanish. The system that we used is a general purpose, general-vocabulary application. Thus, some medical terms were missing from the system's dictionary and were not translated. This rendered some sentences not understandable. We rated all incomprehensible translations as incorrect.

Discussion

Although there is an increasing need for automated translation of medical content, especially in the context of personal health record applications, there has been no reported study on the efficacy of applying existing MT technologies to patient medical records. Our pilot study evaluated the quality of a popular general purpose translator by applying it to a novel use, that is, to the translation of 213 sentences from patient medical reports, from English into four different languages.

This study found that the translation results are quite frequently incomprehensible and inaccurate, for all four languages tested. While the original English sentences were not easy to read, the majority of them were deemed totally comprehensible by each of the coders. However, the reverse was true for the comprehensibility of the translations. In addition, in terms of accuracy well below 50% of the translations were deemed (totally) correct in each language. The results are not equivalent or uniform in the languages tested. The machine translation system performed noticeably better in the English to Spanish direction than in other language translations. One possible explanation for this may well lie in the fact that English and Spanish are much more similar (word order, inflections, etc.) than English and Chinese, Korean or Russian.

Our findings suggest that off-the-shelf and general purpose machine translation systems in their present state are unlikely to be of real help to non-English speaking-patients in understanding their medical records. First and foremost, the incorrect translations could seriously misinform patients and lead to more serious safety problem. Because of liability issues, it is hard to imagine any PHR application would incorporate such a tool unless the accuracy of the translation improves dramatically. The comprehensibility of the translated sentences is also too low for practical use.

We do believe, however, that machine translation could be dramatically improved to the point in which it could be useful and helpful for the task at hand, starting with the possibility of including medical vocabularies or glossaries if one so desired. It should be pointed out that by our observation the majority of the incorrect translations appear to be associated with medical terminology. However, the irregular or complex

grammar structure of medical reports is also a source of errors. Machine translation is a type of natural language processing application and with regards to medicine and medical texts, it has been more successful when applied to more narrowly defined domains (e.g. radiology). If a machine translator is trained for a very narrow domain in medicine (e.g. medication instruction), and is equipped with a comprehensive medical vocabulary, it would become much more reliable, as the vocabulary would be more controlled, and so will the grammar. When dealing with a specific and relatively small domain, the syntactical variance that needs to be addressed is reduced and can be more easily tackled.

One of the limitations of this pilot study is the relatively small sample size and number of coders. The coders of this study are bilingual, have an educational level and exposure to medical terminology well above those of the average US population, and presumably higher than those of the average non-English speaking population in the US. It is to be expected that an average non-English speaking patient would find even fewer of the translated sentences understandable. Another limitation is that the Babel Fish translator we used may not be the best machine translator. As mentioned in the background section, the PAHOMTS system would most likely produce higher quality translations and improve the results for Spanish, but it could only be used for much fewer language options. Nevertheless, based on our experience with the PAHOMTS and other machine translation tools, comprehension and accuracy are commons issues for all machine tools.

In order not to leave one of the most in-need populations – the people with limited or no English proficiency behind – in the development of personal health records, we intend to further explore the use of MT technology. As a start, we would focus on one or two narrow and relatively simple domain areas and employ strategies (e.g. translate the translation back to the original language) for quality assurance purposes.

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Chapter 2.

Electronic Health Records

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Measurement of the Utilization of an Installed Electronic Health Record

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Abstract:

For the past decade, adoption of electronic health records (EHRs) has been proposed as one of the most viable approaches to improving the United States health care system [1]. *Although there is evidence that EHR adoption is slowly progressing, current methods of assessing adoption have yielded significant variance in estimates of EHR utilization. We conducted an environmental scan consisting of a review of the literature as well as a series of discussions with health center and health center network representatives and experts in the field to understand the current state of EHR adoption and use in the United States and assess the feasibility of developing a systematic approach to tracking EHR usage.*

Keywords:

Computerized medical records systems, Utilization, Policy making, Automated reporting, United States health care reform

Introduction

In the face of rising costs and concerns about quality in the United States health care sector, an emphasis has been placed on the critical role that health information technology (IT) will play. Electronic Health Records (EHRs) have great potential to improve patient outcomes, increase patient safety, and bring about overall improvements in the quality of care delivered. EHRs also have the potential to be a critical enabler of a high-performing healthcare system having demonstrated improvements in the quality, increased adherence to guideline-based care, enhanced surveillance and monitoring and decreased medication errors [2]. As a result, the President, Congress and others have placed a great deal of attention on promoting widespread adoption of EHR technology. The 2009 American Recovery and Reinvestment Act (ARRA) authorized approximately $36 billion towards health IT, with a significant amount to promote the '*meaningful use' and adoption of certified EHRs* [3].

Despite the profusion of initiatives aimed towards accelerating the adoption of EHRs and the rising impetus for practices to adopt EHR systems, the health care sector is far behind other industries with respect to IT adoption [4]. At the same time, EHR adoption in the United States lags significantly behind that of many other Western countries [5]. Estimates of ambulatory EHR use in Austria, Belgium and Australia are 75%, 78% and 79-90% respectively while Denmark, England, Finland, the Netherlands and New Zealand have reported rates above 90% [5]. A report released by Harris Interactive showed that the United States was far behind all but a few European countries in terms of EHR adoption [6].

A great deal is also unknown about the use of specific features of EHRs in the United States, and there is no standard set of methods that reproducibly measures their utilization. Issues that contribute to making the question of quantifying adoption challenging include the lack of a clear definition of an EHR, a lack of standards to measure usage and inconsistencies in how EHR functions are described across the myriad of vendor products that are available today.

This study addressed the following questions:

- What are the major methods that have been used to assess EHR adoption and utilization?
- What are the core functions of EHRs?
- What is the nature of EHR use in ambulatory care settings? Which functions are most commonly utilized?
- What are the challenges and barriers associated with adopting and using EHRs?

Methods

Key research activities involved a literature review, review of EHR surveys and a series of key informant discussions. The initial literature review was used to identify EHR surveys and a framework for categorizing EHR functions. To contextualize what we learned from the literature review on EHR adoption and use we conducted a series of discussions with informants in the field.

We conducted a review of published and unpublished literature to identify previous studies of EHR adoption. We systematically searched electronic databases including PubMed, Academic Search Premier, MedLine and CINAHL and conducted targeted Internet searches using the Google and Google Scholar search engines in order to identify government reports, unpublished articles and other relevant resources.

Results of the literature review were also used to identify surveys for analysis of survey instruments. In identifying which surveys to include in our analysis, we used several criteria. First, we focused our search on surveys of ambulatory settings published within the last six years. Second, we sought to identify surveys utilizing nationally representative samples. Finally, surveys of EHR use in health centers were specifically included. To the extent that any additional surveys were deemed to be of use in our study, we also included them in our analysis. We conducted an examination of the common EHR features examined in the surveys to inform development of a comprehensive list of key clinical and administrative features within an EHR system within an EHR system. In developing this list, we also reviewed the initial Institute of Medicine (IOM) core functionalities of an EHR system [7] and expanded on this by examining the HL7 functional model and the Certification Commission for Health Information Technology (CCHIT) criteria for ambulatory EHRs.

To further inform the study, we conducted a series of discussions with three major ambulatory EHR vendors, two key informants that have expertise in the area of health IT adoption in ambulatory care, and five health centers representing a small subsample of early EHR adopters and their protégés. In engaging with discussants, we sought to identify the common features and functions available in the EHR system, assess use of specific system functions, and EHR capabilities for capturing usage data. In addition, we also made an effort to understand vendors' technical architecture and capacity for reporting on system utilization and quality measures.

Results

Published estimates of EHR adoption are of varying quality. In a report comparing existing surveys assessing EHR adoption up till the year 2008, it was found that very few were adequate to accurately capture the state of EHR use in the United States [7]. In addition, while there are many studies which measure the rate of adoption of EHRs, there is significantly less information to be found regarding actual physician use of EHR features. The Robert Wood Johnson Foundation report titled *Health IT in the United States: The Information Base for Progress* defined adoption as "a process that, for measurement purposes, captures the acquisition, installation and use of EHRs" [8]. It was recommended that, in order to achieve accurate results, EHR adoption surveys should assess these three domains. However, many surveys of EHR adoption merely assess system availability (acquisition and installation) rather than the degree of system utilization (use).

Surveys Selected for Review

Our literature search identified three recurring national representative surveys that assessed EHR adoption. The National Ambulatory Medical Care Survey (NAMCS) and the National Hospital Ambulatory Medical Care Survey (NHAMCS) both included the same sections measuring EHR use in practices. The Center for Studying Health System Change Community Tracking Study Physician Survey included a section assessing the use of IT in physician practices.

Four other key national studies emerged. The National Survey of EHR Adoption was developed by the DesRoches et al. study team and represents one of the most comprehensive studies on EHR adoption to date. Also included was the Commonwealth Fund National Survey of Physicians and Quality of Care, a 2003 survey which explored physicians' use of IT tools. The Medical Group Management Association (MGMA) conducted a 2005 survey to assess the adoption of health IT in their medical practices.The2007 Office Systems Survey which was administered by the Centers for Medicare & Medicaid Services (CMS) as part of their Doctors Office Quality Information Technology (DOQ-IT) initiative was also included in our analysis.

Two surveys of health center adoption of health IT emerged. A 2005 survey administered by the Community Clinics Initiative to assess information management in health centers was identified. Finally, the 2006 National Association of Community Health Centers (NACHC) survey of Health Center Use of Electronic Health Information was the first national measure developed to specifically access health center adoption of health IT.

A total of nine surveys were included in our final analysis. Six of these studies were large-scale national studies that measured EHR adoption, two were surveys developed to assess health IT use in health centers, and one was a statewide survey assessing EHR functionality and the level of physician use of the specific functions.

Categorization of EHR Functions.

Based on information gathered from review of the IOM core functionalities, the HL7 EHR functional model and the CCHIT criteria for ambulatory EHRs forty EHR features were identified and organized into the following eight function-based categories: "Organize Patient Data", "Compile Lists", "Receive and Display Information", "Order Entry (CPOE)", "Decision Support", "Communication and Connectivity", "Administrative and Billing Support" and "Other".

EHR Use

Health center network representatives and ambulatory care practices reported that in general the more basic, or first tier, EHR features such as those of patient demographics, recording patient vitals, documentation of notes, entering medication and allergy information, problem lists, referrals, billing (particularly in smaller practices), medical summary and entering insurance information features were the most frequently used. These were common functionalities that were cited as having been implemented in almost all practices.

Meanwhile, features such as drug formularies and eligibility checking received lower levels of use or were not used at all. In the case of drug formularies, some practices reported that it was difficult to have a comprehensive formulary as all insurance plans may not have chosen to participate. Health plans also tended to change their formularies and formularies in the EHR may not necessarily have been updated in a timely way. This resulted in providers not being very keen to use the drug formulary function. Eligibility checking functions were report-

edly very hard to integrate into the EHR. Instead, practices sometimes chose to make use of the eligibility checking through their existing practice management systems.

Additional second-tier functions included clinical decision support such as smart forms, alerts and reminders, drug interaction checking and clinical guidelines. Second tier functions were often not implemented when the systems were first installed and there also appeared to be variability in terms of the size of the practice; larger practices seemed to be more equipped to implement more advanced clinical decisions support features compared to smaller practices.

Electronic Exchange of Laboratory Information

The electronic exchange of lab results was one of the features of the EHR system that was most commonly used. In most instances, EHRs had established unidirectional interfaces with national labs or local labs and sites were receiving results electronically. Many sites reported that establishing interfaces with hospital labs was more difficult and oftentimes there was reluctance on the part of the hospital to establish a results interface with ambulatory care providers and health centers. In cases where results interfaces were established, providers routinely used the EHR to order labs that resulted in printed lab requisitions. A few sites reported supporting bi-directional lab interfaces, but this was not common. However, sites reported a growing trend to support bidirectional interfaces with labs and discussions with vendors also indicate that they are encouraging bidirectional lab interfaces at initial installation.

There was also a growing trend to use point of care (POC) devices in providers' offices for a variety of lab tests including HbA1c, simple blood chemistries, pregnancy tests, HIV testing and cholesterol testing. In cases where POC devices were being used, the extent to which they were integrated with the EHR varied. This resulted in health centers and practices supporting a variety of different workflows.

E-Prescribing

The practices reported that a majority of the e-Prescribing (eRx) done was only partly electronic. In cases where e-Prescribing was being used, the provider entered the prescription into the EHR using the eRx software. However, three different approaches were being employed to route the prescription to the pharmacy:

- *Fully electronic* – Prescriptions are sent electronically to pharmacies in a paperless process, through the SureScripts-RxHub network. In this case, the prescription is electronically routed to the pharmacy information system.
- *eFaxing* – Prescription information is electronically faxed to pharmacies. Using this process, a fax normally prints at the pharmacy and the pharmacist manually keys in the prescription into the pharmacy information system.
- *Prescription printing* – A hard copy script is printed and handed to the patient who fills the prescription at a pharmacy of choice. Among those practices capable of e-Prescribing, this approach is generally used only in instances where patients are not able to indicate which pharmacy they will print the script at or if the pharmacy does not support e-Prescribing.

In general, sites tended to use the eFaxing approach. Reasons cited for this included that, at the time of initial implementation, there were many barriers related to e-Prescribing and that there did not appear to be any financial benefits of the technology. Furthermore, while larger pharmacy chains are generally capable of receiving prescriptions electronically, many smaller pharmacies are not capable of this due to the high cost of implementation on the pharmacy end. A final barrier cited was the inability to use eRx for controlled substances due to current Drug Enforcement Agency (DEA) rules for eRx [9].

Clinical Decision Support

Practices and health center networks reported having EHR systems with Clinical Decision Support (CDS) modules. These modules were capable of numerous functions including providing drug interaction alerts, clinical practice guidelines for particular chronic diseases, and prompts and reminders for health maintenance. Sites also reported that EHR vendors are increasingly making available knowledge resources that allow for context sensitive help from within the patient record. While the availability of this function was not commonly reported, a few sites had implemented it and regarded it as a very useful tool for providers.

Many CDS functions were in the second-tier, i.e. most likely implemented only once the EHR system had been in use for a while. Providers also tended to use those functions only as it was relevant to their practice and specialty.

Several informants also reported that their health centers and ambulatory practices had implemented alerts and reminders in their EHR system in order to support preventive services and e-Prescribing. Although this feature has great potential to be an extremely valuable EHR tool for increasing patient safety, informants indicated that many physicians experienced problems using the drug interaction alerts component of the CDS. Some perceived these alerts to be intrusive or annoying. Others felt the information offered by the alerts was redundant and unhelpful. In both cases, the alerts often acted to interrupt and slow down physicians' workflow. As a result, some practices allowed physicians the flexibility of selectively turning off or adjust the threshold for these warnings. Sites reported that it appeared clinicians significantly took advantage of this option.

Use of Other EHR Functions

In terms of more advanced EHR functions, several discussants reported that they were beginning to use their EHR for referrals and for specialty reports such as radiology reports. Generally, mid and large sized practices were more likely to be expanding current EHR use in this direction. Very few health centers and ambulatory care practices reported being able to receive radiology images. In cases where this was supported, the EHR generally received a link to the image which was hosted by an external Picture Archiving and Communication (PACS) system. This was the preferred method as radiology images can be fairly significant in size and many small and mid-sized provider offices did not have sufficient bandwidth to

support the transport and storage of large radiologic images. In general, practices reported that receiving the radiology report was far more important to them than receiving the images. In cases where practices were not able to receive radiology or other reports electronically, most had at the very least implemented scanning technology that enabled them to scan the paper reports into the electronic health record.

Interoperability and Standards Support

The Health Level 7 (HL7) messaging standard is being used widely to support electronic exchange of information between provider practices and hospital, national and local labs. However, while most sites report using HL7 for messaging, many of them are yet to implement HL7 V2.51. Many of the health center networks that we spoke to used either commercially available or homegrown interface engines and reported that they spent significant amounts of time establishing interfaces with different labs and providers due to the significant variability in the implementation of the HL7 messaging standard.

With respect to data content standards, the National Council for Prescription Drug Programs (NCPPDP) Script is being used for eRx. Most practices also reported the use of the SureScripts-RxHub network to connect to retail pharmacies. Sites included in this study generally supported use of the Continuity of Care Document (CCD) while there were a few sites that indicated that they supported the Continuity of Care Record (CCR) for patient summary data. Although sites reported having the capability to exchange the CCD, they had limited experience in actually exchanging patient summaries as they reported that many sites that they routinely interact with were not able to receive the CCD.

For sites that supported electronic exchange of lab information, there was virtually no active use of the Logical Observation Identifiers Names and Codes (LOINC) for lab results. Sites reported that lab results from national, hospital or local labs were not LOINC encoded even though the EHRs are able to receive LOINC codes. Similarly, there appeared to be no use of SNOMED-CT.

Reporting on Quality Metrics

Unlike monitoring of usage, most of the sites we conducted discussions with were using EHRs to assist in reporting on different quality metrics. Many of the health center networks were reporting on the HRSA quality indicators [10], which include blood pressure control in hypertension, HbA1c in diabetics, pap smears and mammography for women, immunization for children less than 2 years, depressions screening and colorectal cancer screening. Sites did not directly use their EHR for quality reporting, but instead populated a registry or a vendor supplied reporting database with the subset of information that was needed for quality reporting. This approach was preferred over running reports against the EHR production database due to concerns of system speed and response times. Sites also reported that many EHR systems lacked out-of-the box reporting capability for quality metrics and they opted to use more sophisticated tools in the form of registries or custom databases with enhanced reporting tools.

Assessing EHR Usage

Efforts to monitor EHR use varied tremendously from site to site, dependent in part on the availability of IT resources, size of the organization, availability of canned reports within the EHR system and size of practice. In very few cases had sites implemented any robust capability to assess utilization of EHR functions. In general, smaller sites, or sites that relied largely on their vendor for IT support reported that they were not routinely collecting or reviewing usage data. In most cases, the vendor audit logs were a source of information to assess which providers had accessed different aspects of the EHR. This was largely done in the context of ensuring the security and privacy of patient records. Where sites were monitoring system usage at a granular level, they were either working with the vendor IT team to create the report or had independently undertaken the task of building customized reports (this was mostly done by networks). In almost all cases, significant customization was required in order to extract the kind of information sites were interested in from the EHR.

For practices that were currently measuring EHR usage, there was a significant variability in the granularity of data collected. All sites were able to track usage both at the practice and at the physician level and assess the use of specific functions. Usage data was easier to access around basic features such as the use of templates, completing insurance information, signing of forms and keeping track of the functions within the EHR system which had been disabled. However, monitoring clinician use of more advanced features such as CDS was particularly challenging.

Discussion

This study provided valuable information regarding the nature of EHR use and implementation in health centers and practices. There existed variability in the EHR functions that are used based on practice size, practice specialty and length of time for which the EHR has been implemented.

Commonly used EHR functions. Review of current EHR use in ambulatory care settings suggests that in all practices (small, mid and large) there are certain basic clinical and administrative functions that are commonly used. The clinical functions used include encounter notes, medication lists, allergy lists, problems lists, and order entry functions focused around lab order entry and results delivery. The use of eRX appears to be increasing dramatically but current use is still limited.

Current use of Standards. Despite the availability of industry accepted standards and CCHIT requirements that certified EHRs support certain standards, current use in ambulatory care settings appears to be limited. While most sites report using HL7 for messaging many of them are not yet on HL7 V2.51. With respect to data content standards, NCPDP Script is being used for eRx. Some sites report that they generate a CCR or a CCD but have had limited experience in its use as organizations that they interact with often are not able to accept summary documents in this format. There is virtually no active use of LOINC for lab results even though lab results are one of the most commonly used functions within the EHR.

Use of EHRs for Quality Improvement. Practices of all sizes also report that they support clinical decision support functions related to eRx largely in the form of drug interaction and drug-allergy checking. More comprehensive clinical decision support functions tend to be more common in larger practices and may include the use of smart forms, preventive care reminders, clinical guidelines and knowledge resources. While sites report using EHR data for quality reporting, in most cases a third party registry product or alternate database is used to generate these reports. Ambulatory EHRs have limited out-of-the box capability for quality reporting and oftentimes, due to concerns regarding system speed and response times, quality reporting is not done off the production database.

Sites using clinical decision support for eRx report that this has improved medication management and compliance with formulary. Additionally large practices that utilize smart forms and other forms of decision support report higher compliance with evidence-based practices and improved outcomes. An objective assessment of impact of EHR use on quality improvement cannot be made given the rudimentary nature of how EHR utilization is being tracked. Additionally while sites are reporting on quality outcomes the lack of standardization of measures and how these should be collected and reported also presents a challenge

Challenges and Barriers in utilization of EHRs. Our findings suggest that barriers to EHR use are multi-factorial. In many cases cultural resistance of providers and other clinical staff result in limited use of available functionality. In other cases the implementation of new systems have not accounted for good integration with clinical workflows and consequently providers use workarounds or may stop using certain functions entirely. Particularly in the context of CDS sites reported numerous challenges to ongoing use of this feature. In some cases the immaturity of the vendor product and usability issues were cited as reasons for non-use. In some cases regulatory challenges presented a burden for example, sites reported that due to DEA rules they were not permitted the use of eRx for controlled substances. Many of our informants reported that they encountered numerous challenges in exchanging information electronically with labs or other provider sites. Limited interoperability resulted both from lack of use of standards and tremendous variability in how certain standards were being implemented.

Conclusions

Understanding EHR utilization and ongoing challenges and barriers to use will have important implications across the medical and health IT industries. Study findings indicate that there is a common set of EHR functions that all practices are likely to have purchased and that sites would be capable of implementing. Most EHR vendors have capability to track usage of these common functions even though they may not all support the same robust reporting capabilities. By providing tools to health centers and networks to monitor EHR utilization these organizations would be better equipped to promote meaningful use and adoption proactively.

Acknowledgments

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Measuring Use of Electronic Health Record Functionality Using System Audit Information

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Abstract

Meaningful and efficient methods for measuring Electronic Health Record (EHR) adoption and functional usage patterns have recently become important for hospitals, clinics, and health care networks in the United State due to recent government initiatives to increase EHR use. To date, surveys have been the method of choice to measure EHR adoption. This paper describes another method for measuring EHR adoption which capitalizes on audit logs, which are often common components of modern EHRs. An Audit Data Mart is described which identified EHR functionality within 836 Departments, within 22 Hospitals and 170 clinics at Intermountain Healthcare, a large integrated delivery system. The Audit Data Mart successfully identified important and differing EHR functional usage patterns. These patterns were useful in strategic planning, tracking EHR implementations, and will likely be utilized to assist in documentation of "Meaningful Use" of EHR functionality.

Keywords:

Medical Records Systems, Computerized/utilization

Introduction

Early in this decade, adoption of Electronic Health Records (EHRs) was identified as an important factor in improving healthcare in the United States [1]. In spite of this recommendation, recent EHR adoption rates in the United States are low, with only 4% of ambulatory physicians using a 'fully functional' electronic record system in 2008 [2]. With the passage of the American Recovery and Reinvestment Act (ARRA) of 2009, over 19 Billion dollars was targeted for healthcare information technology (HIT) projects to accelerate the adoption of EHRs and other technology. Much of this money will be used for incentives for ambulatory physicians and hospitals that demonstrate "meaningful use" of HIT [3].

At this time, demonstration of "meaningful use" of HIT is still being defined by committees that report to the secretary of Health and Human Services. Early indications are that " meaningful use" will be measured by determining use of certain core functions found within most EHRs. Core functions were identified by the Institute of Medicine and categorized into eight groups including Health Information and Data, Order Entry Management, Results Management, Clinical Decision Support, Population Management, Patient Support, and Administrative Processes [4]. These categories of core functions were used successfully in a recent nation-wide evaluation of EHR adoption [2].

We expect that the adoption rate for certain functions will be required to demonstrate meaningful use of EHRs. For example, it will likely be necessary to document which functions (e.g. Computerized Physician Order Entry (CPOE), Eprescribing, Problem List, etc.) are used by clinicians. In addition, we expect that the level of adoption or extent of utilization of each functionality by each physician will be required. For example, determining if a physicians uses CPOE will not be sufficient, but reporting the extent of this use by providing the percentage of patients that orders entered via CPOE will likely be required.

To date, the method of choice for measuring EHR adoption has been by survey of EHR users. While surveys have their advantages, they also have the disadvantage of being periodic in nature, subjective, and somewhat intrusive. Alternative methods to track adoption of EHR systems were carried out during early implementations of our ambulatory EHR at Intermountain Healthcare. It was found that accessing the EHR transaction logs and data repository provided data that correlated to system usage [5]. Using this new automated source of information, adoption rates could be tracked continuously. For example, the number of physicians entering medication orders per day could be tracked on a daily basis or rolled up by month as shown in Figure 1. These computer tracking methods were shown to have certain strengths. For example, the data were objective and comprehensive, were available on a continual and often immediate basis, extraction of the data was inexpensive, and the data were relatively easy to collect and analyze.

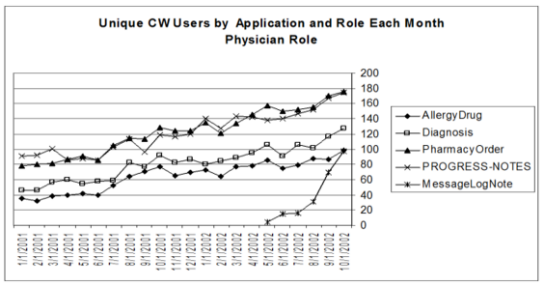

Figure 1- Early example of EHR Adoption Chart showing growth in users by month and by function (Orders, Messaging, etc.). Our early EHR application was known as CW.

Early success with creating computerized, real-time adoption measurement tools from the EHR led to decisions to develop a more robust system to track adoption using data from the EHR. This included tracking usage patterns of different applications or functions of the EHR.

A Pubmed [6] literature search was performed for information on using audit information to measure EHR adoption. However, very little specific information could be found.

This paper describes the development and implementation of system based on EHR audit information to measure EHR adoption and core functional usage patterns.

Materials and Methods

This analysis was performed using the HELP2 Electronic Health Record at Intermountain Healthcare. Intermountain Healthcare is a not-for-profit integrated health care delivery network which operates 22 hospitals (128,000 admissions per year), employs over 700 physicians working in 170 ambulatory clinics (6,023,000 patient visits per year), and insures approximately 500,000 individuals.

Intermountain's clinical information systems are relatively extensive and have been described previously [7]. Inpatient and outpatient data are interfaced to a longitudinal patient record and stored in the Clinical Data Repository (CDR) [8], the underlying repository for HELP2. Providers access different HELP2 modules for different functionality, including documentation of progress notes, problem lists, medication orders, etc. HELP2, has been in use with periodic updates since 1996. Over 13,000 clinicians use the HELP2 EHR each month to access the records of 258,000 unique patients.

Auditing capabilities are advanced and built into the foundation of HELP2 and the CDR. The purpose of the audit tables is to record the actions of users accessing various forms of patient data. For each encounter table, a corresponding audit table keeps a complete record of all transactions to provide an audit trail. Every time a table is updated, the system makes a copy of the new entry, adds the data elements needed for the audit entry, and moves the copy into a duplicate table reserved for audit purposes only. For instance, each time the main encounter table is modified, the corresponding audit table grows by one row. However, the main encounter table contains only the current data for each encounter.

Audit Data Mart

Early versions of computerized EHR adoption tracking of HELP2 pulled transaction data directly from the production data base, usually during off-peak hours so performance of HELP2 would not be impacted. As usage of the EHR grew, along with the demand for adoption metrics, it was no longer feasible to access the production system for adoption metric data. Preliminary analysis of audit logs showed that the data might be suitable for adoption metrics.

Coincidentally, Intermountain Healthcare's compliance department had designed a small system called the Compliance Audit Database (see Figure 2) that aggregated audit information from the CDR to provide reporting functions without impacting production systems. These reports identified users that accessed patient records in the event inappropriate access was reported or suspected.

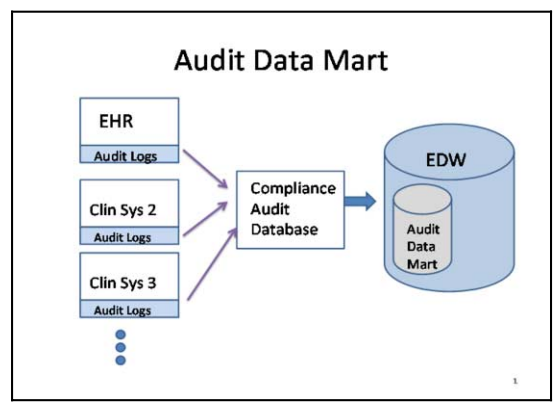

Figure 2- Flow of data from the EHR audit logs to the Audit Data Mart within the Enterprise Data Warehouse and

Early adoption metrics were pulled from the Compliance Audit Database. However accessing audit data from the Compliance Audit Database was problematic for several reasons. The audit data was abstract, and audit table analysts were often necessary to help create meaningful queries. Also, accessing aggregated data across multiple patients was very time consuming as the tables were not indexed ideally for the type of analysis necessary for EHR adoption reporting. There were also security and privacy concerns about accessing audit tables directly because the audit tables were not themselves audited.

To solve these issues an Audit Data Mart (See Figure 2.) was designed with the following goals in mind. Appropriate audit data, scrubbed of unnecessary sensitive information would be loaded from the EHR audit tables or the Compliance Audit Database into data mart tables in the Enterprise Data Warehouse (EDW).

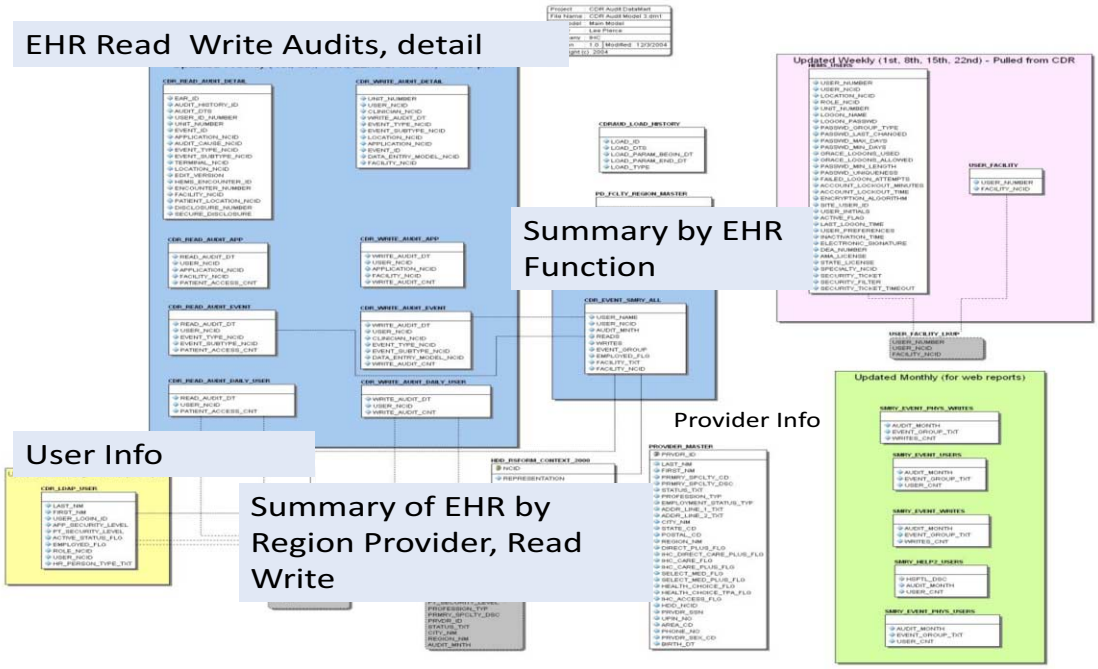

Figure 3 - Entity Relationship Diagrams of Audit Data Mart

Tables would be indexed and optimized for analysis and easy to search. Metadata would be used to describe the content, so analysts can pull data efficiently. Help2 user identification information would be linked to a common user identification scheme, to eliminate the need to match users from other clinical systems. Access to these tables would be audited in the Enterprise Data Warehouse to enable monitoring for security purposes. Access to the audit data mart would be managed by a data steward, and follows access guidelines outlined by Intermountain Healthcare.

The Audit Data Mart can be divided into 4 groups of tables, as shown in Figure 3. EHR Detail Read and Write Audit tables includes detailed information about read and write audits, including patient unit number, application type, data type, etc. User Info is data about the EHR user including name, employment location, role, etc. Provider information includes information about clinicians, including specialty, location, affiliation, etc. Finally, the summary tables aggregate common information into single tables. For example, User name, count of reads and writes per month, role, EHR application or function, etc. Audit data prior to the year 2000 are maintained, so historical reports and trending can be accomplished. The Audit Data Mart can be accessed with SQL or a similar query language tool. The tables are well defined in the metadata of the EDW. Reports can be easily built to answer many EHR adoption questions.

Results

The Audit Data Mart was queried to determine which EHR functions were used most frequently to access patient information for each department within Intermountain Healthcare. Usage of HELP2 EHR functionality was identified for all 836 Intermountain Departments, within 21 hospitals and 160 clinics. The results for the top 25 Departments are shown in Figure 4. The departments are shown in descending order of EHR use. The EHR high-level functions listed include Problems, Notes, Messages, Notifications, etc. This analysis shows the UV218 Emergency Room that the highest HELP2 usage, accessing over 20,000 unique patient records in 90 days, followed by Dixie Clinic and an Internal Medicine clinic, all based within the enterprise. Functions used to access the data include the ED System module, Problem Module, Notes Module, Encounters Module, Allergies Module, etc. This analysis also shows the different patterns of EHR function usage. For example, problem list was accessed on more patients in Dixie Clinic than anywhere else.

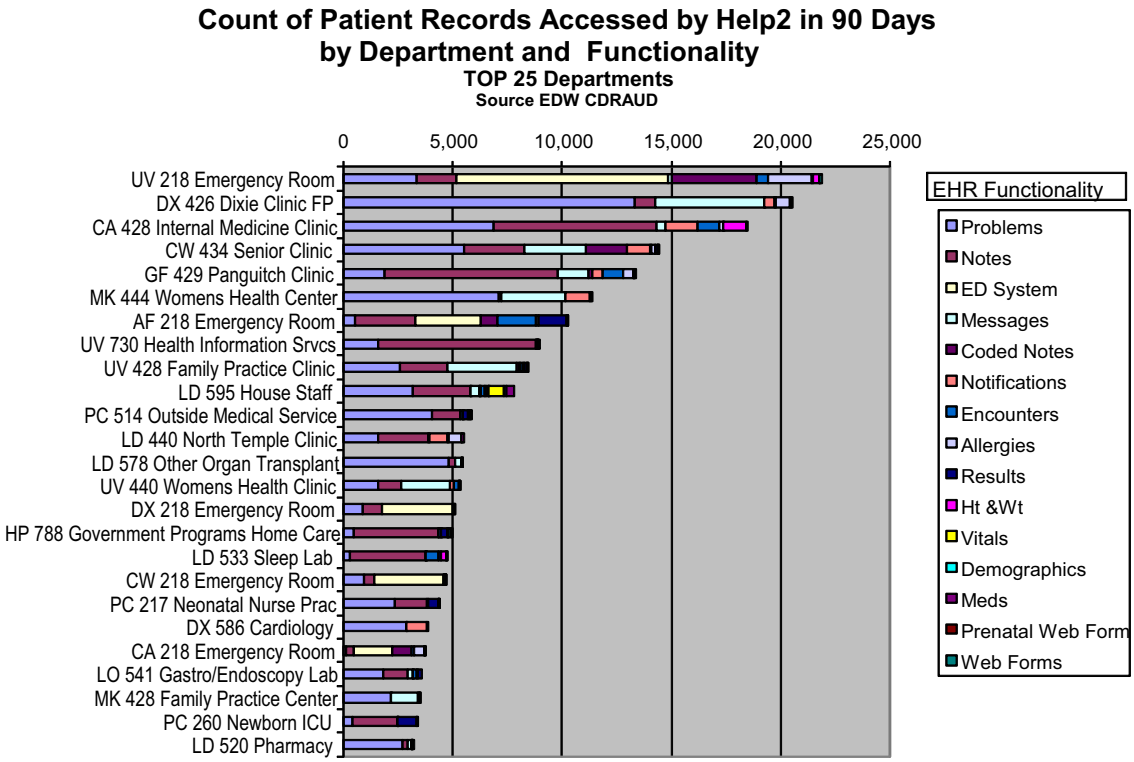

Figure 4 - Count of Patient Records by Department and EHR Functionality

Discussion

Early work on EHR adoption assumed a more or less homogenous adoption model, i.e. that all EHR users accessed the same functionality. Recently research has shown that EHR adoption can be more heterogeneous with users accessing different functions within the EHR [9].

For example, some users adopt more modules and use these modules on more patients. This has been our experience at Intermountain Healthcare [10-12]. Figure 4 shows the different types of EHR use within the top 25 departments. For example, Dx426 Dixie Clinic accessed problems list items on more patients than the UV218 Emergency Room. We have found that adoption metrics from the Audit Data Mart have been critical for tracking EHR implementations at Intermountain. For example, knowing the differing use of Problem List at two sites could trigger an analysis to identify the cause of the low usage. Often, more EHR training is necessary to improve usage of certain modules.

This analysis primarily took advantage of the 'Read Audit' data from the Audit Data Mart, which stores information about how clinical data is accessed. 'Write Audit' data, contains detail about how clinical information is stored. We have used the Write Audit data to identify which modules clinicians use to enter data into the EHR. We expect the 'Write Audit' data to be play a key role in documenting meaningful use of the EHR. For example, we can track which physicians enter CPOE orders, Eprescribing orders, allergies, etc.

The richness and ease of use of the audit data mart has resulted in the ability to rapidly measure EHR usage on a broad scale. In addition, it is easy to customize the reports to meet the needs of various stakeholders. For instance, detailed reports on individual users use of EHR functionality can be done for department use, or high-level summary reports can be run for the entire enterprise. These reports have proven to be useful in strategic planning [10], in tracking progress of current EHR implementations with our employed and non-employed physicians. We foresee this methodology being critical to support the documentation of 'meaningful use' of EHR functionality required by the ARRA incentive laws.

Limitations

There are limitations to using Audit repository data to measure system usage. Audit repository data was not designed to be used for measuring EHR adoption. Understanding the audit

table update process is key to transforming the audit table date into information that can be used for tracking EHR adoptions and functional use. For example, audits of some Help2 module screens such as Clinical Notes Review produce a row in the audit table for each clinical note summary that is shown on the screen. If 25 notes are shown to a user, there are 25 audit table rows written to that audit table. For adoptions and usage metrics, this detail is overkill. One method of managing this is to count only the first 'read' event per patient , per user, per module, instead of counting all 25. What is important is defining the methods of managing the information. We store these transformations in the metadata associated with the Audit Data Mart.

We have found other limitations to using the audit data. For example, some data is just not collected by the audit system. For example, the audit data mart and HELP2 audit data do not contain terminal-specific location information. Therefore, it was not possible to attribute events to a specific terminal or facility. To identify the location of Read Events and Write Events, users must be linked to the location identified by their human resource employment record.

Validation of Audit results

Validating the audit data mart data is critical to success. We shared our adoption metric results with a small sample of departments in order to make sure that our results made sense. We interviewed individual users and asked them which EHR functions they used, and to what extent. In each case the departments' feedback indicated that the audit data mart reports accurately represented their behavior and EHR usage.

Conclusion

This paper describes a method of EHR adoption measurement which capitalizes on audit logs, which are often common components of modern EHRs. This method has been used successfully at Intermountain Healthcare, a large integrated delivery network, to identify EHR usage patterns by functionality within the enterprise. This methodology will likely play a key role in documentation of 'meaningful use' of EHR functionality required by the ARRA EHR incentive laws.

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A Scheme for Assuring Lifelong Readability in Computer Based Medical Records

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Abstract

Medical records must be kept over an extended period of time, meanwhile computer based medical records are renewed every 5 -6 years. Readability of medical records must be assured even though the systems are renewed by different vendors. To achieve this, we proposed a method called DACS, in which a medical record is considered as an aggregation of documents. A Document generated by a system is transformed to a format read by free software such as PDF, which is transferred with the document meta-information and important data written on the XML to the Document Deliverer. It stores these data into the Document Archiver, the Document Sharing Server and the Data Warehouse (DWH). We developed the Matrix View which shows documents in chronological order, and the Tree View showing documents in class tree structure. By this method all the documents can be integrated and be viewed by a single viewer. This helps users figure out patient history and find a document being sought. In addition, documents' data can be shared among systems and analyzed by DWH. Most importantly DACS can assure the lifelong readability of medical records.

Keywords:

Medical record system, Hospital information system, Information storage and retrieval

Introduction

Electronic medical record systems (EMR) have come into practical use. EMR is more convenient than paper based medical records because the carrying of paper files of medical records becomes unnecessary, and accessibility to medical records is greatly improved. A medical record is a record of observations and process of treatments of a patient. In Japan, there is a legal obligation to keep medical records for at least 5 years after the patients' treatment has ended. Some patients have been treated in a hospital for more than 20 years. Thus their medical records must be kept for an extended period of time. On the other hand, EMR has to be renewed every 5 to 6 years. On system renewal, not only hardware but also OS and application software are renewed. An EMR is composed of several systems provided by different vendors, especially in a large hospital. These systems may have to be renewed by different vendors due to changing needs of hospital staffs. In this circumstance, in order that the data stored into the system can be viewed persistently, it must be stored by a consistent well-considered method. Otherwise, when the application software is renewed, the data stored in the old system cannot be viewed. EMR already started without much consideration for the long-term readability of medical records.

To solve this problem, we propose a document based electronic medical record, considering a medical record as an aggregation of documents. A document's information consists of the document body and its meta-information. The data form of the document body is transformed into PDF, JPEG, TIFF or DocuWorks, etc. which can be read by free software universally available. Documents' meta-information is collected in a unified format. In the field of medical imaging, the concept of PACS (Picture Archiving and Communication System) is well-known and widely used. In PACS, image data composed of image body data and its meta-information is managed uniformly, so any images can be viewed by a single viewer. Our proposed system is similar to PACS where documents are substituted for images. Thus we name this system DACS (Document Archiving and Communication System).

By collecting all the documents of a patient, it is possible to view them by a single viewer. In the existing EMR, patients' clinical data are stored in different systems. Each system sets up a web system to let users view it from the patient's clinical record view window. By this method it is possible to access a requested document. However, it is difficult to comprehend a patient's entire clinical history, because different kinds of needed documents can be accessed only from their own window. Hospital staff needs to comprehend a patient's problems and requirements in a short period of time when they participate in the patient's medical care. In this case, they need to know what kind of documents exists for the patient. In addition, they have to view related documents with the one

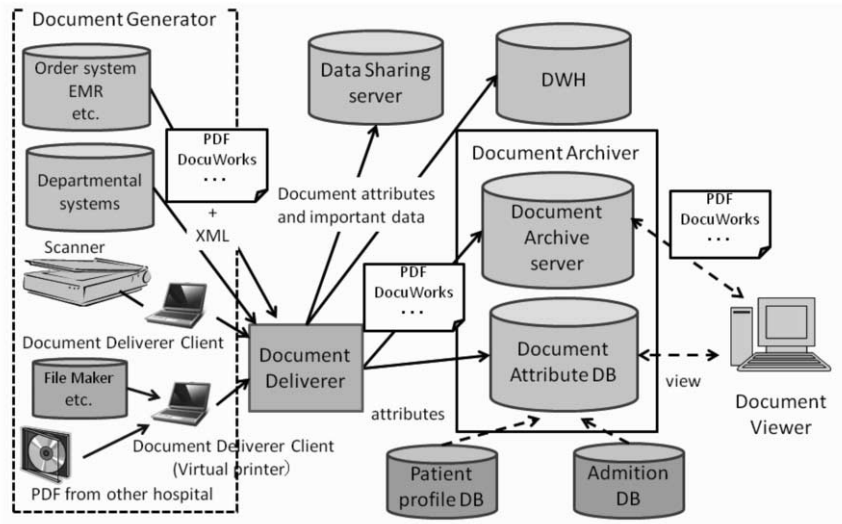

Figure 1- Basic configuration of DACS

currently being viewed, even though they are generated by different systems.

If medical record data is handled by documents, a worry arises that the data in the documents might be difficult to process. This data is sometimes required to be shared among different systems. There is also a request that the data in the documents be used for analysis. To fulfill these requirements, we proposed a method for collecting important data in a document with document's meta-information.

Methods

Fundamental Concept of DACS

In DACS, medical records are handled as an aggregation of documents instead of data. Typical document types are examination reports, operation records and discharge summaries which are created for respective events. In addition, chronologically continuous data is converted into a series of documents by setting an intersection. For example, a progress note that is written continuously for an inpatient is divided by day and by the department of the creator into a series of documents.

The basic configuration of DACS is shown in Fig.1. Systems that generate documents are called Document Generators. All the generated documents are transferred to a Document Deliverer. Next, the Document Deliverer transfers them to the Document Archiver, the Data Sharing Server, and the Data Warehouse (DWH). The Document Viewer, which runs on each EMR terminal, accesses Document Archiver to display documents.

Document Body and its Attributes

A Document generated by a system is transformed to a standard format read by free software. In our DACS implementation, PDF, JPEG, TIFF or DocuWorks are used for said format. Document information is separated into a document body for readability and its meta-information.

Document meta-information consists of document attributes. The mandatory attributes are patient ID, document class code, event date, and department code. Document class code is unique to each document class in a hospital. The document class is defined by the smallest granularity. They are grouped into super-classes by the external table file, because a classification scheme varies according to the requirements of the subsystems.

Event date is the date most appropriate for the document. For example, the event date of an examination report is the date on which the examination took place rather than the date on which it was created. Documents such as discharge summaries and flow-sheets are records of a certain period of time. For these documents, attributes for the start date and end date are provided. In case two or more documents of the same class were created for the same patient on the same date, the documents need to be identified by time. So time attribute is also provided.

A document sometimes has several departments as an attribute, such as the department that placed the order, that created the document, or where the patient was hospitalized. A suitable one is selected for each document class.

In addition to the aforesaid mandatory attributes, a numbers of optional attributes are defined. The patient profile information, such as patients' names, can be retrieved from the system through patient ID. Although there is important information

such as class of inpatient/outpatient or document's author information, some of the latter are practically unavailable due to documents' origin. So we did not make them mandatory. We limited the mandatory attributes to those required for the Document Viewer to be described shortly.

In order to share with other systems important data included in a document, and use it for data analysis, such data is extracted from a document. The data is presented by item code, item name, value name and value code if it exists. The item code must be assigned uniquely in a document class. Thus uniqueness of an item can be ascertained by the item code along with the document class code.

These documents' attributes and important data in the documents are conveyed by the XML format.

Transferring Documents from Document Generators

There are 4 types of Document Generators. 1) Physician order entry system, EMR, etc. 2) departmental system 3) document scanners 4) virtual printers.

Types-1 and 2 are intersystem connection type and are essentially the same. In most settings, printed output image is available, so the image is converted into PDF format and the document's meta-information is embedded in the prescribed XML format when it is sent to the Document Deliverer.

Intersystem connection in Type-2 is typically a transmission of a report. An originating system generates a PDF file from a print output image, and an XML file including the document's meta-information. Then it transmits them to the Document Deliverer when the report is approved.

In Type-3, a scanned image is transformed to DocuWorks format. Because QR code is printed on sheets, the document's meta-information can be recognized by reading it. This DocuWorks file and the XML file including the document's meta-information are transmitted to the Document Deliverer. We call this module a Document Deliverer Client. Documents are then transmitted to the Document Archiver and digitally signed and time-stamped using XAdES [1].

The virtual printing system of Type-4 is similar to Type-3. When the virtual printer outputs a print image using its driver, a DocuWorks file is transferred to the Document Deliverer Client. In case patient ID, event date, and document class ID are set at predefined positions in header and footer of an output document, they can be read automatically. In case these data are not set, they are input manually. In Types-3 and 4, a DocuWorks file together with a prescribed XML file is transmitted to the Document Deliverer from the Document Deliverer Client.

Delivering Documents

The Document Deliverer performs the task of delivering documents received from Document Generators. The Document Deliverer lightens the load of Document Generators for document archiving. FTP, CIFS and SOAP are available protocols for transferring document information from Document Generators to the Document Deliverer. Although bidirectional communication over SOAP is reliable, most developers prefer FTP because it is easy to implement. The Document Deliverer receives a document body file and its meta-information in the XML. It registers the document body and its meta-information to the Document Archiver. The Document Deliverer also delivers the data received to the Data Sharing Server and to the DWH. Compared to the method in which each Document Generator directly sends document information to the Document Archiver, the Data Sharing Server and the DWH, data transmission via Document Deliverer greatly reduces the load of Document Generators.

Preserving Documents

Document body and document attributes are stored into the different databases in the Document Archiver. No medical specialization is needed for the server in charge of the document body. Here we employed a Document Management System (DMS) product from Fuji Xerox. On the other hand, for the database for document attributes medical specializations are necessary. This database is needed for the Document Viewer. Besides information received from the Document Deliverer, patient profile information and admission history are also necessary. These are obtained from the hospital information system.

Viewing Documents

There are two ways for viewing documents. One is focusing on a patient to view various documents of that patient, and the other is focusing on a document type to view the documents of patients. The former is the prerequisite for EMR, while the latter is a function required for department operation. We call these viewers Medical Record Viewer and Register Viewer, respectively.

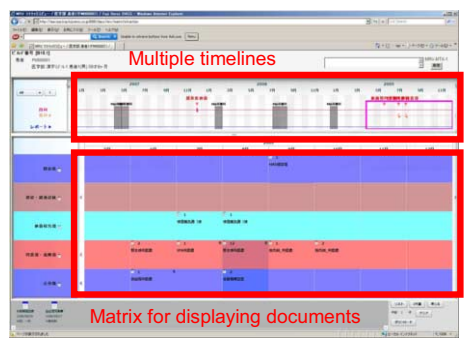

Figure 2- Matrix View

A Medical Record Viewer has two types of viewers: Matrix View which shows documents in chronological structure, and Tree View showing documents in class tree structure. The Matrix View (Fig.2) is designed to overview the patient's medical history with information over half a decade shown on one screen. Multiple timelines are displayed in the upper pane. Patient encounters (creation of progress notes) in each department and examinations carried out for the patient (submission of examination reports) are marked on timelines. Hospital admissions and important event such as operations are also dis-

played. Documents in the area specified by a thick frame on the timeline pane are browsed at the lower pane. The lower pane displays the documents in matrix form. Rows correspond to document classes and columns indicate periods. Because many document classes exist even in one patient, all the items presented in rows cannot be seen without scrolling. So we design a method to accomplish this. In this method, the thickness of the layer changes flexibly according to presence of documents. Because many documents are rarely generated on a same day, most of them can be viewed without scrolling.

When a document is designated in this pane, a browsing window called Focus View (Figure 3) is opened to display the content. The Focus View is set double-screen as default.

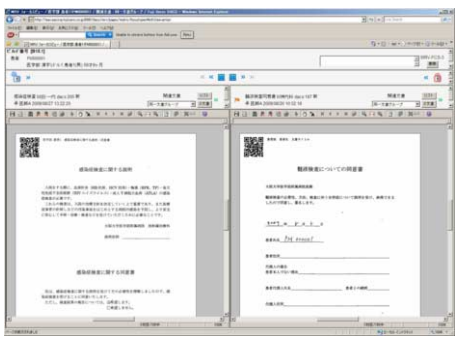

Figure 3- Focus View

Tree View is designed for searching a document. The document to be searched can be accessed according to date, document class, inpatient or outpatient by tracing classification folders.

Register Viewer is a viewer meant to read through documents in a specified class. It needs access control. For example, doctors in charge can access all the documents generated by their department. On the other hand, they cannot see the documents generated by other departments as a whole. Additionally, the hospital staff who engage in a special work for patients should be permitted to access the documents created by the staff. For example, the technician in charge of echocardiography should be able to view all the echocardiography reports. However, other hospital staff should not be permitted to access this view.

Printing Documents

Fuji Xerox's DMS has the function of outputting all the files of a patient for a designated period to a predefined directory. Numbers representing orders for print are set in the filename of the output files so that the print module can print them in a predetermined order.

Shared Database and DWH

By storing data in the Data Sharing Server, the data can be shared among different systems. In spite of the variety of data types, all the data can be stored in the scheme of item code, item name, value name and value code with the originated document's attributes such as patient ID, document class code, and event date. In this data scheme, one value is saved in one record. The primary key of the database file is a composition of the document class code and the item code. By linking with the table where the primary key corresponds to a concept code, items originated from different documents with the same concept code can be recognized as the same item. When no data in a document are set in the XML format, a fixed data is stored in the item code field in order to store the document's attributes.

The data scheme of DWH is the same as that of the Data Sharing Sever. Because not all of the important data is shared among systems, The Data Sharing Server keeps the limited items for few months in order to keep good response time. DWH, on the other hand, keeps all the important data and document's attributes sent from every Generator.

Results

We are now preparing for the renewal of the hospital information system of Osaka University Hospital which is going to start in January, 2010. It includes various types of physician order entry systems, medical record entries such as initial visit reports, progress notes, discharge summaries, etc. which are produced by NEC. In addition, there are many special departmental systems which are produced by different vendors. DACS is implemented in this new system. Most of the system is already in place. All of the clinical documents generated by various types of systems except for laboratory test results can be collected in the Document Archiver. For each Document Generator, to send documents by the proposed method, a program module for it had to be made. This method was so simple that all the systems in our hospital could make it. There were some systems that could not be customized. For these systems, the method of virtual printer was effective.

There are some paper based documents which originally cannot be digitalized. These documents also have to be collected for management by paperless computer based medical record. For these documents, scanning is practical and effective [2]. After scanning the document data are handled in the same manner.

Because all the documents are collected into the Document Archiver, they can be viewed by a single viewer. The Matrix View that we developed in this project is distinctive. The timelines of the Matrix View on which a constellation of clinical events marked will help users comprehend the trend of the patient's history by pattern recognition. The Focus View which is for seeing a document's contents has two screens. Thus the present one can be compared with the past one in the same document class. It can also view a discharge summary concurrently with examination reports during the same hospital admission.

Medical records are sometimes demanded for disclosure. In case of a lawsuit, all the medical records must be printed out for preservation of evidence. If some of them are missing, it may be regarded as concealing evidence. It is impossible for the EMR that integrates documents by web systems to print them out in readable order. Furthermore users can easily neglect to print out some part of the record. Because DACS ag-

lect to print out some part of the record. Because DACS aggregates all the documents, it is easy to print out all the records in a designated order without omitting anything.

Even though DACS is document based, important data in documents can be shared among different systems and be analyzed by DWH. We selected the data which may be used by other systems or be analyzed for clinical research in each document class. The requirement of our method is only to assure uniqueness of item code in each document. The vendors which develop the systems (Document Generators) can easily comply with this requirement and embedded them in the XML format.

The most essential point of DACS is to assure lifelong readability of medical record. Because the documents' bodies are viewable by free software, it will be read over a long period of time. Furthermore the structure of the document's meta-information is so simple that conversion of the data stored in a DACS to another new system is not difficult. Thus documents stored in a DACS will able to be viewed continuously.

Discussion

The scheme for securing lifelong readability of medical records is fundamental for management by paperless computer based medical records [3]. A medical record can be considered as an aggregation of documents. The essence of our method is that the document's body data is transformed into data forms which can be read by free software universally available and is collected with the document's meta-information.

For exchange of documents between systems, CDA (Clinical Document Architecture) is often used [4]. CDA is expected to be foundational for the realization of semantic interoperability for clinical statement. Our proposed method also uses XML as a conveyer of documents' meta-information, which corresponds to CDA header. Thus our method corresponds to a use case of CDA level-1 using external files. In order to share and analyze data, important data is also conveyed by the XML format. In CDA, data about patient is written in entry element in the part of the document body where code should be assigned as OID. In our method, the item code is simply required to be unique in a hospital. The concept code is assigned when the XML format is received by the Data Sharing Server or the DWH. That is because CDA aims at data exchange between facilities, code system used in CDA should be clearly demonstrated in the document. On the other hand, our method aims data exchange within a single facility. Thus it is easier to assign codes systematically after receiving a document. If the method for sending a document is complicated, it is difficult to collect all the clinical documents in a hospital. The XML format of our method is so simple that any system can easily generate it. It is speculated that it will take time for CDA to become widespread. Before that, our method is a practical solution.

Because DACS aggregates all the clinical documents, it enables users to view them concurrently even though the documents are generated by different systems. In paper based medical records, files for patients are separated according to inpatient or outpatient status. In computer based medical records, all the records for a patient can be viewed without decoupling. However, sometimes there is a lot of information even on one patient. We developed a document viewer system which automatically arranges clinical documents to help users figure out a patient's history and find a needed document.

The hospital information system of Osaka University Hospital consists of several server computers and more than 2000 PCs, which are connected by 1 Gbps network. On this hardware, physician order entry systems, document creating systems, a reservation system, PACS, various types of departmental systems, an accounting system, a physical distribution system, etc. are running. DACS is one of these applications. A hospital information system in a large hospital usually consists of many systems produced by different vendors. A hospital information system can be operated as EMR without DACS by showing clinical information by using web system. However, in order to integrate various types of systems that generate clinical documents, DACS is desirable. Furthermore, to secure medical record readability over an extended period of time, we had found our DACS method to be most practical.

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Experience Implementing a Point-of-Care Electronic Medical Record System for Primary Care in Malawi

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Abstract

Due to the fact that health care professionals in Malawi are often overstretched, the use and quality of health data can be compromised. The Malawi Health Management Information System (HMIS) has streamlined data collection and reporting and increased the use of data to improve care. Obstacles remain, including incomplete reporting and low staff morale. With the Baobab Health Trust and the Malawi Ministry of Health, Partners In Health piloted an innovative point-of-care data system for primary care that functions alongside OpenMRS, an open source medical record platform. The system has given access to a patient-level primary care dataset in real time. Initial results highlight some of the benefits of a point-of-care system such as improved data quality, emphasize the importance of sharing data with clinical practitioners, and shed light on how this approach could strengthen HMIS.

Keywords:

Point-of-care systems, Primary health care, Malawi

Introduction

Background

The convergence of falling information technology costs, improved computer literacy and greater availability of open source software platforms has increased access to electronic medical record systems in resource-poor settings. Early successes in some locations include timely delivery of lab results, tracking of drug supplies [1] and easier aggregate reporting [2]. The potential to improve patient care through better compliance with standardized guidelines, clinical decision support and other measures is promising. While such initiatives are in early stages with less documented successes, a preliminary evaluation of the Malawi Ministry of Health's (MOH) use of an electronic data system for antiretroviral therapy suggests the results are positive [3].

Malawi has poor health and economic indicators relative to other countries in Southern Africa and the world in general. In 2005, 41.7% of a population of 12,884,000 lived below the poverty line. The life expectancy at birth was 41 for both males and females, compared with averages of 47 and 49, respectively, in nearby countries [4].

Human resources in Malawi's health sector are scarce. A 1998 estimate indicated that 36.3% of physician posts and 18.4% of nurse and/or midwife posts were vacant [5]. As of 2002 the coverage rate of physicians and nurses per 1,000 patients was 0.022 and 0.589, respectively, compared with averages of 0.217 and 1.172 in other nearby countries [4]. Staffing shortages have resulted in increased reliance on health professionals with only two or three years of training [6], and task-shifting of some activities, such as data capturing, to staff with little or no formal training [7].

In 1999, the health information system in Malawi was restructured into a new Health Management Information System (HMIS), with the goal of overcoming the lack of reliable data and inadequate use of data in healthcare planning. A small set of indicators was chosen to minimize the burden of data collection. The system was primarily paper-based, including client health booklets, facility-based registers, data aggregation and monitoring workbooks and annual planning and review tools [2]. District-level HMIS Coordinators entered data into an electronic system which was then aggregated at a central level. As of 2002, facility-level information was available on a monthly basis for the first time. Obstacles remain in spite of the successes, including [2]:

- inadequate reporting from some facilities,
- staffing shortages for qualified personnel,
- data aggregation by clerks with little formal training [7],
- low motivation of HMIS personnel,
- insufficient data use at the local level, and
- low data use where quality is perceived to be poor [7].

Partners In Health (PIH) began a partnership with the Malawi MOH in early 2007 in rural Neno District. Building on its experience in Rwanda, Lesotho and elsewhere, PIH implemented OpenMRS, an open source electronic medical record system designed to support the delivery of healthcare in developing countries [8], by collecting HIV and TB data. PIH

saw potential in the Baobab ART system (BART), a point-of-care electronic data system developed by the Baobab Health Trust [9], but this system was not fully compatible with OpenMRS. Primary care data collection was not a part of PIH's initial electronic medical record system, so data from HMIS had to be relied upon.

Goal

To address some of the shortcomings of the HMIS dataset and improve access to data at the point of care, PIH sought to work with the Baobab Health Trust to develop a point-of-care data collection system for primary care. It would be based on the Baobab ART system (BART) and be fully compatible with OpenMRS. It should improve the quality of patient-clinician interactions and increase the use of the data for planning purposes in Neno District. It was also hoped that collecting this dataset at the point of care could demonstrate the feasibility of the approach in addressing some of the challenges affecting HMIS. Finally, the integration could pave the way for a full integration of BART with OpenMRS, bringing the benefits of the OpenMRS community [10] to existing Baobab implementations.

Challenges

Internet access is very important to the development and piloting of a new electronic medical record system, but connectivity from local Internet Service Providers (ISPs) was not available in Neno District. Finding an alternative source for Internet connectivity was key to PIH's operations as a whole and the development of its electronic medical record systems in particular.

Power supply in Malawi is unreliable. While most of the health facilities in Neno District are connected to the grid, power outages ranging from a few hours to an entire working day are common. Utility line power surges are a problem, as are lightning strikes. A point-of-care electronic data system must work when the power is off for long periods of time and must be resistant to power surges and lightning strikes.

To keep costs low and reduce downtime, equipment for the point-of-care system would need to be low cost, easy to use, and reliable. It should fit smoothly within the existing workflows of the hospital. Given the power issues mentioned above, the equipment should have low power consumption. A reliable supply chain for IT hardware and consumables, such as printer labels, must also be established.

Integrating BART and OpenMRS also required a technical solution. The OpenMRS application is programmed in Java and runs on the Apache Tomcat web server with a MySQL database [8]. PIH started its implementation in Malawi at version 1.3 of OpenMRS, and has since migrated to version 1.4.4. BART is programmed in Ruby on Rails and uses version 1.0.18 of the OpenMRS data model, making it incompatible with the OpenMRS implementation used by PIH. Due to the different programming languages of the applications, integration was not trivial.

Inconsistent spellings of names and addresses are common in the HMIS dataset. To avoid unnecessary patient duplication, the system needed an easy way to find a patient record, and an ability to compare slightly different spellings of a name. Data validation would be crucial to avoid common entry errors.

With high patient loads and overstretched staff, the system would need to be as easy-to-use as possible. Given that most staff at the hospital were not familiar with computers, it would need to be intuitive in order to require a minimal amount of training. Time-saving measures would have to be adapted wherever possible, and the new processes would need to be easily integrated into existing workflows. To encourage adoption and consistent use of the system, it would need to be immediately useful to clinicians while also providing a perceived benefit to the local MOH management team.

Materials and Methods

Hardware and power

PIH purchased a VSAT Internet connection for its program activities in Neno District Hospital but could not install connections at other sites due to the high cost. The Internet network was extended around the hospital with low-cost wireless technology, but the rugged topography of Neno District prevented point-to-point connections between the hospital and any of the other health centers in the district. Faced with these connectivity limitations, PIH decided to pilot the point-of-care system exclusively at Neno District Hospital.

PIH benefited from advances in the implementation of BART in addressing power problems. Four 12-volt deep cycle batteries in series provided backup power. A 48V, 10 Amp charger was protected from voltage spikes by a surge arrestor. The system was connected to the main building ground to prevent surges and lightning strikes from damaging the equipment. A Low Voltage Disconnect (LVD) device was installed after the batteries and the load to prevent them from being drained too low, preserving their lifespan. As a sum of its parts, the system functioned like a large online uninterruptible power supply. The computer and network hardware chosen were generally low-power DC equipment to enhance the battery life.

Table 1 - Summary of power supply equipment

Item	Number	Unit	Total
13A Surge Arrestor	1	$70	$70
10A 48VDC Charger	1	$133	$133
102 Ah 12V Battery	4	$200	$800
48V LVD	1	$160	$160
Total			**$1,163**

PIH also utilized the experience of Baobab in the selection of hardware. The data collection devices were low-power (13 Watts) thin client touchscreen computers modified by Baobab receiving Power Over Ethernet (POE) from a special network switch wired to the batteries. The thin-client approach precluded potential problems of computer viruses. A label printer was used to print a unique patient identifier as a barcode and summaries of encounters for the patient passports. A barcode scanner was used to quickly find patient records. The printer was powered directly off of the batteries, and used rolls of

labels and thermal transfer ink ribbon. The application and OpenMRS were installed on a single low-powered server (30W idle, 60W peak load).

Table 2 - Summary of point-of-care equipment

Item	Number	Unit	Total
Baobab touchscreen	5	$400	$2,000
Barcode scanner	5	$60	$300
Thermal label printer	5	$410	$2,050
Custom POE power supply for printer	5	$100	$500
24 port POE switch	1	$375	$375
Linux server	1	$1,670	$1,670
Ethernet cabling	1	$200	$200
Total			**$7,095**

Table 3 - Summary of consumables purchased in first year

Item	Number	Unit	Total
Box of 12 label rolls	3	$310	$930
Box of 12 ink rolls	3	$60	$180
Total			**$1,110**

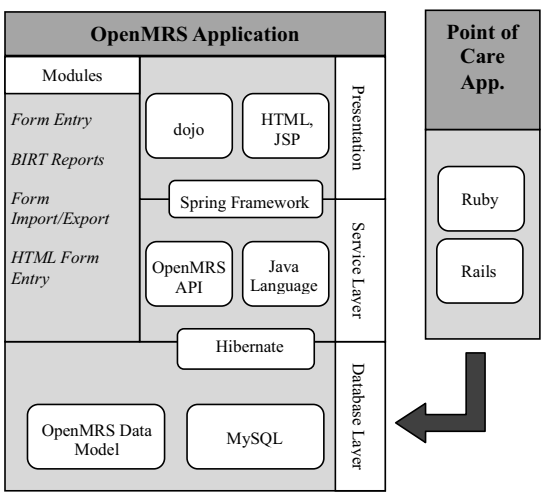

Figure 1 - Linking the OpenMRS web application with the new point-of-care system

Software

Options considered for integrating the Baobab technology with OpenMRS included working together at the database layer, using a java ruby bridge to allow the Baobab application to write to the OpenMRS Application Programming Interface (API) [8], or rewriting the entire application in Java. In the end the database layer was chosen for its simplicity and potential for adoption by Baobab at other sites (see Figure 1).

Patients sometimes need to be looked up by name if the passport is not available or the barcode is unreadable. To avoid patient duplication due to inconsistent spelling, a soundex algorithm was developed that matched similar sounding letters (eg, r's versus l's and c's versus k's), counted double letters as a single letter, and ignored vowels. Unlike classical soundex algorithms, the first letter was also accounted for, allowing names such as 'Kathleen' and 'Catherine' to be compared:

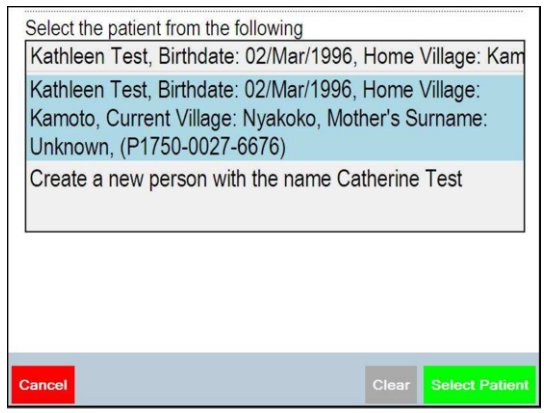

Figure 2 - Example results from soundex algorithm

The new system maintained conventions of the BART user interface designed to make it easy to use, displaying one question per screen and using large buttons to facilitate data entry.

Figure 3 - Example user interface

Data validation was also used where possible to prevent data entry errors (eg, unrealistic patient weights).

The data collected by the point-of-care system included basic demographics, height, weight, diagnoses and treatment prescribed, and was consistent with the data collected by HMIS. However, HMIS collects diagnosis data on a set of only 63 indicators and some broad definitions (eg, 'All other non-communicable diseases') are not conducive to a patient-level dataset. The new system allows clinicians to select from a list of more than 530 diagnoses allowing for explicit answers be-

fitting a patient-level dataset. In the future, these diagnoses will need to be mapped to the HMIS indicators and to an established coding system such as SNOMED.

Various time-saving measures were put in place. The system shows a list of common treatments for a particular diagnosis in order of frequency (see Figure 4). An encounter label can be printed, summarizing information entered electronically to avoid writing it out by hand. A patient summary screen displays recent information about the patient for easy reference. Reports were programmed using the Eclipse Business Intelligence Reporting Tool (BIRT) for the OpenMRS BIRT rendering module. These included a weekly summary of clinical activity and a summary for a single diagnosis including most common village (an epidemiological value), and most common treatment combinations (to address prescribing habits). These reports were delivered each Monday during the morning report at Neno District Hospital.

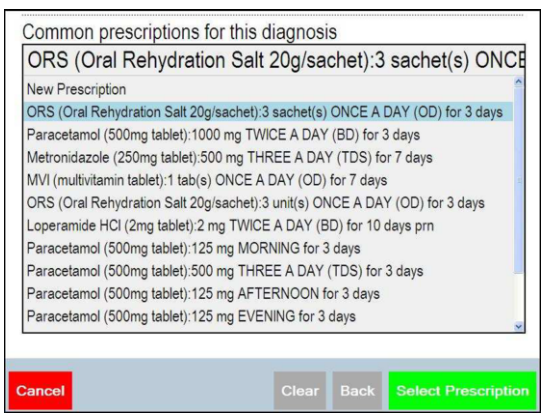

Figure 4 - Common prescriptions for gastroenteritis

The implementation of the point-of-care primary care system was done in a phased approach, allowing key elements of the process to be fine tuned (see Figure 5). Starting with patient registration in June 2008 allowed many of the hardware and networking issues to be worked out without impacting the clinical workflow and registered many patients before new data collection was added. Diagnosis was captured by clerks in September 2008 and by clinicians in January 2009. Capturing of treatment was added in May 2009 once the "suggested prescription" feature had been implemented. Weight and height were added in July 2009.

<table>
<tr><th>Month</th><th>Reg.</th><th>Wt/HT</th><th>Diagnosis</th><th>Treatment</th></tr>
<tr><td>May 2008</td><td>Not done</td><td rowspan="3">Clerk(p)</td><td>Clerk(p)</td><td rowspan="2">Clerk(e)</td></tr>
<tr><td>Jun 2008</td><td rowspan="4">Clerk(e)</td><td rowspan="2">Clerk(e)</td></tr>
<tr><td>Sep 2008</td><td rowspan="3">Phys(e)</td></tr>
<tr><td>Jan 2009</td><td rowspan="2">Clerk(e)</td></tr>
<tr><td>May 2009</td><td></td></tr>
<tr><td>Jul 2009</td><td>Clerk(e)</td><td></td></tr>
</table>

Figure 5 – Phased implementation of paper (p) and electronic (e) data capturing at Neno District Hospital

Results

Implementing a point-of-care data collection system at Neno District Hospital has given PIH and its MOH colleagues access to a rich set of data. Nationally-unique patient identifiers, (more than 1,000,000 of which have been issued at Baobab sites), have been assigned to patients at Neno District Hospital, and demographic information has been collected.

Table 4 - Summary of cumulative patient registrations at Neno District Hospital as of September 30th, 2009

Gender	Under 15	Over 15	Total
Male	5,171	5,942	11,113
Female	6,065	8,734	14,789
Total	11,236	14,676	25,912

The real time dataset is easier to make use of than the HMIS dataset. By integrating data entry into the point-of-care, data accuracy should increase due to reduced transcription. The collection of diagnoses and treatment information by clinicians also obviates the need to have staff with limited training and limited supervision enter the data.

Table 5 - Five most common diagnoses, January through September 2009

Diagnosis	Number	%
Upper respiratory tract infection	7,773	26
Malaria	7,608	25
Musculoskeletal pain	4,482	15
Dyspepsia	674	2
Gastroenteritis	658	2
Remaining diagnoses	9,057	30
Total	30,252	100

Producing a list of common treatments for a diagnosis helps save the clinicians' time and provides suggestions for reference in unfamiliar cases.

Table 6 - Top five most common treatment combinations, Upper Respiratory Tract Infection, September 2009

Treatment	Number	%
Paracetamol 1000mg TDS	98	18
Ibuprofen 400mg TDS	76	14
Chlorphenamine 4mg OD + Ibuprofen 400mg TDS	63	11
Paracetamol 1000mg TDS + Cotrimoxazole 2 tabs BD	37	7
Chlorphenmine 4mg BD + Ibuprofen 400mg TDS	28	5
Other treatment combinations	252	45
Total	554	100

The patient-level dataset is linked with electronic HIV and TB data, unlike the HMIS data. Retrospective data entry of patient-level data from HMIS registers is generally not practical due to difficulties in comprehending the handwritten text.

The power backup system continues to function during extended power outages. The first set of batteries installed lost their charge capacity in November 2008, but a Low Voltage Disconnect has prevented this problem from occurring again. The touchscreens occasionally have calibration issues, causing unresponsiveness. PIH does not have the capacity to correct this problem so the units have to be sent to Baobab to be fixed. A more reliable off-the-shelf solution with an extended warranty will be desirable.

Discussion

The biggest challenge to the new system has been its adoption by MOH clinical staff. Initially, minor technical problems might cause a clinician to stop using the system. Likewise, they were unlikely to use it if their patient loads were too high, and unplanned staff shortages are common. A series of focus group meetings helped to identify common problems and increased user confidence in the system. Equally important, the weekly reports have become popular with the local MOH management team. Their enthusiasm has trickled down to the clinicians using the system and has increased its use over time, as a comparison of patient registrations and diagnoses shows:

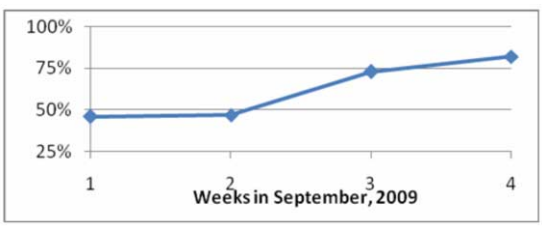

Figure 6 - Percent of patients registered electronically at Neno District Hospital with a diagnosis recorded

Not all of the patients who are seen at the registration desk visit an outpatient clinician, so the figures from the final two weeks of September in Figure 6 represent a high proportion of the patients who actually saw a clinician.

Conclusion

Malawi's Health Management Information System (HMIS) has provided decision makers at the district and central level with monthly access to facility-level data. Persistent problems such as a lack of qualified staff, low morale among data collectors and poor training and supervision among those responsible for aggregating the data have adversely affected data quality. Together with the Baobab Health Trust and the Malawi Ministry of Health (MOH), Partners In Health (PIH) has piloted an innovative electronic system for collecting primary care data at the point-of-care. Since clinicians creating the data are actively involved in capturing it, common data entry mistakes are reduced. The amount of time required to use the system has been minimized by integrating it into the general workflow of the clinic. Summary reports in OpenMRS have increased the overall use of the data and have had a positive effect on the use of the system as a whole. Political will on the part of MOH management will be essential if the system is to continue being adopted successfully. This early success highlights the potential for such an approach to address problems in the HMIS dataset and the general collection and use of medical data in resource-poor settings.

Acknowledgements

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Touchscreen Task Efficiency and Learnability in an Electronic Medical Record at the Point-of-Care

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Abstract

The objective of this study was to determine the relative efficiency of novices compared to a prediction of skilled use when performing tasks using the touchscreen interface of an EMR developed in Malawi. We observed novice users performing touchscreen tasks and recorded timestamp data from their performances. Using a predictive human performance modeling tool, the authors predicted the skilled task performance time for each task. Efficiency and rates of error were evaluated with respect to user interface design. Nineteen participants performed 31 EMR tasks seven times for a total of 4,123 observed performances. We analyzed twelve representative tasks leaving 1,596 performances featuring six user interface designs. Mean novice performance time was significantly slower than mean predicted skilled performance time ($p < 0.001$). However, novices performed faster than the predicted skilled level in 208 (13%) of successful task performances. These findings suggest the user interface design supports a primary design goal of the EMR – to allow novice users to perform tasks efficiently and effectively.

Keywords:

Electronic medical records, Developing countries, Human computer interaction, Usability, Predictive human performance modeling

Introduction

Electronic Medical Records (EMRs) provide important benefits to healthcare delivery such as improving the quality of patient care, decreasing medical errors, and reducing costs [1-3]. In developing countries and low-resource settings we believe the potential of EMRs to improve patient care is magnified, given the utility of existing paper medical record systems. However, a combination of technical and socioeconomic challenges impedes the successful adoption of EMRs in these settings. The healthcare environment is characterized by a lack of a reliable infrastructure, large-scale health crises such as HIV/AIDS, and a health worker shortage [4]. An EMR implemented in this context must support the tasks of clinicians with no prior computing experience who endure poor working conditions and a high patient-to-clinician ratio. High rates of staff turnover further complicate the successful implementation of EMRs by increasing the number of new clinicians who need to learn to use a system efficiently and effectively.

Learnability and efficiency are two aspects of system usability that are critical factors for successful implementation of health information technology in developing countries. Learnability refers to the effectiveness with which a new user can perform tasks. Efficiency is the time required for a user to perform a task, given a design. Our long-term goal is to develop an EMR user interface that is both learnable and efficient for novices and experienced users alike in a developing country. The objective of this study was to evaluate the efficiency and learnability of an EMR designed to manage HIV/AIDS patient records in Malawi. In particular we wanted to measure the efficiency of the EMR for new users in comparison with the efficiency level that experienced users should be able to attain given a particular user interface design. As a first step towards evaluating the design, we used health sciences students at the University of Pittsburgh to represent novice EMR users with the intent to refine our evaluation with novice users in Malawi.

Baobab Anti-Retroviral Therapy (BART) EMR in Malawi

Malawi, like many countries in sub-Saharan Africa, is experiencing a devastating HIV/AIDS epidemic that has infected close to 1 million people, or about 8% of the population. Baobab Health Trust, a Malawian non-governmental organization, has partnered with Malawi's Ministry of Health to implement an EMR in six HIV/AIDS clinics to improve the delivery of care and support monitoring and evaluation of Anti-Retroviral Therapy (ART). Clinics using the Baobab ART (BART) EMR were providing free ART to 23,667 patients as of December, 2009. A core feature of the BART EMR is a Touchscreen Clinical Workstation (TCW) deployed at the point-of-care (Figure 1). The TCW is a low-cost information appliance that captures data during patient visits. TCWs support clinical decision-making by guiding health workers through patient en-

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counters consistent with national treatment protocols for ART [5, 6].

Baobab Health Trust has innovated hardware and software solutions to introduce point-of-care computing in low-resource settings. These innovations include alternative power approaches, adaptation of hardware to increase system reliability in environments with high humidity or dust, and large-button touchscreen user interfaces. The TCW user interfaces are wizard-like, presenting the user with a single question per screen (Figure 2). The constraints of the task and the setting – that is, a multistep, ordered process often completed by individuals lacking domain knowledge – lends itself to a wizard-like user interface design. The choice of a wizard-like design for the touchscreen interface does not, however, guarantee efficiency.

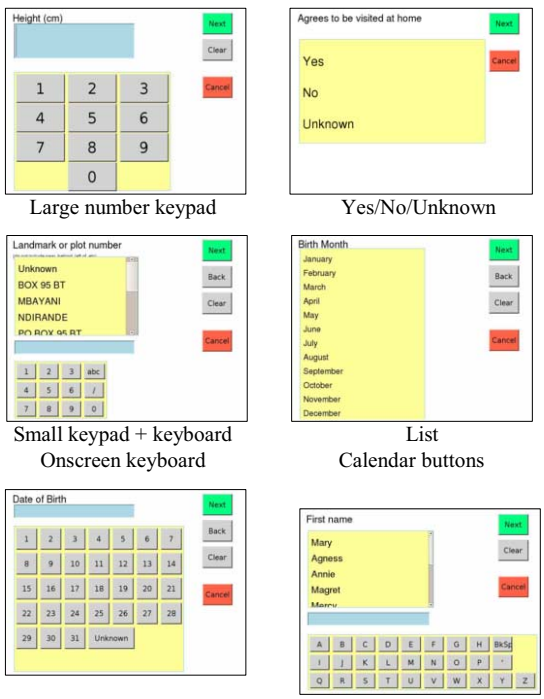

Figure 2- Six touchscreen user interface designs for collection of data at the point-of-care

HCI4D

Human Computer Interaction for Development (HCI4D) has emerged over the past decade within the field of HCI as a specialization that seeks to translate the tools and methods of HCI in developed regions for use in low-resource settings. Practitioners of HCI4D believe that the challenges and methods of HCI in developed regions will resemble the methods required in low-resource settings. A fundamental HCI principle known as "the user is not like me", which refers to the inherent differences in perspective between system developers and users, would appear to support that belief. However, the community has only recently begun to establish shared knowledge about the differences between users in low resource settings and users in the developed world [7].

Figure 1- A health worker in Malawi uses a touchscreen workstation at the point-of-care

Predictive Human Performance Modeling

Since the early 1980s, HCI researchers have addressed the problem of how to predict the efficiency with which a skilled user will be able to complete a task using a specified interface design. An HCI technique called the Keystroke Level Model (KLM) has been refined and tested to become a reliable and validated tool for predictive human performance modeling. KLM is capable of predicting the mean time for task completion by a skilled user, using a given system design, with an approximate 20% margin of error [8].

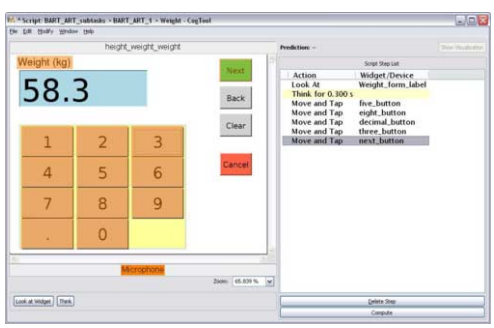

Figure 3 - CogTool interface for task demonstration using a BART user interface screenshot

CogTool is a free software application that automates the process of creating a predictive model using KLM and allows a user to rapidly create predictive models based on the user input mode, such as mouse and keyboard, voice, or touchscreen [9]. To predict a task performance time the user first draws overlays on a screenshot or mock-up of the task interface to indicate the location, size, and other properties of the widgets that must be manipulated to successfully complete a task. After preparing overlays, the user demonstrates the optimal sequence of steps required to perform a task (Figure 3).

Upon the completion of the task demonstration, CogTool generates a KLM prediction that yields a time estimate in milliseconds. The resulting estimate is the predicted total time required for a skilled user to perform a given task.

Methods

To measure relative efficiency of use, we first selected commonly performed touchscreen tasks from the EMR for evaluation. We observed novice users performing the touchscreen tasks and recorded timestamp data from their performances. Using CogTool, we predicted the skilled task performance time for each task.

Novice Human Performance Measurement

Participants

Participants were required to be adult, novice touchscreen EMR users, without prior experience using a touchscreen interface for an EMR. No prior medical training or familiarity with computers was required for the participants to be eligible for the study. Participants were health sciences students recruited at the University of Pittsburgh using posted flyers and were offered a gift card worth $25 for their participation.

Task

We selected 31 EMR tasks that are commonly performed by nurses and patient registration clerks in an ART clinic. The selected tasks did not require prior knowledge of HIV/AIDS disease management. The tasks belonged to the following clinical work processes: patient registration, patient medical history, and patient vitals collection. Patient registration tasks required patient information such as name, address, and contact details. Questions about medical history required information about the patient's prior ART treatment. Patient vitals measurement questions collected the patient's height and current weight.

User Session

We designed a five-minute training period to simulate the training provided to users of the EMR in Malawi. The session included demonstration of a representative task and a description of the core functionality of the system. Additionally we introduced concepts in the EMR that are unique to patient care in Malawi. For example we explained the concept of “ancestral traditional authority”, referring to the tribal home area of the patient, which would be unfamiliar to most participants. Once the training session was completed we gave participants an opportunity to ask any questions about the system. Following a time for questions we instructed participants to attempt to solve any subsequent problems they encountered on their own, instead of asking for help.

We prepared a series of seven mock patient encounters with an actor playing the role of a patient responding to questions from the user. The actor was prepared to play the role of all seven different patients during the user session.

Before the patient encounter began, participants practiced one representative task in the form of logging into the system with a username and password. For each patient encounter, participants performed all 31 selected tasks once. Most tasks required system users to directly ask the patient for information before entering the data into the system using the touchscreen computer. During the task performances we recorded written observations about problems that users encountered and unanticipated user behaviors.

We designed the session to last up to a maximum of one hour or seven patient encounters. Following the session, participants answered a one-page questionnaire about their computing experience and their subjective satisfaction level when using the EMR.

Event Logging

While participants used the system, the EMR software logged their activities by recording timestamp, contextual and value data entered for each user interface event. Examples of user interface events include button presses, page load time, and list item selections. For each event, the application recorded the current time, user ID, task name, and interface widget name.

Predictive Human Performance Modeling

To measure skilled efficiency of the EMR, we used CogTool to predict estimated performance times for skilled use of the 31 tasks. CogTool allowed us to rapidly build a predictive model of skilled human performance for each task.

The task models included not only the EMR user interface events, but also the time required for the user to see the question displayed by the EMR, ask the patient for information, hear the patient's response, and manipulate the interface to successfully complete the task based on the patient's answer. After we created the model for each task using CogTool, the software generated an estimated time prediction in milliseconds for each task.

Efficiency and Errors

We recorded novice performance errors to be able to analyze rates of errors in novice task performance with respect to efficiency and interface type, and to determine where novices succeeded or failed to complete tasks. Performance errors refer to any user interface event performed by the participant that was not modeled as part of the optimal sequence to successfully complete a task. For example, if a participant made a typographical error, then used the backspace button to correct the mistake, this was considered a performance error in a successfully completed task. Successful completion of a task is defined as having entered the correct value specified in the mock-patient data set for each patient encounter.

Results

The purpose of this study was to determine how efficiently novices perform touchscreen EMR tasks relative to a prediction of skilled use. To accomplish our goals, we compared

Table 1- Novice errors for six interface types

Interface type	Performed Tasks	Tasks with corrected errors		Successful tasks		Failed tasks		Tasks with missing data	
List	266	8	(3%)	250	(94%)	0	(0%)	16	(6%)
Calendar buttons	266	16	(6%)	264	(99%)	1	(0%)	1	(0%)
Yes/No/Unknown	399	13	(3%)	390	(98%)	2	(1%)	7	(2%)
Large number keypad	266	15	(6%)	259	(97%)	3	(1%)	4	(2%)
Onscreen keyboard	266	47	(19%)	252	(95%)	14	(5%)	0	(0%)
Small keypad + keyboard	133	78	(70%)	111	(83%)	22	(17%)	0	(0%)
Total:	1,596	177	(11%)	1,526	(96%)	42	(3%)	28	(2%)

novice performance times to the predicted times for skilled task performance. Additionally we analyzed the novices' rates of error and efficiency with respect to the user interface design.

We conducted a preliminary analysis of twelve out of the 31 total tasks. The user interfaces for the twelve selected tasks feature six designs (Figure 2) that are representative of the interface designs for all 31 tasks. The resulting data set contains 1,596 observed task performances (Table 1).

We created preliminary CogTool models for the use of a touchscreen EMR based on observed data collected in a pilot study.[10]

Using the results of the pilot study, we calibrated the CogTool model to improve prediction accuracy for skilled task performance. We used CogTool to predict a skilled performance time in milliseconds for each of the twelve tasks.

Participants

Nineteen health sciences students from the University of Pittsburgh responded to posted flyers and participated in the study as novices. All participants performed the 31 tasks seven times for a total of 4,123 observed task performances. All of the participants performed the seven patient encounters in less than one hour.

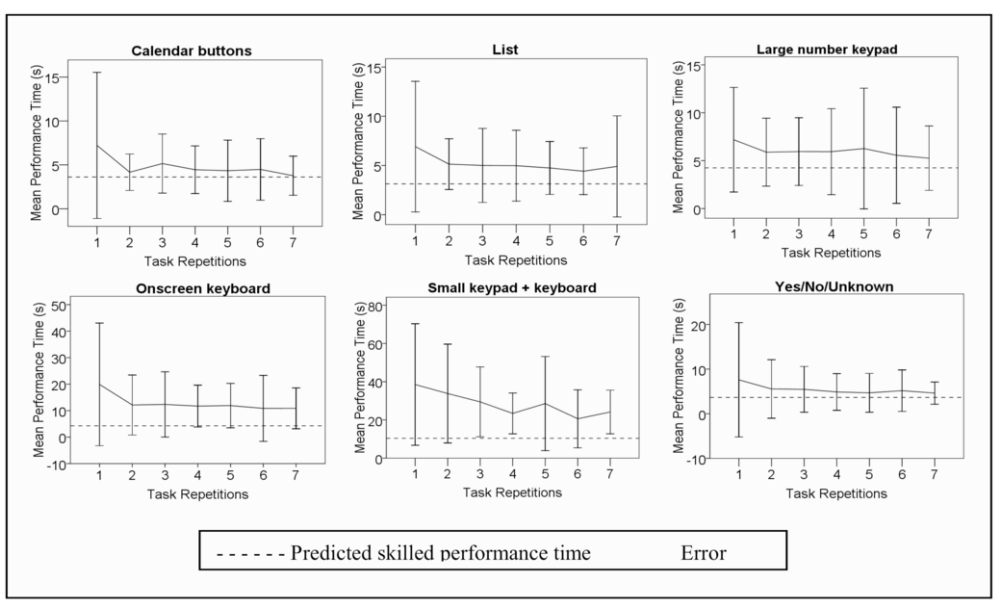

Figure 4-Mean novice task performance time by user interface design

Efficiency and Learnability

Figure 4 displays the mean novice task performance time and the predicted skilled performance time for the six interface designs. Mean novice performance for all tasks was significantly slower than the predictions of skilled use (Wilcoxon $Z = -18.58$, $p < 0.001$). Although mean novice performance times were slower, novices performed tasks faster than the predicted skilled level in 208 (13%) of the observed task performances. Novices performed within 20% of the predicted skilled level (the accepted standard margin of error for KLM predictions) in 444 (28%) of all observed task performances. Performance times for interfaces that did not require onscreen typing (Calendar buttons, List, Large number keypad, Yes/No/Unknown) were faster than performance times for interfaces that required onscreen typing (Onscreen keyboard, Small keypad + keyboard).

Errors

Table 1 displays the number of novice task performances containing one or more corrected errors and tasks successfully completed for the six interface types. Novice users completed 96% of task performances successfully. Tasks requiring the use of the onscreen typing contained the highest rate of tasks with performance errors (70%) and lowest rate of successful task completion (83%).

Conclusion

Our findings suggest that, while novice EMR users perform touchscreen tasks more slowly than predictions of skilled use, they are able to perform at a skilled level some of the time within the first hour of system use. Novices were able to perform tasks within the margin of error for the predicted skilled performance times in 28% of the task performances. This is important because a primary design goal of the EMR is to allow novice users to perform tasks efficiently and effectively.

Performance times were highly variable between novice participants for all tasks, but it is common for task performance times in user studies to vary by as much as an order of magnitude.[11] However, not all interfaces demonstrated equivalent variability in task performance. In particular the variability in performance times for interfaces containing an onscreen keyboard was noticeably higher than for other interface types. Similarly, the onscreen keyboard interfaces had the lowest rates of successful task completion and the highest rates of performance errors compared to other interface types. A possible explanation for the poorer performances with onscreen typing tasks is firstly that the keyboard used an alphabetical layout while most participants were accustomed to a qwerty keyboard layout, and secondly that onscreen typing tasks required two to seven times more touches than other tasks – increasing the overall complexity for onscreen typing tasks.

A primary limitation of this study is the differences between users recruited in Pittsburgh and the typical users of the system in Malawi. Future work will measure novice performance for users with the cultural, educational and socioeconomic background that is representative of EMR users in Malawi.

Acknowledgments

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Process-Aware EHR BPM Systems: Two Prototypes and a Conceptual Framework

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Abstract

Systematic methods to improve the effectiveness and efficiency of electronic health record-mediated processes will be key to EHRs playing an important role in the positive transformation of healthcare. Business process management (BPM) systematically optimizes process effectiveness, efficiency, and flexibility. Therefore BPM offers relevant ideas and technologies. We provide a conceptual model based on EHR productivity and negative feedback control that links EHR and BPM domains, describe two EHR BPM prototype modules, and close with the argument that typical EHRs must become more process-aware if they are to take full advantage of BPM ideas and technology. A prediction: Future extensible clinical groupware will coordinate delivery of EHR functionality to teams of users by combining modular components with executable process models whose usability (effectiveness, efficiency, and user satisfaction) will be systematically improved using business process management techniques.

Keywords:

Electronic health records, Workflow management systems, Business process management, Clinical groupware, Modular architecture

Introduction

Productivity is the ratio of an output to the input required to generate it. EHR productivity is EHR output—value of accumulated digitized patient data—divided by EHR input, or cost to obtain this data. The relationship between EHR effectiveness and efficiency is mediated by EHR processes, and EHR productivity cannot be improved without flexible EHR processes. The maximum EHR productivity that can be achieved within an interval of time is a function of all three of initial EHR effectiveness, efficiency, and flexibility. The concept of EHR productivity is relevant to both meaningful use of EHRs and EHR business process management.

A concise and common sense description for meaningful use of an EHR is "Processes and workflow that facilitate improved quality and increased efficiency" [1]. This resembles BPM's systematic optimization of process *effectiveness*, *efficiency*, and *flexibility*. At this point it is worthwhile to define some terms:

- Systematically optimize: improve in a consistently organized manner
- Objectives to be optimized
  - Effectiveness: ability to achieve output goals
  - Efficiency: ratio of output goals to required input resources
  - Flexibility: adaptability to changing goals and environmental conditions
- Environmental conditions
  - Dynamic: changes over time
  - Uncertain: difficult to predict
  - Risky: rewards and penalties apply

A closed-loop control system uses the difference between observed and desired output to automatically generate system inputs that will reduce the observed difference (Figure 1). For example, a thermostat compares observed temperature to desired temperature to decide whether to turn a heater on or off. Feedback control theory [2, 3] includes models and techniques to automatically optimize system behavior in response to changing environmental conditions. A negative feedback control system formulation of BPM, applied to systematic optimization of EHR performance, serves a useful purpose. It places EHR BPM into broader historical context that leads back to cybernetics and control theory [2].

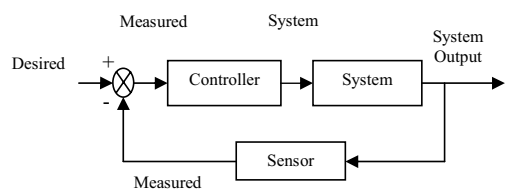

Figure 1 – Negative Feedback Control

Process-aware [4] EHR business process management systems are ideal vehicles for implementing closed-loop patient care systems [3] because there is a means—workflow engines executing process definitions—to directly influence EHR behavior and state. For example, minimizing the difference between observed and desired measures of health population status, or between observed and desired levels of medical practice efficiency, are forms of closed-loop optimization.

Future evolution of EHR technology will create greater effectiveness, efficiency, and flexibility in the face of dynamic, uncertain, and risky environments. The only practical means by which this will be achieved will be if EHRs include within their very technological nature the ability to systematically change internal processes and workflows to better meet set objectives while operating in typical environments. For these reasons the next generation of EHR systems will be process-aware EHR business process management systems.

Materials and Methods

Two EHR BPM Prototypes

We developed EHR BPM prototype modules to systematically optimize EHR effectiveness and efficiency. These prototype modules were built on a free and open-source EHR workflow management system (WfMS) with a modular component-based architecture. (Specialty-specific user interface and non-user interface components are combined into specialty-specific modules controlled by a workflow engine executing specialty-specific process definitions to generate workflow-based clinical groupware used by 4000 users at 300 sites in fourteen specialties [5, 6]).

Systematic Optimization of EHR Efficacy

For our measure of EHR effectiveness we chose a combination of compliance with medical protocols and control of key clinical values that affect patient health. PROCARE stands for PROvision-based Clinically Active Reporting Environment (Figure 2). PROCARE is a closed-loop patient care system that uses a patient class event hierarchy to trigger process definition execution by an EHR workflow management system. The patient class event system and associated process definitions improve measures of clinical performance over time.

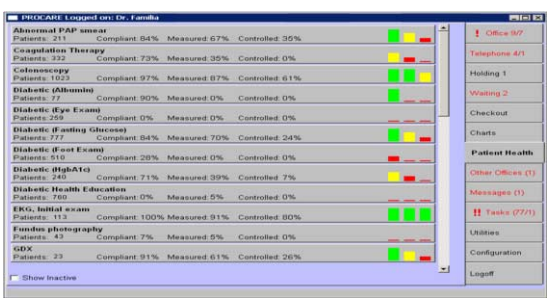

Figure 2 – PROCARE Clinical Dashboard

A provision is a forward-looking restriction or qualification in a contract or agreement. For example, a patient can be in a predefined class of patients provided they meet that class's predefined criteria (age between 0 and 18, BMI > 30, etc.). A patient class event hierarchy (Figure 3) detects at risk patients, calculates aggregate statistics that summarize clinical performance for a patient population, and automatically triggers workflows to help manage risk.

PROCARE's clinical summary dashboard (Figure 2) displays for each measure of clinical performance four numbers (corresponding to the four levels of the patient class event hierarchy): number of patients in the class for which the measure applies, percentage of patients in each class that are compliant with a predefined protocol, percentage of patients for whom appropriate and timely measurements are available, and percentage of patients for whom observed measures are controlled (within target normal limits).

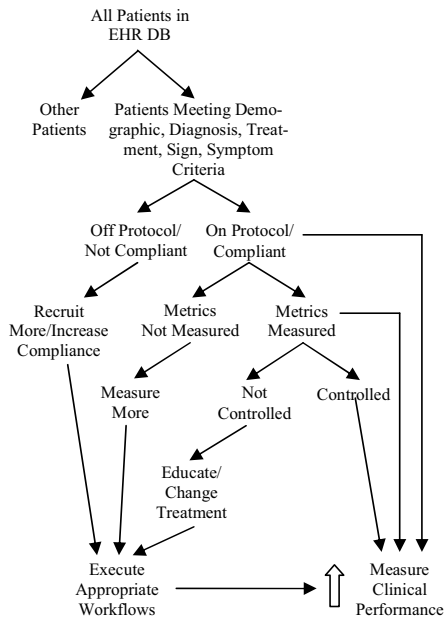

Figure 3 – Patient Class Event Hierarchy

Selecting a measure of clinical performance (such as colonoscopy in Figure 2) displays a patient list management screen (not shown) for creation or refinement of the policies that link patient class events to automated workflows. For example, process definition steps could include role or user work items, work items that appear when the patient is physically present, instructions that appear automatically whenever a patient chart is opened, or messages to external systems that trigger email or phone calls. Execution of appropriate workflow moves patients from non-compliance to compliance, unmeasured to measured, and uncontrolled to controlled categories, causing a shift from red to yellow to green graphical indicators on the summary dashboard.

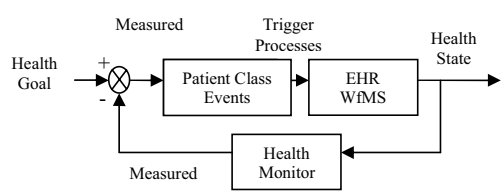

Figure 4 – PROCARE: Closed-loop Population Management

PROCARE uses a BPM approach (automated triggering of process definitions to systematically improve a measure of EHR effectiveness) to implement a closed-loop patient care system (Figure 4).

Systematic Optimization of EHR Efficiency

For our measure of EHR efficiency we chose to improve medical practice throughput and throughput time. PROCESS stands for PROcess Comparison for Efficient System Specification. PROCESS uses process mining [7] techniques to visualize, compare, and improve ambulatory EHR patient encounter task workflows. PROCESS is directing at improving processes in medical practices by:

1. Generating process models of existing practices.
2. Comparing measures of productivity (throughput and throughput time).
3. Explaining differences in productivity in terms of differences in processes.
4. Suggesting process improvements for low productivity practices.

We randomly chose nine pediatric practices relying on the same EHR workflow management system. We used process mining and visualization tools to compare throughput and throughput times across the practices for October (traditionally a busy month for pediatricians).

We looked for process activity patterns that might explain differences in global productivity measures (Figure 5). For example, practices 5 and 7 had high volumes but low throughput times, and displayed an accumulation of tasks between tasks H (Get Patient) and E (Current Meds) in Figure 6, which are both tasks for the nurse role.

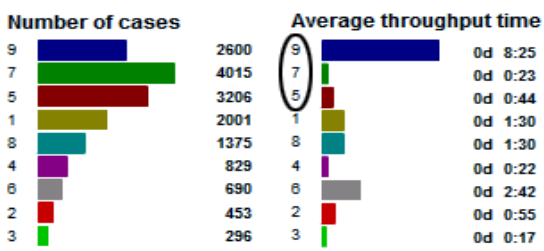

Figure 5 – Nine Medical Practices, Productivity Statistics

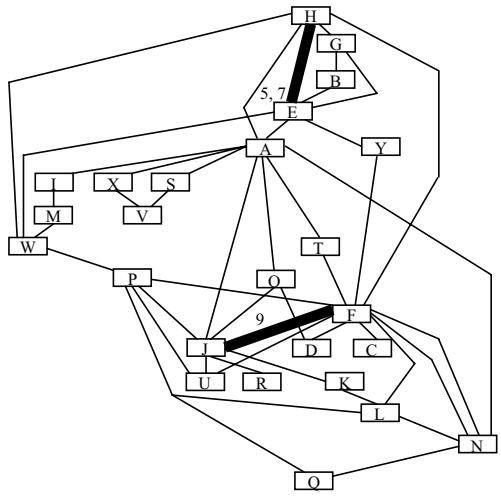

Figure 6 – Nine Medical Practices, Process Model

Table 1 – EHR Patient Encounter Tasks

A. Allergies	J. New Note	S. Sick/ Established
B. Anticipatory	K. Order Labs	T. Sick Visit, Est Patient
C. Chart Review	L. Order Tests	U. Sick Physical PPOP
D. Chart Review by	M. Order Treatment	V. SOAP Chart
E. Current Meds	N. Physical	W. View Chart
F. Examination	O. Preview Report	X. Well/Established
G. General Pediatric	P. Quick View	Y. Well Visit, Est Patient
H. Get Patient	Q. Quick View, Sick	
I. Labs	R. RTF Report	

In contrast practice 9 had lower volume but a dramatically higher average throughput time (Figure 5), and an accumulation of tasks between tasks F (Examination) and J (New Note), which rely on the physician role, a scarcer (and more costly) resource. This triggered investigation and consultations between the practice and a practice skills instructor to change and improve workflows.

In contrast to PROCARE, where our object is to systematically improve EHR WfMS effectiveness, our object with PROCESS is to systematically improve EHR WfMS efficiency, resulting in Figure 7 as a conceptual mapping back to the negative feedback control model initially presented.

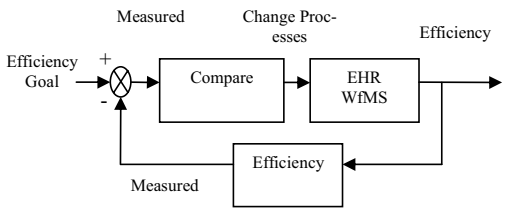

Figure 7 – PROCESS: Closed-loop Process Improvement

Practical and Conceptual Results

Our foray into EHR BPM had practical and conceptual results.

At the practical level, the PROCARE prototype played an important role in communication with regional clinical stakeholders using the same EHR WfMS. We used the prototype to explain the patient class event hierarchy and plan an enterprise-wide version of PROCARE as part of a regional health information exchange. The PROCESS prototype has been a valuable artifact to focus our internal discussion regarding developing a new service to provide to our EHR WfMS customers. Initial inspection of the resulting process models has already triggered useful practical investigations directed at improving medical practice workflows.

At a conceptual level, we became convinced that a business process management approach to systematically optimizing EHR effectiveness, efficiency, and flexibility is the most consistent, comprehensive, and useful framework within which to achieve meaningful use of EHRs at the point of care. EHR workflow engines, executing process definitions, can coordinate specialty-specific components, modules, and workflows to provide approximate specialty-specific clinical groupware solutions. These EHRs will still require BPM process optimization techniques to realize their full potential.

Combining EHR with BPM technology promises to (1) model and simulate interactions among physicians and other clinical and non-clinical staff, systems, and EHR components to create a shared mental model of how to optimize care coordination processes and results; (2) coordinate and manage handoff of patient care tasks within and across organizational boundaries; (3) provide real-time feedback to physicians and other care coordinators about care-in-progress to support in-line patient care process adjustments; and (4) monitor care coordination outcomes compared to performance targets and systematically improve care coordination process flows.

Conclusion

As summarized in Aalst and van Hee [8], the development of information systems has passed through four phases: (1) decomposition of applications, (2) movement of data into shared databases, (3) movement of user interface management out of applications, and (4) movement of process management out of applications into workflow management systems. Compared to other industries, today's EHRs, while complex and sophisticated in many ways, have not yet migrated process management into foundational workflow management systems.

Non-process aware EHRs *do not distinguish between unitary tasks at the same fine degree of granularity* as EHR WfMSs. Traditional EHRs often have high resolution screens with a multitude of simultaneous data review and entry and order entry options. Multiple user events, spanning multiple tasks, are often committed together to the underlying database, conflating together logically separate workflow steps. In contrast, an EHR WfMS typically presents just the data review and entry and order entry options on each screen that are relevant to single step in a task workflow sequence. For example, a nurse checking allergies and then current medications are two different tasks that at highly granular resolution should be distinct and acquire different time stamps.

Non-process aware EHRs *do not capture all the potential meaningful timestamps for those events that they do log*. They may log when data and orders are committed to a database but they do not typically log when tasks are first available to be accomplished, when they begin, when they complete, and other relevant timed-stamped events such as cancellation, postponement, or forwarding. Much of this missing temporal information is invaluable for understanding why bottlenecks occur, why certain tasks are subject to rework, and what slack resources are available elsewhere in the system.

Non-process aware EHRs, even if their event logs result in useful process models and actionable insights, *lack means to actively influence changes to workflow*. There are no process definitions or workflow engines to execute them; so there are no process definitions to change and thereby influence and improve effectiveness and efficiency. With respect to EHR effectiveness, a patient classification system without ability to trigger automated workflow is a passive reporting system (in which reports must be handed to staff for disposition, "Please put a note in each patient's chart so that the next time they have an appointment…"). A more active reporting system feeds directly back to a workflow management system to automatically perform useful tasks. With respect to EHR efficiency, even if a process model has an obvious flaw, there is no way to consistently and automatically deflect behavior at critical process junctures in order to improve throughput and throughput time.

In summary, compared to process-aware EHR workflow management systems, traditional EHRs (1) do not track tasks at high degree of resolution, (2) do not distinguish among a large number of useful time stamped events, and (3) have no means for process model insights to drive improvements through use of automated workflow. The next necessary step in the evolution of ambulatory EHRs is squarely at the intersection between electronic health record systems and workflow management/business process management systems. These hybrid clinical groupware systems will be more systematically optimizable than traditional EHRs with respect to clinical effectiveness, practice efficiency, and user satisfaction (that is, usability).

There are a number of research topics that we realize are relevant to EHR effectiveness and efficiency improvement mod-

ules such as herein described, including the relationship between process definitions and clinical guidelines [9, 10, 11]; ambulatory process patterns [12], mining [13], and flexibility [14]; and especially learning business process models [15]. As we continue development of EHR BPM modules, we will continue to absorb insights from these and other business process management and medical informatics research areas. In turn, we hope that our and other process-aware EHR systems can become useful sources for process data and case studies, and test beds for further research ideas and initiatives.

Acknowledgements

Many thanks to Prof. Wil van der Aalst for taking time to answer our questions about business process management research.

We also wish to acknowledge the larger academic medical informatics and business process management community. Work-a-day experience (and pressure) of maintaining and enhancing an existing EHR WfMS/clinical groupware product serving millions of patients, thousands of users, and hundreds of ambulatory medical offices does not typically afford us the opportunity to consider the larger intellectual enterprise in which we play a small part. Without the Web and the generous and open manner in which medical informatics and business process management research ideas and results are shared, we would lack access to information resources to contextualize what we have done and hope to do.

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Understanding Resistance towards Electronic Patient Health Data in South Australian Family Practice

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Abstract

This paper reports the results from a survey of 131medical practitioners in South Australian General Practice concerning adoption of a computerised system for storing and potentially amalgamating health information from several practices. Practitioners were primarily influenced by the positively perceived potential for such technology use to improve patient health and well-being outcomes and secondarily by the negatively perceived potential for unwanted change in the status, control and autonomy of their professional role. Practitioner attitude reflected how they resolved the competing influences. The data suggest that strategies for implementing such systems should address individual perceptions by increasing belief in the potential for patient improvement or by decreasing belief of the inevitability of unwanted role change.

Keywords:

Medical informatics, Family practice.

Introduction

This paper explores potential adoption of amalgamating Health Informatics (HI) technology by South Australian practitioners in general practice medicine (GPs). General Practice in South Australia mostly operates as solo practices, partnerships or incorporated bodies averaging 2.5 GPs each and, estimated to see 85 percent of healthcare consumers annually, is integral to delivering any comprehensive, coordinated and continuing healthcare strategy to the wider health system [1-3]. Within this scenario, HI is promoted by all levels of government as an emergent interdisciplinary label for the application of computers to improving the efficiency and effectiveness of healthcare management [4]. Yet implementing HI systems requires adoption of electronic patient records and potentially the need to reengineer traditional workflows and disrupt existing business and clinical processes [5].

Previous to this study, Australian Governments had targeted GPs with funding initiatives to increase the use of computers in general practice medicine [1]. Nowadays almost all practices have at least one computer, and some are seen to have designed their processes to increase the use of technologically supported systems in order to increase practice income [6]. Nonetheless a study between 2003 and 2005 reported that some Australian GPs who had access to computers and clinical software chose not to use them, and only a third kept all patient data in an electronic format [6]. Other findings indicate HI systems that are viewed as improving diagnostics, reproducing accepted models of clinical reasoning or providing immediate patient benefit have been adopted, while those aimed at improving the overall efficiency and effectiveness of healthcare appear to be have been resisted [7-9].

Understanding why people accept a particular innovation remains a challenging and complex issue, and medical practitioners have been cited as classic examples of 'professional' populations where understanding decisions of what innovations are adopted and when has been especially problematic [10, 11].

Method

The purpose of this study was to test tentative hypotheses from an earlier qualitative enquiry. Directed at a small sample of GPs to try and capture potential reasons why they tend to resist (or not) adoption and implementation of HI systems, findings suggested sources of GP resistance stemmed from deeply held GP beliefs, feelings, anxieties and values that could be challenged by such technology adoption [4]. The importance attached to forces pushing for resistance reflected GP beliefs about their professional and organisational role and the use of technology in their workflow. Findings also suggested motivation for adoption reflected GP belief in the efficacy of the technology to improve health outcomes of their patients and the wider population. The importance attached to forces pushing for adoption reflected the perceived relevance to the GPs' role of such potential for improvement. Strategies aimed at increasing such technology uptake by providing financial incentives enhanced any motivation to adopt, particularly within the practice boundary. However, perception of change needed in environmental antecedents which impacted the GP's relationship with their patient was seen as undesirably changing the GP role in the delivery of healthcare.

These data led the authors to formulate a series of hypotheses about the relationships between these forces influencing GP intention, rewritten as five main hypotheses (Table 1). Testing these hypotheses formed the basis for a questionnaire distributed to a representative sample of GPs, and the findings are

presented in this paper. Drawing from literature and based on the recurrent themes, propositions and hypotheses derived from the qualitative study, a 'concern' dictionary was developed to test the hypotheses and explore potential strategies to reduce resistance. The resultant conceptual model (Figure 1) frames the hypotheses and reflects the view that GP resistance towards new HI technology adoption is the outcome of the perceived advantages (or otherwise) of potential changes in valued antecedents associated with their role.

Table 1- Hypotheses concerning GP resistance towards new HI technology adoption

H_1: *There is a direct positive relationship between the potential for new HI technology to undesirably change their role (C1) and emergent GP resistance to adopting new HI Technology (DV)*

H2: *There is an indirect negative relationship between the potential for HI technology to improve patient outcomes (C2) and emergent GP resistance to adopting new HI Technology (DV).* ***H2a:*** *There is a direct negative relationship between GP perceptions of the potential for HI technology to improve patient health and well-being outcomes (C2) and the potential for undesirable change to the GP role (C1).*

H3: *There is an indirect positive relationship between the context in which they perform their role (C3) and emergent GP resistance towards adopting new HI Technology (DV).* ***H3a:*** *There is a direct positive relationship between GP perceptions of the context in which they perform their role (C3) and the potential for undesirable change to the GP role (C1).*

H4: *There is an indirect negative relationship between the influence of incentives on HI technology adoption decision-making (C4) and emergent GP resistance to adopting new HI Technology (DV).* ***H4a*** *There is a direct negative relationship between GP perceptions of the influence of incentives on HI technology adoption decision-making (C4) and the potential for undesirable change to the GP role (C1).*

H5: *There is an indirect positive relationship between the attributes of a GP role (C5) and emergent GP resistance to adopting new HI Technology (DV).* ***H5a:*** *There is a direct negative relationship between GP perceptions of the attributes of a GP role (C5) and the efficacy of new HI technology (C2).* ***H5b:*** *There is a direct negative relationship between GP perceptions of the attributes of a GP role (C5) and the role context (C3).* ***H5c:*** *There is a direct negative relationship between GP perceptions of the attributes of a GP role (C5) and the influence of incentives to adopt new HI technology (C4).* ***H5d:*** *There is an indirect positive relationship between GP perceptions of the attributes of a GP role (C5) and the potential for undesirable change to the GP role (C1).*

Anticipated to underpin GP resistance, measurement of change to the GP role focused on the perceived potential for change to their autonomy, control, status and relationship with their patient. Measuring context antecedents focused on collecting information on the extent to which perception of the environment (such practice characteristics as the number of practice GPs and nurses and the current use of clinical and billing software) influenced GP resistance. Anticipated as a positive force for adoption, measurement of the potential for HI technology use to underpin improved patient health and well-being outcomes focused on the relevance of improvement in different patient populations. The survey also sought to measure the influence of incentives and what modifications in existing strategies might potentially improve the penetration of HI technology use in GP practice. This included the extent to which incentives were seen to address the value of the GP role, data, participation in policy decision-making and patient attitude toward GP use of such technology. The survey also encompassed individual and role attributes that in combination potentially ameliorated or exacerbated GP perceptions of other influences (such as their self-perceived professional, technological and innovative traits). Interview content had indicated experience as a GP and hours worked per week on direct patient care were potentially influential, while literature on professionals and technology adoption studies suggested alignment with professional organisations, age and gender may be relevant to GP attitude [12, 13].

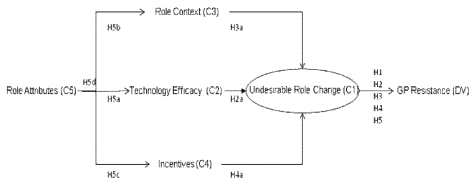

Figure 1- Theoretical Model of Forces of Influence on GP Resistance

Pre-testing the instrument resulted in rewording of ambiguous questions, alternate shading to better differentiate questions and an indication of the estimated GP time commitment being added to the survey introduction. Respondents were targeted from member practices of three South Australian Divisions of General Practice. This gave a potential sample size of 650 GPs from 210 practices. Questionnaires were distributed resulting in a return rate of 131 usable replies (20.15%). The sample demographic profile was found to roughly reflect both the South Australian and Australian GP population.

Data Analysis and Results

Data analyses were performed using the statistical computer program SPSS (version 16) for Windows. Factor Analysis was performed to reduce each construct of items to fewer factors, to make the data set more manageable and to facilitate testing a theoretical model with valid variables [14]. Principal Axis Factoring was chosen because the aim was to describe structure and using Squared Multiple Correlations provides more accurate estimates of initial communalities [15]. Only factors with eigenvalues >1 were extracted and only items correlating at >0.4 with the factor were considered. The single factors extracted were transformed into new variables.

The endogenous construct readily transformed to one factor. To avoid confusion for the sample, the item scale used reflected a high score for intention to adopt new HI technology. By reverse scoring all other items, a high score in the subsequent factor indicated an intention to *not* adopt. Examination of the case-wise diagnostic statistics identified 28 cases (21.9%) showed more intention to resist than take-up new HI technology. The constructs of influence seen to underpin GP motivation to adopt new HI technology also readily transformed to single factors. A high score in the subsequent Technology Efficacy Factor indicated a strong belief in the potential of HI technology to improve patient outcomes. A high score in the Incentives Factor indicated a strong belief in the positive influence of financial incentives on GP adoption.

Factor correlation showed all five factors to have the anticipated significant relationship with GP intention to resist. The results also suggested the relationship between role attributes with GP resistance may be fully mediated by the perceived potential for undesirable role change as hypothesised. However, the influence of GP belief in the technology efficacy and the influence of financial incentives were at best partially mediated by the perceived potential for undesirable role change, while the influence of GP's context was not mediated at all. Also, the anticipated influences of both GPs' context and role attributes were reversed. It is noteworthy that the correlation between GP intention to resist and technology efficacy and undesirable role change were of similar strength, casting doubt on the anticipated mediating effect of undesirable role change on all other influences. Thus factor correlations supported the hypothesised significance (albeit not always the pathway) of relationships between the original constructs of influence and GP intention to resist in H_1, H_2, H_3, H_4 and H_5. However the anticipated mediation of the GPs' role attributes relationship with GP intention to resist by the GP context (H_{5b}) and financial incentives (H_{5c}) was not supported, nor was the anticipated mediation of the GP context influence on GP resistance by the potential for undesirable role change (H_{3a}) supported. Yet a significant relationship between financial incentives and belief in technology efficacy had not been hypothesised.

A series of ANOVAs were carried out to examine the effect of the categorical variables on the derived factors. The *F*-values showed solo GP status, accreditation, practice nurses employed, experience as a GP and AMA membership all had significant relationships with GP intention to resist adoption. On the other hand, none of the categorical variables had a significant relationship with GP context and incentives, while hours worked, gender and practice designation had no significant relationship with any of the factors or with GP intention.

Analysis to determine whether the derived factors were predictive of GP intention to resist utilised Exploratory Factor Analysis through multiple regression. The first model with all categorical measures of attributes showed their coexistence had the effect of suppressing the previously identified significance of some of the relationships with GP intention. While not disproving the significance of the relationships per se, this highlighted they were only significant outside of the regression model. Nonetheless, this appeared to illustrate the individual and practice attributes did not have significant individual or collective direct relationships with GP intention and were more likely, singularly or together, to indicate a moderating influence(s) on the relationships of the derived factors with GP intention. The addition of Role Context as a predictor predicted the DV significantly better, and addition of Incentives as a predictor explained 33.3% of the variance in GP intention. This model also suggested the relationship between Role Context and GP intention may in some manner be mediated by the influence of Incentives, which was tested through mediated regression [16]. Yet this relationship was not clearly supported by this sample. Even so, it seems conceptually reasonable that the influence of GP consultation type range and frequency on GP intention to resist adoption was, for some GPs at least, impacted by incentive strategies that attempted to increase GP adoption of new HI technology. It is noteworthy that the complete loss of significance of the range and frequency of their consultation types in this model, meant there was no evidence of direct influence on GP intention in the presence of the other factors. While the addition of Role Attributes as a predictor predicted GP intention significantly better, the anticipated significance of the direct and indirect Role Context relationships with GP resistance were not supported by this sample. Thus Hypotheses H_3, H_{3a} and H_{5b} were not supported wholly or in part. The addition of Technology Efficacy as a predictor suggested belief in the efficacy of the technology may in some manner mediate the influence of both incentives and role attributes on GP adoption intention. Mediated regression suggested the influence of Incentives was only partially mediated by Technology Efficacy. While this relationship had not been hypothesised it seems conceptually reasonable that for at least some GPs, belief (or not) in the potential of new HI technology to improve patient outcomes would mediate the impact of financial incentives on GP intention. Mediated regression also showed the influence of Role Attributes on GP intention was partially mediated by Technology Efficacy. Hypothesis 5a was therefore supported for this sample.

The addition of the perceived potential for undesirable role change as a predictor to the model represented all the constructs and the categorical variables and explained 65.2% of the variance in GP intention to resist adoption ($F_{(21, 97)} = 8.658$, $p<.001$). This also suggested the influence of Role Attributes on GP intention was in some way mediated by Undesirable Role Change, while testing showed Role Attributes was partially mediated by Undesirable Role Change, showing Hypothesis H5d was supported. However there was no change in the significance of Technology Efficacy relationship with GP intention, so Hypothesis H2a was not supported. Similarly, there was no change in the significance of Incentives relationship with GP intention, so Hypothesis H4a was not supported. A summary of how the study hypotheses were either supported or not by these regression results can be seen in Table 2.

Table 2- Summary of support for Hypotheses

H_1	F_1, DV	Yes
H_5	F_5, DV	Yes
H_2	F_2, DV	Partially
H_3	F_3, DV	Partially
H_4	F_4, DV	Partially
H_{5a}	F_5, F2	Partially
H_{5d}	F_5, F_1	Partially
H_{2a}	F_2, F_1	**No**
H_{3a}	F_3, F_1	**No**
H_{4a}	F_4, F_1	**No**
H_{5b}	F_5, F_3	**No**
H_{5c}	F_5, F_4	**No**

In order to establish whether a more parsimonious representation of relevant predictive factors of influence on GP resistance could be identified, hierarchical linear regression was performed with only factors that had a significant individual relationship with GP intention in the presence of the other factors. This excluded the Role Context Factor and the categorical individual and practice attributes as predictive variables. The subsequent model ($F_{(4, 122)} = 44.772$, $p<.001$) explained 59.5% of the variance in GP intention. Although not predicting GP intention as accurately as the model with all the constructs and categorical variables, this model was seen to represent the key common factors influencing GP attitude formation and identified the potential for HI technology to improve patient outcomes as statistically the most important factor in predicting GP intention to resist adoption. Although not statistically significant, the negative β-weight of the Technology Efficacy and the positive weight of Undesirable Role Change was seen to increase, giving the net effect of widening their relative impact on GP intention to resist. This could arguably be the outcome of change in the influence of Incentives on GP resistance in the presence of the categorical variables. This suggested the range and frequency of consultation types in combination with individual and practice attributes may be more appropriately seen as indicators of a moderating influence on the relationship between Incentives and GP resistance. Thus, moderation of the Incentives Factor and GP resistance relationship may be indicated by different combinations of individual and practice attributes for different GPs. Also, the anticipated indirect relationship between the Role Attributes and Undesirable Role Change Factors emerged as a significant direct relationship. While not hypothesised, the study showed a direct relationship between Role Attributes and GP resistance was probable.

Discussion

It seems conceptually reasonable that the potential perceived for undesirable changes to the GP role would be a barrier to GP adoption, while resistance would be abrogated by belief in the potential of the technology to improve patient health outcomes. Also, that GP use of HI technology and the propensity to use technology would be influence the perceived desirability of any potential for technologically facilitated change to their role. It finally seems reasonable that the influence of incentives targeted at increasing GP uptake of new HI technology on attitude formation would be moderated by the range and frequency of consult types in combination with other individual and practice attributes. This thinking is represented in the modified research model (see Figure 2).

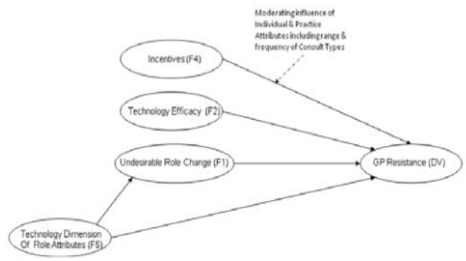

Figure 2- Most parsimonious hypothesised Model.

The role attribute construct supported the focus of [13] and others, regarding the importance of the current use of technology in understanding new technology adoption, yet it was GP use of and propensity to use such technology compared to other GPs that became significant. Similarly, the Role Context Construct became exclusively a measure of the GP consultation types as a consistent indicator of resistance, with Factor Analysis excluding perceptions of the healthcare system, profession and practice context antecedents. Although this may be seen to reflect inappropriately formulated questionnaire items, it also confirmed consistent themes uncovered in this research:

- Unlike extant literature concerning adoption of new technology with non-professionals [13], GPs did not generally see mastering the use of computers for data entry in the practice of medicine as a barrier to adoption, particularly if use was evidence-based.
- The autonomous nature of the GP role in an environment of demand for their services essentially means any change in their workflow must be voluntary.
- The GP did not spend time considering the potential for change unless they believed they could exert some immediate control over change outcomes.
- The smaller the practice, the more likely practice attributes could be seen as an indicator of GP attributes. Hence the more important it is to address individual GP concerns over practice uptake of change.

Conclusion

The poor uptake of HI technology by GPs may simply reflect the ineffectiveness of past and existing strategies and challenges contemporary thinking in aiming to design generalised models of technology adoption behaviour. Considering an individual's interaction with the system and context makes this change behaviour more comprehensible and supports the thinking of [17, 18] when they cite the importance of understanding individual, system and context interactions.

These findings indicate anticipated change to role or valued contextual antecedents were potentially powerful inputs to emergent resistance. Thus adoption strategies should consider the collective influence on GP perceptions of individual and practice attributes (such as the range and frequency of consultation types, current GP use of HI technology and current practice implementation and use of HI technology). Such focus

would better emphasise the relevance of patient populations potentially benefiting from such technology adoption and be more likely to overcome belief of the inevitability of undesirable change to the GP role. Effective strategies to overcome resistance to HI technology diffusion should thus emphasise benefits to the GPs' patient rather than change to their role.

Financial incentives would more likely be effective in changing GP practice behaviour for example, if uptake was within the realm of GP control and they addressed such specific concerns as the potential for incurring unremunerated practice costs. A situation could then be created where the forces for adoption were stronger than the forces for resistance. However this research suggested certainty about unwanted outcomes could raise the impact of factors that encourage rejection and stategies would be less effective if non-adoption, resistance or rejection was predicated on GP perception that implementation would lead to fundamental change to their role. Then, a strong motivation to move away from adoption would likely underpin an imbalance of forces favouring resistance. Adoption can then be seen as the outcome of the relative strengths of opposing forces, not simply a consequence of diffusion.

This research was directed towards understanding the reasons for GP resistance as the identified gap in the existing body of knowledge [19]. It is anticipated this research provides theoretical grounding and empirical evidence for the direction of future investigations into acceptance of technological innovation in different contexts and settings, particularly by the medical professional in a healthcare context. The exploratory nature of this research uncovered GP and practice attributes of potential influence, yet their significance to GP resistance was neither proved nor disproved. This allows for future research to theorise different combinations of individual and practice attributes as potentially indicative of moderating influences on the process of GP attitude formation.

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Usefulness of the functionalities of an Electronic Medical Record on a Latinamerican Medical Web Portal

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Abstract

The medical record is a key component in the modern health systems, a fundamental basis of higher functionalities that guaranties quality care and the possibility of improved clinical management. The dissemination of information systems for the electronic medical record (EMR) has a growing acceptance and use in developed countries. This type of recognition however has not been widespread in Latin America. Realizing this we conducted a web survey to users of a Latin American medical portal to assess their perception of the EMRs usefulness. Among the results we found that over 90% of respondents were in favor of its use, with values that exceed 80% in the analysis of the utilities by categories. More in-depth studies are needed to determine the reasons for the lack of dissemination and implementation of EMR in our region.

Keywords:

Data Collection, Computerized Medical Record Systems, Medical Records.

Introduction

There is now enough evidence that supports the fact that electronic health records improve quality of care and that it optimizes the costs of the process [1]. Despite the evidence, the use of this tool has not flourished in Latin America.

The Institute of Medicine (IOM) stated that the electronic clinical record should be a longitudinal collection of electronic health information provided by any member of the healthcare team. They also stated that records should provide real time access to authorized users; the EMR should also provide knowledge bases and decision support systems to improve the quality, safety and efficiency of patient care [2]. Some observational studies found that there are practical, logistical and organizational constraints that reduce the effectiveness of the traditional paper record to store and organize the growing number of clinical observations. The electronic medical record (EMR) was designed to overcome many of these limitations, as well as to provide additional benefits that can not be obtained through a static view of events [3-5]. These technologies have spread rapidly in the developed world, with varying degrees of acceptance by professionals. Many studies have evaluated its utility either from the use or the selection of the system [6-8] but in much of Latin America the use of an EMR has not expanded the same rate as the rest of the world [9]. This may be due to either economics or adoption resistance from healthcare personnel [10-13]. Several studies on EMR usefulness have been published in the United States and Europe [14-16], with favorable results in the values of utility and degree of agreement with these informatics systems.

The objective of this paper is to evaluate the perception of usefulness and use of EMR to users of a Latin-American medical web portal.

Materials and methods

This work was done in the medical web portal called IntraMed (www.intramed.net) that is a medical network of science content with distribution in the geographic area of Latin America, with over 250,000 subscribers and a frequency of use of approximately 50,000 different users per month. The site has the functionality that enables the professional specialist or user to target relevant content. The site has 480 main pages with knowledge subsets for 32 medical specialties by region (15 countries). In each of these dynamic pages by specialty, the content is structured with news, medical articles, continuing medical education and events. There is also content common to all non-medical specialties and notes of general interest.

The study was conducted using an "e-research" framework, a study/survey methodology that uses the Internet to obtain the results [17]. The survey was developed using a structured questionnaire available online to users registered to the site. It was available at the site between July 15 to August 15, 2008. This inquiry assumed that the "online" study population was limited to Internet users accessing this website. The study was cross-sectional and descriptive. The characteristics of the electronic survey were to be in structured format and optional filler.

Measuring instrument: The survey was developed based on a Likert scale of 5 points, covering the classification from very

useful to useless. The development of the survey was supervised by the epidemiology and statistics area of the Hospital Italiano de Buenos Aires. Survey validation was done with 20 users who analyzed and answered 50 questions. After analysis the total number was reduced to 40 to eliminate the confusing or non relevant.

The survey was available for all users once they entered the Intramed web portal, after validation by username and password. At the survey introduction, the prospective survey taker had the option to answer at this moment, do it later or not answer. After this they would either continue with the survey or be thanked. In either situation the survey would not be re-requested when accessing the site at subsequent times.

If the user agreed to take the survey he or she was presented with text explaining the purpose of the study and the voluntary acceptance of their data as part of that investigation. The responses were stored in a database that conserved the demographic information and the selected choices with absolute technical impossibility of identifying the user's personal data.

The survey assessed the perception of users regarding the functional benefits of the EMR in the following domains (Figure 1):

1. **Functions of the proper EMR**: registry of the progress notes, list of medical problems.
2. **Documentation functions**: recording lab results, registration of images, scanning and storage of physical documents in the EMR, documentation of vital signs.
3. **Functions related to preventive care and decision support system**: record of immunization, registered allergies warning, and reminders about the implementation of preventive practices.
4. **Prescribing and ordering functions**: medication registration, consult medication prescriptions recorded and print them.
5. **Referrals related functions**: to receive response of the Referrals professionals.
6. **Health education and access for the patients (PHR)**: submit reminders to patients by phone or mail, to enable patients to access information about their histories prior authorization of the professional, create and print education programs and information for their patients.
7. **Administrative functions**: would be able to use administrative data from other centers that use the system, data coverage from patients.
8. **Interoperability**: the ability to encode diagnosis of their patients, share their recorded information of the patients with other professionals.

We also requested the following: (Figure 2):

- Year of professional certification (graduation)
- Work location(s).
- Private or public or both workplaces.
- If they used some type of personal device (PDA) and/or computer systems for recording patient information (in cases that this answer was yes, the survey instrument registered the type of system they used).
- Describe main shortcoming of the system.
- Training received (or did not) to use the system.
- The availability of technical assistance.
- The registry format used.
- Finally, if they would continue using traditional registration in paper and if they would use an EMR.

The results were expressed with frequency and percentage.

Results

The survey was available at the medical web portal for users of this website, between July 15 to August 15, 2008. During this period over 16,702 different users entered in the portal (exposed population) of whom 5171 users responded to the survey (30.96% response rate), 70% were Argentineans. Sixty-five percent (65%) of the respondents worked in pediatrics, internal medicine, surgery and gynecology.

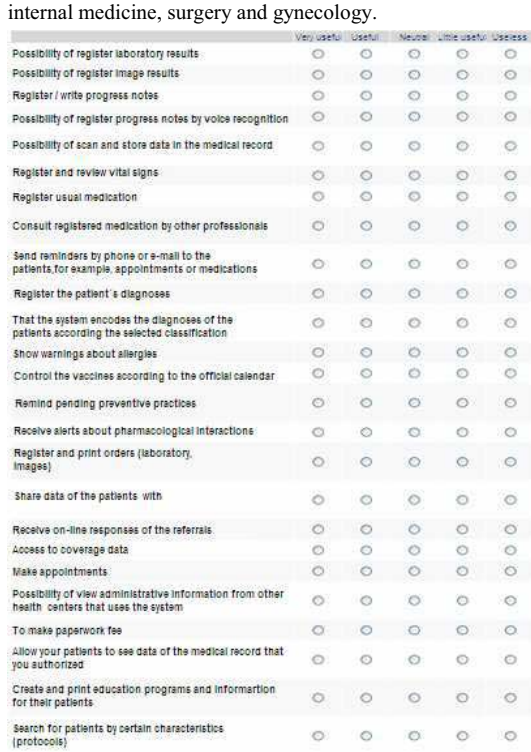

Figure 1 – Questions as useful domains.

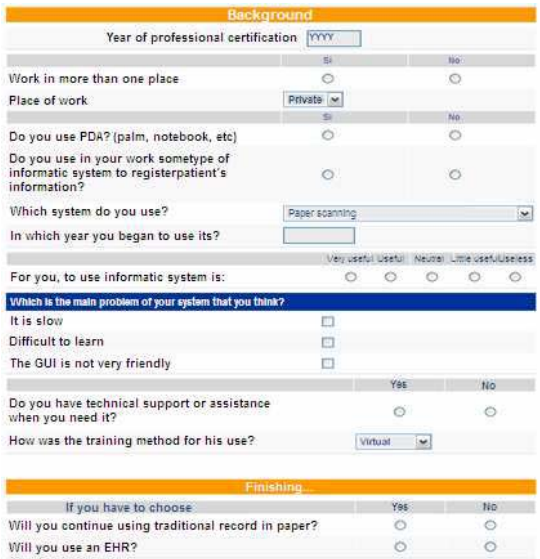

Figure 2 – Context questions.

Context Characteristics

With regard to the context of the workplace of the respondents: 69% of professionals worked in more than one place, with 47% of those working in both the private and public sectors. Sixty-one percent (61%) used personal electronic devices, and 56% had an informatic system at their workplace (12% digitizing, 31% own informatics developments, the rest divided between document scanning systems, vendors development and other systems). Thirty percent (30%) began using devices less than 5 years ago, while 40% have been using between 5 to 20 years. The complete results of the domain of context can be seen in Table 1.

Utility of the functionalities

Analyzing the functionalities, the results were the following (Table 2):

A. Functions of the EMR itself

To record or write progress notes: 95% found it useful or very useful, while only 1% disagreed and felt that this feature was not useful or useless.

Progress notes recorded with voice recognition: were evaluated as useful or very useful in 58% of cases and useless or unhelpful in 13% of cases.

Availability of a list of diagnoses of their patients in the EMR: was found to be useful or very useful by 96% of respondents.

B. Documentation functions

Ability to record laboratory results: was considered useful or very useful in 97%.

Recording of the images: was useful to 95% of the survey respondents.

Scanning and storage of physical documents in the EMR: was considered useful or very useful in 87%.

Documentation of patient vital signs: was at 88% useful or very useful.

Table 1 – Context characteristics of the users that answered the survey

Context	n	%
Male	3309	64
Average age (years)	47	
Years from certification:		
<10 years	1445	27
10-20 years	1186	23
>20 years	2353	47
Work in more than one place	3565	69
Workplace:		
Private	1444	28
Public	962	18
Both	2445	47
Use of electronic devices	3176	61
Use of health information system	2880	56
Which system:		
Digitizing	603	12
Scanning	134	3
In-house development	1606	31
Vendors development	509	10
Since when you use it:		
<5 years	1569	30
5-10 years	846	16
10-20 years	1186	23
>20 years	695	13
As regards the utilization:		
Useless/Little useful	36	0.7
Neutral	82	2
Useful/Very useful	4814	93
System deficiency:		
Slow	2110	41
Difficult	514	10
Unfriendly	1445	28
Do you receive support?	2103	40
How was the training:		
Virtual	465	9
Face to face	1103	21
Both	624	12
Others	1405	27
Non response	1574	30

C. Functions related to preventive care and decisions support

Warnings on recorded allergies of the patient: were found useful or very useful in 94% of cases.

Immunization record: was at 86% of the cases.

To receive reminders about the implementation of preventive practices: 87% of respondents found it useful or very useful.

Drug interactions warnings: this value was 91%.

D. Prescription and orders functions

Register usual medication: was useful or very useful in 96% of the time.

To consult recorded medication by others professionals: were 91% useful.

To record and print prescriptions: were considered useful or very useful for 85% of respondents.

E. Referrals related functions

To receive responses of the referrals professionals: 84% of respondents found useful or very useful.

F. Health education and access by patients (PHR)

Send reminders to patients by phone or mail: was evaluated as useful or very useful by 75%.

Allowing patients to access information about their histories, prior authorization by the professional permission: was considered useful or very useful 55% of the time, 25% of the professionals maintains a neutral position.

To create and print information and education programs for their patients: was found useful or very useful 84% of the time.

G. Administrative functions

Respondents rated as useful or very useful knowledge of the details of health insurance of their patients (75%), methods for allocating appointments (72%), the display of administrative information (66%) and the ability to search for patients according to certain characteristics for research studies (85%).

H. Interoperability

The professionals found the possibility of coding the diagnosis of their patients, as well as share registered information of their patients with other professionals very useful or useful in 83% of the time.

The 93% of respondents found useful or very useful to use informatics systems. When questioned about which system weaknesses you find most disturbing 40% said that the slowness, 28% to be unfriendly or less intuitive and 10% argued that the difficulty of use was the most glaring deficiency.

With regard to training and use: 41% of users of informatics systems have responded that count with technical support or assistance when needed. Regarding training, 9% did so in a virtual way, 21% face to face, 12% both ways, 27% used other methods of training and 30% did not answer this question.

As final answer, 60% of respondents said that would not still using paper records, while 28% prefer to continue using it. Finally 93% responded they would use EMR, while only 4% expressed as negative.

Discussion

While the survey had a large range and was answered by over 5000 people from more than 21 Spanish-speaking countries, we recognize the limitations of this study. It may be biased because the surveyed were users of a website which could be interpreted as an indirect indicator of their preference or ability to deal with software tools. In any case it was an interesting initial sample which analyzed EMR utilities for Latin-American health professionals.

Table 2 – Perception of the functionalities of the EMR

	Functionalities	Useless (%)	Little useful (%)	Neutral (%)	Useful (%)	Very useful (%)	NR (%)
A	Register / write progress notes	0,31	0,85	2,32	19,49	75,46	1,57
A	Possibility of register progress notes by voice recognition	4,45	8,88	25,51	21,95	36,2	3,02
A	Register the patient's diagnoses	0,19	0,25	1,37	18,66	77,63	1,9
B	Possibility of register laboratory results	0,12	0,37	1,12	18,58	78,8	1,01
B	Possibility of register image results	0,21	0,7	2,42	20,17	75,29	1,22
B	Possibility of scan and store data in the medical record	0,79	2,24	8,24	29,43	57,55	1,74
B	Register and review vital signs	0,68	1,8	7,54	31,04	57,05	1,9
C	Show warnings about allergies	0,23	0,5	3,35	21,74	72,23	1,95
C	Control the vaccines	0,7	1,64	9,21	32,66	53,01	2,78
C	Remind pending preventive practices	0,62	1,3	8,7	35	51,89	2,49
C	Receive alerts about pharmacological interactions	0,31	0,85	5,12	27,11	64,36	2,24
C	Send reminders by phone or e-mail	1,64	4,87	16,79	33,84	40,8	2,05
D	Register usual medication	0,17	0,21	1,9	25,45	70,61	1,66
D	Consult registered medication by other professionals	0,37	0,99	5,41	32,99	58,4	1,84
D	Register and print orders	0,93	2,15	9,19	30,44	54,52	2,78
E	Receive responses of the referrals	0,93	2,07	10,06	33,24	51,09	2,61
F	Allow your patients to see data of the medical record that you authorized	6,73	9,44	25,64	30,4	24,17	3,62
F	Create and print education programs and informartion for their patients	1,2	2,13	10,13	36,51	47,3	2,73
G	Access to coverage data	1,06	2,69	17,62	38,64	37,19	2,8
G	Make appointments	1,78	3,64	19,24	36,3	36,07	2,98
G	Possibility of view administrative information from other centers	2,03	4,8	23,26	32,22	34,15	3,54
G	To make paperwork fee	3,71	6,07	27,29	30,28	29,18	3,46
G	Search for patients by certain characteristics (protocols)	1,06	1,8	9,38	30,77	54,28	2,71
H	That the system encodes the diagnoses	1,14	2,63	10,95	28,06	55,06	2,17
H	Share data with colleagues	0,91	2,26	11,6	37,69	44,98	2,55

Regarding the context, there is a tendency in favor of males, which also can be observed for those with more than 20 years of graduation. More than half of respondents worked in more than one place, and most of them are in favor of the use of computer systems.

All the functionalities of the EMR, with the exception of the PHR and administrative applications, were categorized as useful or very useful with high values of acceptance.

The lowest values obtained were in the area of the PHR, which may be because it is a relatively new tool, little known, which raises security and confidentiality dilemmas still not entirely resolved. A deeper analysis will be necessary to explore these issues. This area also had high percentages in neutral rating.

The categories of the EMR functionalities such as progress notes or diagnosis registration, documentation and preventive care were the highest rated in the study.

With respect to the support and training, less than half of respondents stated that did not have support or assistance. A minority was trained virtually; overall there was a high rate of non-response for this particular question. There seemed to be some discrepancy between the usefulness of virtual training and the low values for these types of educational tools in this question.

In conclusion, our research has shown a consistently positive trend towards the use of EMR in the Latin American physician population. Further studies are required to more deeply explore the reasons for the slow dissemination and limited implementation in the field of health in Latin-American region, despite the fact that opinion surveys show high rates of agreement in favor of its usefulness.

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How are clinicians involved in EHR planning? A process analysis case study of a region in Denmark

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Abstract

Experience shows that to achieve a successful implementation of EHR clinicians must obtain joint ownership of the decisions made during the EHR-process. The EHR planning process in the Region of North Jutland, Denmark was studied with the aim of answering the question; "Why are not all Danish physicians overjoyed by the introduction of EHR? A case study was carried out from Oct. 2003 till April 2006 using process analysis. The EHR project management's strategy meant that there was no workload reduction. This was seen as one of the main barriers for the physicians to achieve real influence. History shows that clinician's on the one hand and administrators on the other have different perceptions of the purpose of the patient record and that they both have struggled to influence this definition. To date, the administrators have won the battle. This was the major reason for the approach chosen for the EHR planning process in North Jutland, Denmark. It explains the conditions made available for the physicians, which led to their role being reduced to clinical consultants - rather than real participants.

Keywords:

Medical informatics, Hospital information systems, Planning techniques, Hospital organization and administration, Organizational decision making, Workload reduction.

Introduction

The Danish healthcare system is public and financed by taxes, and Danish hospitals are governed by the Danish Regions. In the last decade there has been extensive discussion about the electronic patient record (EHR) in Danish hospitals - among politicians, the administration and clinicians as well as in the media. Concurrent advances in information technology indicate that the EHR can be the solution to many of the problems associated with the paper based patient record, e.g. accessibility and data validity. As a result the Danish national strategy for IT in the healthcare sector published in 1999 [1] required all the Danish counties to implement an EHR. This caused the County of North Jutland (CNJ) to develop an overall IT-strategy [2]. In March 2004 a local EHR working group was set up to make the requirement specifications for the EHR and to choose between four possible systems.

However, experience has shown that the introduction of the EHR often brings with it a number of new problems, including some of an organizational nature [3-14]. Experience has also shown that for an EHR implementation to be successful the clinicians must obtain *positive clinical benefits* as a result of its implementation and *joint ownership* of the decisions made during the EHR-process. A prerequisite for joint ownership is *early* involvement of clinicians, the best possible *representation* of all groups of clinicians, giving the clinicians *real influence* in decision making and the possibility of *workload reduction* [4;15-18]. When it comes to development and implementation of EHR, experience shows that physicians are a very important group of clinicians because their acceptance is crucial to whether or not the EHR is brought into use in the intended way [19-24]. In this perspective, the research focus was on *physicians* as a relevant social EHR technology-carrier-group[1] in the EHR planning process at CNJ. Besides the physicians, IT-professionals and administrators were identified as significant social EHR technology carrier groups in the EHR planning process in CNJ.

Purpose

The purpose was to study *"Why are not all Danish physicians overjoyed by the introduction of EHR?"* by answering the following research questions:

Research questions

1. *Did the physicians have the necessary resources (interest, power, organization, information, access and knowledge) during the EHR planning process at CNJ to change their status from potential to actual social carriers of the EHR-technology?*
2. *Can the answer to the above research question be understood by studying the differing amounts of "meaning[2]" each of the relevant social groups, (physicians, IT-professionals and administrators), attached/attaches to the EHR?*

The new knowledge generated hereby will benefit both the continued development of the EHR process at CNJ and the future development and implementation of new technology in other Danish hospitals.

[1] A group of actors or a social entity which chooses the new technology and carries it forward towards the next phase in the process.

[2]Significance, goals, interests, needs (a concept used in the SCOT theory)

Theoretical framework

This research combines the Socio-technical carrier of technology theory [18;25-27] with the Social construction of technology theory (SCOT)[28].

In order to shed light on the interactions that occurred between the different relevant social groups during the planning process at CNJ (the *case* perspective) - i.e. within a relatively short timeframe - the Socio-technical carrier of technology theory was used. According to this theory, a new technology is chosen and carried forward in the technological development process by the actors or the social entities involved – the *social carriers of technology* - only if they have the necessary resources (interest, power, organization, information, access and knowledge) to change their status from being potential to *actual* social carriers of the technology. Every qualitative change in a technological development process can be traced back to a change in the *composition* of the social carriers of technology and in the conditions necessary to achieve the status of an *actual* social carrier of technology.

With a focus on physicians, this study was carried out at CNJ studying:

- The vested interests of the different relevant social carrier groups of technology in relation to the EHR
- Their options (power) to carry through these interests
- The degree of support from their professional association
- The amount of knowledge and information they had about EHR both in general and particularly regarding the different options available
- Their opportunities to see and test the system in practice (access).

The SCOT theory provided a framework for understanding the underlying reasons for the different social group's vested interests in the patient record - and the power they had or did not have to bring forward those interests. According to the SCOT theory, every stage in the development of a new technology involves choices between various options. Besides rather narrow, purely professional considerations, social factors (interests, power) determine what options are chosen. The *historical* perspective was, therefore, included in an attempt to uncover what "meaning" has been given by the different relevant social groups to the patient record from its origins in a paper format to the electronic format of today - in order to gain an understanding of the historical and current interests and the balance of power between the social groups.

Materials and Methods

Design

The study was designed as a case study with focus on a process orientated technology analysis of the EHR planning process in the County of North Jutland (CNJ) in Denmark. The research period was from Oct. 2003 till April 2006.

Population

In the *case* perspective, the relevant social groups were the physicians and IT-professionals in the EHR working group and the IT-Board of the county of North Jutland. In the *historical* perspective they were physicians and IT-professionals associated with the Danish hospital sector and hospital managers and EHR decision makers at regional level.

Data collection and analysis

Data were collected through:

- Observations at EHR working group meetings
- Interviews with 8 physicians (all) and 2 IT-professionals in the EHR working group and 2 members of the IT-Board
- Insight gathered from documents.

Data were analysed using the software programme ATLAS [29] with a focus on the six conditions to be a social carrier of EHR (interest, power, organization, information, access and knowledge) – and an "open mind" towards other themes.

The analysis was divided in two parts; a technology-carrier analysis for answering the first research question and a SCOT analysis for answering the second. Finally the initial question; *"Why are not all Danish physicians overjoyed by the introduction of EHR?"* was answered by a synthesis of the two analysis.

Trustworthiness

Trustworthiness was sought through data triangulation, approval of the transcripts by the interview persons and a thoroughly description of all activities throughout the process (transparency).

Results and analysis

Technology carrier analysis

All the physicians in the EHR-working group were asked to make requirement specifications for an EHR and to choose between four EHR systems. They expected *real* involvement in the EHR-planning process because of the nature of the tasks they were asked to carry out. The job implied a great deal of considerations, decision-making and choices during the process. Furthermore it required *true* involvement of all social groups for them to be able to reach agreements that included everyone's interests to the greatest extent possible. The EHR project management's strategy for the planning process led to the physicians *not* achieving *real* influence in the planning process. The predominantly informal planning strategy meant that there was no clinical work load reduction at all during the process. This was the main barrier for the physicians to achieve *true* involvement in the process, and it affected all six conditions - interest, power, organisation, information, access and knowledge - required to obtain the status of *actua*l social carriers of the EHR. Another serious barrier was that six of the eight physicians became members of the EHR working group eighteen months after the group was formed – and without any kind of pre-preparations prior to their enrolment. It meant that they – when it came to information and knowledge – were left far behind the other members of the group. None of the well

known prerequisites for obtaining joint ownership among users to decisions taken during an EHR processes were met during this EHR planning process. These are [4;15-18]:

- The best possible *representation* of all groups of clinicians
- *Early* involvement of clinicians
- *Real influence* in decision making
- The possibility of *workload reduction.*

The empirical data show that the EHR project management had underestimated the workload associated with the planning process. An interview with the project manager revealed that no attempts were made to learn from the experiences of management of EHR planning processes in other counties - including experiences about the need for workload reductions in one form or another. Besides the barriers for true involvement already mentioned the physicians did not have the necessary power, organizational support or knowledge to achieve *real* influence in the planning process or to *ensure* that clinical interests would be accommodated in the forthcoming EHR.

The Danish Medical Association was in no way involved in the process. The organizational support and encouragement that the physicians in the working group achieved during the planning process was given from colleagues at the main hospital in the region. Compared to the physicians the IT-professionals achieved much more power and organizational support. Their office (called "IT-Health") was in charge of the project management. At the same time, the director and the three heads of department at "IT-Health" were members of the IT-Board / the EHR Steering group respectively. Thus, the IT-professionals were part of the decision-making authority.

The physicians were specifically asked to concentrate on the *clinical* aspects of the EHR during the process. Because of the "dialogue based planning process[3]" the four systems became almost alike with respect to clinical aspects, and therefore clinical criteria were given up as criteria for selection of the system. The final choice of EHR system was then primarily made on the basis of the interests of the IT-professionals and the IT-Board, i.e. according to technical and economic criteria and not clinical criteria. The old saying; "knowledge is power" showed to be very true. The reality was; the more technical knowledge – the more power. Some of the physicians refused to chose between the systems before better information, access and knowledge about the systems was availably. That option was declined by the IT-Board, who had the power to make the final decisions. The physicians were - when it came to the possibility of *real* influence on which system to chose - powerless. Because of the working conditions they were given, their role in the process was reduced to the role of clinical consultants informing about physicians' needs in the requirement specifications and other documents. However, they were not able to fill this role completely because of lack of time. Therefore, also this work was to a large extent taken care of by IT-professionals from "IT-Health" with a past clinical background (not physicians).

A new way of carrying through the tender-process (part of the planning process) was used in CNJ; a "dialogue based process". It made dialogue between the members of the working group and the four vendors possible. The physicians felt that this made them able to gain insight in more aspects of the systems and to argument for their demands and wishes for the EHR. Because of the dialogue they succeeded in having a number of their demands written into the final contract requirements.

Social group	Interes	Power	Organization	Information	Access	Knowledge
Physicians	☑	☑	☑	☑	-	☑
IT-professionals	☑☑	☑☑☑	☑☑☑	☑☑☑	-	☑☑☑
IT-Board	☑☑☑	☑☑☑	☑☑☑	☑	-	☑

☑☑☑ = Actual social carrier of EHR

Figure 1 – Visualisation of the degree to which the conditions to become an actual social carrier of the EHR were fulfilled for the different social groups.

SCOT analysis

Internally Danish physicians form an inhomogeneous group with respect to their vision on both problems and solutions associated with the paper based patient record. They were therefore divided into two groups; "Clinical physicians" and "Frontrunners" by the researcher. Throughout the history of the patient record the two groups of physicians have had an *internal* struggle for the power and the right to define the purpose of this. The "Frontrunners" have through history advocated for the introduction of new versions based on visions of future clinical benefits – primary (clinical work) as well as secondary (teaching and research). The "Clinical physicians" have tried to "hold back" on this development, partly because they have felt no need for new versions, partly to "keep up" with daily clinical practice. However, in the long time perspective the "Clinical physicians" have always had to accept new - increasingly standardized - versions of the patient record. In the short-term perspective, however, more examples shows, that the "Clinical physicians" have succeeded in curbing the development for a time [19;23;30]. Because of a growing interest in the use of patient data for secondary non-clinical purposes (management and governance) among administrators and IT-professionals, the two groups of physicians have, however, recently taken a common *external* position when it comes to the *primary* purpose of patient data. This is as being for *primary clinical* use in daily clinical practice. Secondary clinical use - and other secondary purposes - must not compromise the primary use.

The Danish physicians have not only had an *internal* struggle throughout the history of the patient record for the power and the right to define the purpose of the patient record. Also an *external* struggle against administrators has been fought ever since the "birth" of the Danish patient record approximately 150 years ago. Administrators have historically shown a growing interest in patient records, because better possibilities to extract data for primary and secondary *clinical* purposes at the same time meant better possibilities to extract data for secondary *non-clinical* purposes. The development of the electronic health record was originally started by the "Front runners" with the *internal* control of treatment quality as its objective. This has over the years been taken over by administrators with *external* control of quality, efficiency and financing

[3] See explanation later

as its objective. At the same time, the argument about *patient safety* which for many years was used solely by physicians as an argument for using patient data for *clinical* purposes is now also used by administrators to legitimize the use of patient data for *non-clinical* purposes. The "Front runners" - and thus the medical profession - have in recent years lost most of the influence on the development of the patient record to the administrators, and the physicians' power and right to define the purpose of patient records appears today less than ever before.

Physicians and administrators have historically had and still have different understandings of the purpose of the patient record. Throughout history the two groups have fought for their *own* understanding whenever new versions of the record have been introduced. The planning process in the county of North Jutland, Denmark was an example showing this. Physicians here fought for their clinical interest against administrators and IT-professionals – the interests of the two latter groups to a large degree being the same. All three groups fought for the purpose of patient records to meet and support their *own* interests and work areas.

Conclusion

The answer to the first research question is on the basis of the technology analysis, that none of the conditions required in order to obtain the status of *actua*l social carriers of the EHR - interest, power, organisation, information, access and knowledge - were met for the physicians in the EHR working group. Their status as potential carriers of the EHR remained unchanged at the end of the planning process.

The answer to the second research question is on the basis of the SCOT analysis, that the different meanings the three social groups attach to the EHR are rooted in an inherited balance of power between physicians and administrators specifically. Ever since the "birth" of the Danish patient record, clinicians and the administrators have fought for the power and the right to define its purpose. Administrators have so far won this battle and seem to have a stronger position today than ever. This inherited battle of power was the major reason for the approach chosen for the planning process in the county of North Jutland. It is considered to be the reason for the conditions made available to the EHR working-group by the IT-Board during the planning process. Conditions that led to the role of physicians in the planning process in North Jutland being reduced to one of clinical consultants - rather than *real* participants.

The answer to the initial question; *"Why are not all Danish physicians overjoyed by the introduction of EHR?"* is that many physicians have bad experiences with technically immature systems or systems useless in the clinic but of greater benefit to administrators and economists. In addition, many physicians fear - based on bad experiences – that the medical profession will not gain *real* influence in the continued development of the electronic patient record. Physicians fear that this will result in records that do not provide positive clinical benefits but rather is a barrier to carrying out the daily clinical work. Many physicians therefore have a reluctant attitude towards new EHR development initiatives today.

Summary of findings

In order for physicians to be able to acquire joint ownership in the planning process a "dialogue based process" is recommended with:

- Work load reduction
- *Real* user involvement, *early* involvement and the best possible *representation* of users
- Working conditions that support *real* user involvement
- Sharing of past experiences at all levels (strategic, tactical and operational)
- Involvement of the Danish Medical Association, also at *County*/R*egional* level

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Integration of Healthcare Information: from Enterprise PACS to Patient Centered Multimedia Health Record

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Abstract

Every single piece of healthcare information should be fully integrated and transparent within the electronic health record. The Italian Hospital of Buenos Aires initiated the project Multimedia Health Record with the goal to achieve this integration while maintaining a holistic view of current structure of the systems of the Hospital, where the axis remains are the patient and longitudinal history, commencing with section Computed Tomography. Was implemented DICOM standard for communication and image storage and bought a PACS. It was necessary adapt our generic reporting system for live up to the commercial RIS. The Computerized Tomography (CT) Scanners of our hospital were easily integrated into the DICOM network and all the CT Scans generated by our radiology service were stored in the PACS, reported using the Structured Reporting System (we installed diagnostic terminals equipped with 3 monitors) and displayed in the EHR at any point of HIBA's healthcare network.

Keywords:

Electronic medical records, PACS, Radiology information systems.

Introduction

In medical literature there are several definitions of medical records. The Institute of Medicine (IOM) defines it as the repository of information about a single patient, generated by health care professionals as a direct result of interaction with a patient or with individuals who have personal knowledge of the patient (or with both) [1]. According to Von Bemmel a medical record is "composed of findings, considerations, results of examinations and information about treatments followed in relation to the morbid process" [2]. Electronic Health Records (EHR) aren't outside these definitions. However, this last concept is more difficult to define. A large number of health organizations have information systems with different levels of development and integration, storing the information of clinical patients in different ways. The IOM defines EHR as a record that resides in a system specifically designed to support users by providing accessibility to complete and accurate data, alerts, reminders, clinical decision support systems, links to medical knowledge, and other aids [1].

On the other hand, images management and PACS (Picture Archiving and Communication Systems) development were conceived with the aim of achieving significant benefits for radiology departments, in terms of reducing film storage space needed and the staff's time, and ensure immediate access to the images. It is recognized that several of the major benefits of PACS is providing processed images and reports to physicians in a timely fashion. This improves care, facilitates clinical management and expands the capacity to conduct remote consultations [3]. The complete implementation of a PACS system has been often been an evolving process within a clinical institution with the concurrent evolution of hospital information systems with multimedia applications, facilitating images distribution [4]. And it also has been taking a growing interest in other areas which use diagnostic imaging, different to radiology, (e.g., cardiology, pathology, nuclear medicine).

Most centers that have implemented Healthcare Information Systems (HIS) and PACS, the latter was implemented in exclusively in radiology departments or in fewer cases in an integrated manner [5-7]. This way, most healthcare centers with HIS leave outside their clinical data repository (CDR) the multimedia elements, having them managed by stand alone applications, in an isolated way.

Ideally, the integration of this multimedia information must be fully and transparently with other CDR information. Thus, maintaining this integral approach, not looking forward to a separate repository for each service, but the professional been able to access multimedia information in the context of the patient's medical record, without changing application [8].

Then emerge the need for a Multimedia Health Record, in which the PACS in no longer a departmental component and becomes part of the storage system in which the CDR relies, and its information can be access in the context of the entire patient's information in the electronic medical record.

Objectives

Incorporate into our EHR the different studies that generate the various ancillary services in its original formats (images,

movies, audios, signals, etc.) beyond the text in the report.

Materials and Methods

Setting

The Hospital Italiano de Buenos Aires (HIBA) is a non-profit health care academic center founded in 1853, with over 1,500 physicians and 4000 employees. HIBA has a network of two hospitals with 750 beds (200 for intensive care), 500 home care patients under care, and 23 clinics. It has an insurance plan that covers approximately 150,000 people and also coordinates insurance for another 1,500,000 people who are covered by affiliated insurers. Each year over 38,000 inpatients (pediatric and adult) are admitted to its hospitals that are located in Buenos Aires and its suburban area. HIBA has more than 2,200,000 outpatient visits annually from patients from across the country and Latin America.

Since 1998, HIBA began to implement a Healthcare Information System (HIS) by coordinating clinical information with the administrative applications that were already in use [9-10]. It is an in-house project that currently handles all the information related to health care both clinical and administrative from capture to analysis.

All of our systems are web based, and among the most important components are:

- Electronic Health Record (EHR): is the access point to every piece of health information recorded in our healthcare network, as different GUI's for each level (ER, Inpatient, Ambulatory, Home Care, Day Hospital). It is problem-oriented and patient centered EHR system that includes a computerized provider order entry (CPOE) is available throughout the HIBA network.
- RPTGen: Generic Reporting System, transversal to the whole network. Is the Information System for each Ancillary Service, and also enables free text reporting. Its output is a CDA Document [11].
- Terminology Services: an interface vocabulary of our own, allowed us mapping of local vocabulary (thesaurus) to reference vocabulary SNOMED CT, and is in use by each of our applications [12].
- Master Patient Index, Scheduling System, Admissions, ADT, Intranet, among others

HIBA has used HL7 standards since 1999 [10]. Framed by the process of integrating the information systems for the EHR, Ancillary Services and Patient Services, the Department of Medical Informatics developed a document repository for clinical documents (consultation notes, discharge reports, etc.) and final reports from ancillary services, using HL7 and CDA documents to achieve full system interoperability.

Along with these developments it was necessary to incorporate desktops computers, not only in the development area and servers, but also through our entire healthcare network. Currently every point of care has a computer connected to the network, which can access de EHR and the rest of our applications; and there is more than 3000 point of care in our network.

The Radiology Department is a complex department, in many different locations inside the hospital because of its massive growing. It has over one hundred physicians (including residents) and other hundred and twenty healthcare professionals including technicians and nurses. Each month near 60.000 diagnostic procedures are performed, including MRI, CT scan, PET, US, X-Ray, Mammography, Angiography and Interventional Radiology.

Preliminary Stages

To ensure the success of this project, we developed a staged project management process. Each phase was well defined, resourced, and had the advantage of benefitting from strong administrative support.

Feasibility Study

In order to sustain support we elicited and defined institutional expectations with our planned objectives. During this feasibility period three major objectives redefined scope and project.

To achieve a complete and transparently integration of multimedia information it was necessary to maintain a holistic view of current systems in the hospital and specifically the electronic medical record and its interaction with the rest of systems. I.e., the multimedia component would be incorporated as any other piece of health information. But the main focus would remain the patient and his longitudinal record. We sought to avoid (as a concept) service independent repositories that would have increased physician workload.

In summary, we sought to provide professionals with seamless access to patient information within the context of clinical history without requiring a change of application.

Scope

It was necessary to define whether a service is in the scope of the project. This involved defining the departments that generates multimedia information whose inclusion into the EHR has clinical relevance. Taking into account national and international experiences, how they managed digital imaging and subsequent storage, and available standards.

It was also necessary to take into account the volume of each individual study and the organizational logistics that would present as a result of the change. We needed to explore workflow, equipment requirements –technical, physical, and ergonomic issues-. And, of course, our impact study dealt with the financial parameters.

Risks

As an extended project, it was necessary to take into account corporate and technological risk areas, scope redefinition, and changes, which would impact on the project from project inception to its implementation.

Equipment

It was necessary to make an inventory of equipment that generates clinical information in the form of images, audio, video, their ability to generate that information in an electronic manner to store it on the clinical record.

For each ancillary department we generated document detailing the inventory by hierarchical sub-area. This inventory was provided by the sector and completed by our team. In each group of teams was detail the possibility of issuing or receiving messages DICOM and its potential compatibility with the various types of messages [13].

Definitions

During 2006 our project team carried out surveys in each ancillary department. We decided to take the Radiology Department as our starting point, including the following sections: Computed Tomography, Radiology, Interventional Radiology, Digital Angiography, Positron Emission Tomography and Magnetic Resonance.

Ultrasound and mammography services were partially included in the project, because all administrative processes, technical and medical, including the report would change as the others, but without incorporating the images.

We decided to use the DICOM standard for communication and image storage, HL7 messaging which was already an institutional standard, and for administrative information a CDA standard (Clinical Documents Architecture) for reports [14-16].

All studies will be stored for an indefinite period of time, with lossless compression (without loss of information). Based on the analysis of the images generated by each section, we estimated that the storage needs for all Radiology Department would be 12 Terabytes per year. Is left out of the calculation the area of mammography, because the storage required only for this section is equivalent to all the rest of the project, the high cost of digital mammography devices and high definition monitor, besides its application is still somehow discussed among radiologists [17].

At last, some changes took place the radiological process to achieve the main objectives:

- Film less Service
- Reduce primary information in modalities, optimizing technology use and standards application.
- Change the reporting method, from traditional dictation to structured reporting.

With these definitions, we sought to reduce report turnaround time, which will allows faster access to the image by the referring physician.

Results

RIS

In spite of the fact that HIBA does not have a standalone Radiology Information System (RIS) its administrative functions are integrated within HIBA's HIS. Because of this, it was necessary to adapt our system of generic reports (RPTGen) to match the RIS commercial standards. Amendments were made in RPTGen for all involved. This included administration, technical, nursing, physician and systems professionals. This was done to reflect new or suggested post implementation processes for the Radiology Service.

At the same time we designed and developed a new structured reporting system, which output are CDA documents with coded entries and was integrated into the RPTGen.

PACS

Hardware

HIBA acquired an IBM System I server 570 (5 microprocessors Power 6), with a storage capacity of 40 Terabytes.

Software

We acquired a Picture Archive and Communication System (PACS) developed by the Spanish company UDIAT Center Diagnosis: RAIM. It enables a full integration with our systems and works with all required international standards.

Modalities

Through the different sections of the department we integrated DICOM (Digital Imaging and Communications in Medicine) modalities with our PACS network. Our aim was to make a full bidirectional integration including DICOM send, storage, print, modality work list (MWL), MPPS (modality performed procedure step):

- CT: we have five CT Scanners; three were able to make a seamless integration with the mentioned standards. An older device, just accepted DICOM storage and query & retrieve. And the oldest needed a "dicomizer" in order to perform DICOM SC (Secondary Capture).
- Radiology: we acquire a CR Solution with phosphorus chassis, seven single scanners and one multi scanner, with remote operation panels distributed near the most common image acquisition places (ICU, ER, Operating Rooms).
- Interventional and Dynamic Radiology and Digital Angiography were integrated using dicomizers.
- MRI: we have three scanners, all of them had a seamless integration with the mentioned standards.
- PET: one single Position Emission Tomography scanner fully integrated

Besides we were also able to successfully integrate most workstations. Following literature recommendations we decided to

install high resolution diagnostic terminals equipped with 3 monitors:

- Reporting Monitorss: 17-inch LCD screen with standard resolution for using the reporting system.
- Diagnostic Monitors: 2 monitors between 19 and 22 inches, four of them are three megapixels monochrome screens.

Communication

A network dedicated to the project, independent of the existing bi-LAN, with a category 6 cabling (1 gigabit per second) and category 7 inter-nodes. This DICOM network communicates PACS server with each DICOM node installed (modalities, workstations, terminals diagnostic, printers).

Integration

This is the key issue of the development of this project and the main purpose of it. The EHR is a gateway to all patient clinical information. Now, it includes the images and other multimedia information, accompanied by a report complying with the rules of the CDA standard, viewed from the EHR as all results of the studies generated by the Hospital, with the difference that includes a link to the corresponding images (Figure 1).

The installation of a PACS for managing digital images, the use of standards and modern systems used in the HIBA, helped seamlessly integrating systems described above. In this way, any image digitally generated by any of the mentioned modalities is automatically stored in our PACS and immediately creates an empty report in CDA (until the radiologist makes de definitive report) linking to the images. This web viewer is a Java application that requires minimal resources and runs on PC's with Windows OS from 98 to Vista.

Point of Departure and Current Status

At the conclusion of the stages of development and testing, it was decided to begin a pilot test in the Computed Tomography Section of our Radiology Department. After two months, we began wide spreading our implantation to the rest of the department, with a two months interval between sections. In year 2010 we will begin implementing other ancillary services: Pathology and Hemodynamic.

Discussion

There are recognized challenges of integrating the various modalities beyond DICOM Conformance Statement (especially those modalities of the past century); but this technical issues in most cases have a solution [18, 19].

A project of this magnitude implies a great deal of technological challenges (adequacy of internal networks, acquisition of the diagnostic stations to replace the negatoscopes, high availability systems, modernization of modalities, development and acquisition of software). It is also important to note some organizational challenges that have a high impact on the daily workflow of physicians in our institution. These include changes in the way of reporting for specialists (report dictation vs. direct reporting with structured systems).

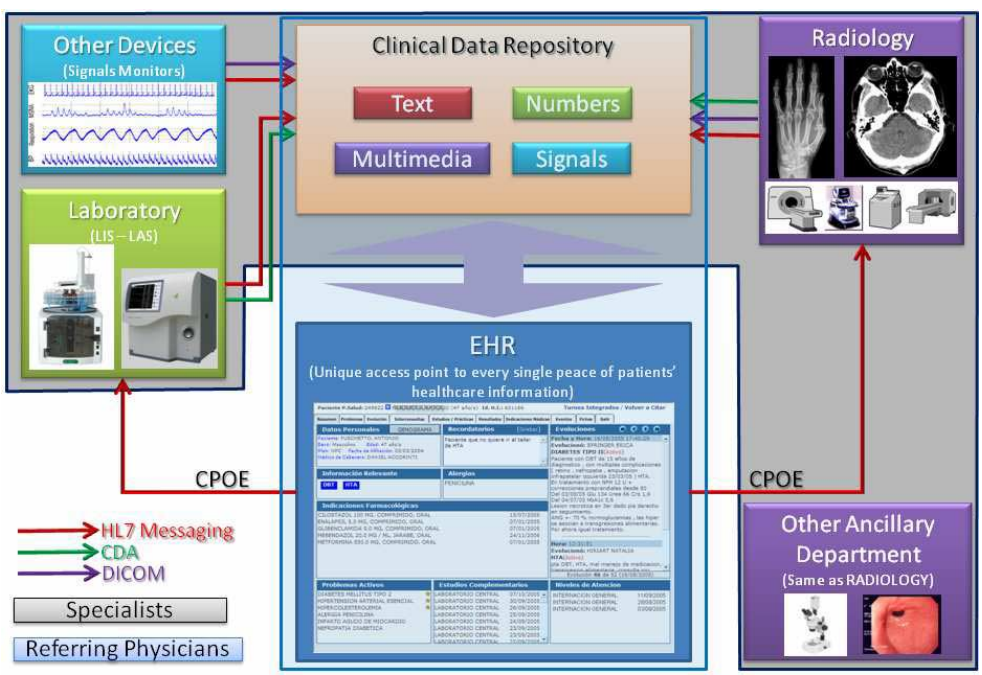

Figure 1 – Schema showing the EHR as the universal Access point to the clinical information for referring physicians

Despite the clear clinical and operational benefits of the project, clearly need to raise its economic justification. The savings would be generated by replacing image printing consumables and the improvement in the radiological process that will allow us to relocate 60 employees (typist).

Our filmless policy is not possible in all cases, depending which patient (outpatient, inpatient, etc..), the social security or medical program, type of study (radiography, ultrasound, mammography, ECG, etc..) and referring clinicians (HIBA, external, etc.).

Another economic aspect to investigate was the time in which, by legal or regulatory reasons, was necessary to store multimedia objects. In this aspect, technology improvements make storage costs dwindling, but it was necessary to define the cost per storage unit, to ensure feasibility over a period of time.

Conclusion

Taking into account our goals and the points outlined above, it is clear that, in our approach, a PACS is not a mere repository of images, but a documentary repository of multimedia elements in a Healthcare Information Systems setting, which provides data to the EHR. This is why the project is called "Multimedia Health Record" and not "PACS Project". And while making the Radiology Department as our starting point, the goal is to integrate all the ancillary services within this single repository, making a multidepartamental PACS.

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The Avoidable Misfortune of a Computerized Patient Chart

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Abstract

The implementation of clinical information systems is demanding, particularly in hospitals, where reliable and well functioning information and communication tools are critical. In this paper we present different approaches to understanding and identifying challenges concerning the implementation of new electronic patient chart functionality. The context of the study was the development and implementation of the new system, which was withdrawn shortly after deployment in a medium-sized University Hospital. One year prior to the deployment we performed an observational study of current information and communication system usage in two hospital wards. Eight months later we conducted a usability test of the new functionality in a laboratory configured as a hospital ward. Four months after system deployment, the studies were followed up by interviews with healthcare personnel, members from the hospital implementation project group, and vendor representatives. The results of the studies show how the different approaches identify and reveal important issues that, if they had been taken into account, could have increased the chance of successful implementation of the system.

Keywords:

Clinical information systems, Observational study, Usability testing, System implementation.

Introduction

Several large Norwegian University Hospitals are in the process of implementing new patient chart functionality to be integrated with their existing electronic patient record (EPR) systems. The new functionality, which includes prescription and administration of medications, will replace central parts of current paper-based patient charts. Implementation of the new functionality into existing systems and clinical practices is an expensive, high risk process. Errors in the medication process might jeopardize patient safety, and usability problems of the system might lead to a disproportionate use of health care provider time on the system [1]. It is therefore crucial to reveal and realize potential risks and problems when designing the system and planning the implementation process.

In this paper we present different approaches to understanding and identifying the challenges related to deployment of new patient chart functionality in a Norwegian hospital. First, we present an observational study performed as an initial investigation of current information and communication system usage in two hospital wards. Secondly, we present results from a usability test of the new functionality conducted in a laboratory configured as a hospital ward. The studies were followed up by interviews conducted four months after deployment - and withdrawal - of the new functionality. Healthcare personnel, members from the system implementation project, and product owners from the vendor organization were interviewed. The findings and results from the interviews, the observational study, and the usability studies are summarized and discussed.

Background and Motivation

The patient chart - a collaboration and communication tool

The paper-based patient chart is a central collaboration and communication tool for health care personnel, particularly regarding medications. Physicians use the patient chart for prescribing medications, while nurses administer the medications to the patients and sign the same chart. The presentation of the patients' previous, current and administered medications gives both physicians and nurses a fairly good overview of each patient's medication status. In addition, the chart includes information about the patient's most recent laboratory and test results, and plans for further treatment [2].

Potential benefits of computerizing the patient chart (i.e. enhancing the quality and efficiency of health care and reducing the number of medication errors) are well recognized. It is the objective of both health record system developers and other healthcare stakeholders to replace the paper with a similarly efficient interface to the computerized patient record, and several attempts - however few successful - have been made to replace the paper-based chart with electronic versions.

Usability of Clinical IT Systems

Usability can be defined as the "extent to which a product can be used by specified users to achieve specified goals with effectiveness, efficiency and satisfaction in a specified context of use" [3]. In hospitals, the usability of the clinical systems is of particular importance. In the health industry, where the demands for effectiveness is increasing, the introduction of new technological solutions can potentially be lethal for the patients if the systems are poorly designed or if they are not tailored to the specific context of use in each hospital. For exam-

ple, Koppel et al. found a number of problems related to cumbersome medication charting and fragmented computer displays in a widely used commercial computerized physician order entry system [4]. Kjeldskov and colleagues found that usability problems may persist in time, as problems with an EPR system still remained after one year of extensive use [5]. Although usability testing is a well known and established method, it is a method that has to be adapted to the usage domain [6, 7].

Study Context

The focus of the study presented in this paper is the development and deployment of new patient chart functionality in a medium sized university hospital with 650 beds and approximately 5000 employees. Due to the complexity of the functionality and the workflow processes related to the chart, the new functionality was limited to medication issues, i.e. prescription and administration of medications. The new functionality was fully integrated with the existing EPR system.

The new functionality was deployed at the same time as the hospital moved to a brand new hospital building. The new locations implied organizational changes and new technical solutions. The new medication system was designed to function in the new hospital wards and with new routines for prescribing and administering medications. A brand new pharmacy automation system was intended to handle single-dosage medications prescribed via the new medication functionality in the EPR, and sending the medications by the pneumatic dispatch to the wards if they were available in the pharmacy automation system. The administration part of the system was intended for use with laptops on trolleys in the patient rooms. The system was integrated with bar code readers that could be used to identify patients and medications during drug administration.

Methods

The observational study was performed one year prior to the deployment of the new system. The usability study presented in the paper was conducted four months before the system deployment, and the follow-up interviews were performed four months after the system implementation and withdrawal.

Study 1: Structured Observations

Study 1 was performed to investigate and identify clinicians' information and communication behaviour in typical ward situations.

The approach is based on a previously developed method for performing structured observation of clinicians [8]. The observations were conducted by three senior medical students. The students performed non-participatory observations of physicians and nurses during various clinical situations, such as preround meetings, ward rounds, medication prescription and administration, and discharging patients.

The observers followed one main actor (i.e. a physician or a nurse) at a time. They recorded context information like situation type, trigger, co-actors, and roles, and sequences of information and communication acts. These sequences consisted of co-actors/information sources (e.g. colleagues, patient chart, patient record, EPR, physician's desk reference (PDR)) and information types (e.g. medication, diagnosis, findings and examination results). The data was recorded by means of paper forms consisting of both pre-defined codes and free-text fields, and subsequently transcribed to and processed in Microsoft Excel. The free-text fields would typically include explanations or the reason for choice of information source.

During the study, the observers spent a total of 24 days (appr. 150 hours) in two hospital wards, where patients with pulmonary diseases such as Chronic Obstructive Pulmonary Disease were treated. Six physicians (4 residents and 2 interns) and five nurses were followed. More than 3170 information and communication acts were recorded.

Findings – Observational study

Figure 1 shows how the distribution of the different information types the nurses and physicians used the paper-based patient chart to retrieve information about. The results show that nurses use the paper based patient chart mainly to retrieve information about medications (87,8 % of the time) and examination results (12,2 %). Physicians, on the other hand, review medication information in half of the cases (48,9 %), they review test and examination results in 45,6 % of the cases, and they also use the chart for other purposes like planning. This demonstrates that the physicians use the chart to get an overview of the patient and as a planning tool, including prescription of medications, while nurses mainly use the chart almost exclusively as an information source for administering medications.

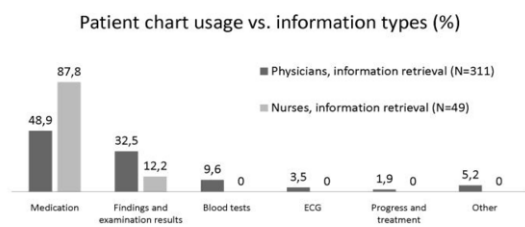

Figure 1 - Percentage distribution of patient chart usage

Figure 2 shows how the different information sources/systems are used by physicians and nurses to retrieve (upper part of figure) and to register (lower part) medication related information. The results further show that physicians use a wide variety of sources to inquire about medications: The paper-based chart (51 %), the patient (11,4 %), nurses (7,4 %), EPR (9,4 %), and the Physicians´ Desk Reference (PDR) (13,1 %). Nurses mainly use the chart (70,5 %) for information about medications, however physicians (21,3 %) and the EPR (6,6 %) are inquired as well. These results confirm the different tasks and information needs of different user groups like physicians and nurses. Physicians enquire different sources to get an overview of the patient's condition, confirm and re-check a

patient´s medication. Nurses use the chart when administering medications, and inquire physicians with questions about for example medication dosages. In addition to administering medication, nurses perform a control of the medications prescribed by questioning its correctness.

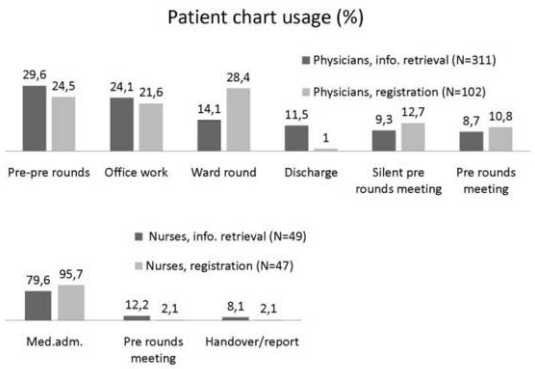

Figure 2 - Percentage distribution of medication related acts

Figure 3 shows how the patient chart is used in different situations by the physicians (upper part) and nurses (lower part). The results show that the nurses mainly use the chart when administering medications, while the physicians use the chart in several different clinical situations.

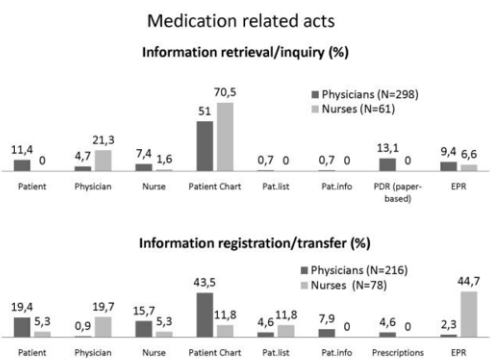

Figure 3 – Patient chart usage in different clinical situations

Study 2: Usability Testing of Patient Chart Functionality

The usability testing of the new EPR functionality was conducted during two one day workshops in a Usability Laboratory at The Norwegian EPR Research Centre. The usability laboratory is 80 square meters, and during the tests it was configured as a section of a hospital ward with two patient rooms, one office, and a hospital corridor. Video recordings of the participants and the system in use during the tests were done from the adjacent control room.

Two nurses and two physicians were recruited as test participants, three of them from the hospital deploying the new functionality. Health informatics researchers and two nurses from a local hospital acted as patients during the tests. Researchers functioned as facilitators, and one representative from the EPR system vendor was present at the second workshop. The vendor representative remained in the control room during the usability tests, but took part in the discussions following the tests. Data from two patient cases (personal, medication, physician and nurses' notes) were entered into the system prior to the tests, and the "patients" were instructed in their medical history.

During the tests, the physicians and nurses worked in pairs. They were instructed to perform their usual tasks during a preround meeting, a ward round, and medication administration, by means of the new chart functionality. The instructions were deliberately of little detail, in order to drive the scenarios by the medical problems in the patient cases. Prior to the test the participants were given a short introduction to the system, and after the tests there was a focus group discussion where the participants (including the "patients") summarized and discussed their experiences. The discussions were led by the facilitators. The tests and the discussions were captured on video for later analysis. After the focus group discussion of the second test, the participants could explore and test the system more informally, without the "patients" present.

Findings – Usability Test

A number of important usability issues were identified during the test and discussed in the debriefing sessions. The findings spanned from user interface problems to architectural issues and resulted in both suggestions for improvement of the system and recommendations related to the implementation process. The main findings are summarized below.

Lacking overview

The main problems revealed in the test were related to the lack of overview of the patients' medications. The physicians experienced that it was difficult to get an overview of the patient's current medications. Little space was given to the list of medications in the user interface of both the order entry part and the administration part, resulting in a lot of scrolling both horizontally and vertically in order to view important information.

Another problem perceived by the nurses was that when a medication was given to a patient and registered in the system with the bar code reader, the entry disappeared from the 'Current medications' list and re-appeared in the historic overview. The users found this little intuitive and cumbersome, as it was not immediately possible to see what medications the patient had been recently given.

Functionality problems

When the bar code reader was used, the system had to be set to ‘bar code reader mode’. This was perceived as an unstable system state, and the implication of the mode shift was difficult to understand.

Another problem occurred when one of the physicians wanted to stop a patient's medication for a short period of time. Since this function was placed in the medication administration

view, the physician was not able to locate it. However, the physician considered stopping a medication temporarily to be an order entry task, not a medication administration task, and the functionality should therefore be available in the order entry part of the system.

Implementation, training and use of the system

Some of the medication administration functionality was complicated, particularly related to the bar code reader. We therefore emphasized to the hospital that it was important that all nurses were trained in practical use of administration of medications using bar code reader, patient identification bracelet, and medications.

The medication user interface did not have separate menu choices for unexpected events, such as 'patient vomits drug'. There existed a general 'cancel' function, but the usage of the function appeared unclear in the usability test.

The results from the usability study were communicated to the hospital project group and the system vendor through a report. However, no changes in the system were made prior to the implementation.

Intermezzo: A Predictable Death?

The system tested in the usability laboratory was put into operation when the hospital moved to the new hospital building, but due to a number of problems during the start-up period, the system was withdrawn after a short period of use. The reported problems were related to among others logistic problems with deliveries of medications, organizational changes, and high workload in connection with the migration to the new buildings. However, the triggering factor was a protest from the physicians regarding lacking functionality and the poor usability of the system.

Post Mortem: Retrospective Interviews

In mature software engineering industry, it is common to gather, analyze and learn from projects by performing 'Post-mortem analysis' (PMA) [9, 10]. Such analysis includes gathering project metrics and evaluating performance, and is mainly performed as an internal exercise for the development team, who will be able to improve their practice in future projects. Users and stakeholders are normally not involved in the PMAs directly because the correspondence between a functionality or non-functionality of a system and the underlying development process is not always evident. In our study, however, we wanted to understand the reasons, from a user perspective, for the dismissal and rollback of the system. We therefore interviewed different stakeholders of the system: One nurse and two residents from the hospital where the system was deployed, two consultants from the hospital system implementation group, and two project leaders from the system vendor. The nurse and one of the physicians also participated in the usability test presented in this paper. The interviews with the nurse, the physicians, and the project leaders were individual, while the two consultants from the implementation group in the hospital were interviewed together.

The interviews lasted from 15 – 45 minutes and the main topics were 1: *What challenges were revealed through the methods described in this paper, and what challenges appeared at the hospital after system deployment,* and 2: *What were the main challenges when the system was in operation*?

According to one of the physicians, the main problems experienced with the user interface of the new system was the difficulty of getting an overview of the patients' medication status, medication actions, and changes.

One of the physicians also explained that they quite early decided to use the old paper chart in addition to the electronic system. When the system was in operation, they experienced that the nurses did not always administer the prescribed medications. A medication was not visible to a nurse if he or she opened the administration module shortly after the task was due. The result was that the patient was not given medication, accompanied by discussions about who were responsible for the mistake.

The interviewees also identified some major problems regarding medication delivery that affected the work of the nurses: the pharmacy automation system did not always deliver the ordered drugs; hence the nurses had to check the local storage, and possibly order the drugs from the pharmacy. They also experienced that medications were sent to wrong wards, due to a cumbersome routine for updating the EPR system. This caused delays and increased the workload of the physicians.

Results and Discussion

We are interested in whether the system rejection could have been predicted, or indicated, from the usability and observational studies. We have grouped findings from observations, usability tests and interview results into broad categories of issues, which can be summarized as belonging to lack of detail or content in different aspects of requirements, models, and implementation.

Information co-occurrence in user interface: whether information or functions that are needed together have high proximity in time or effort.

"The main problem was that it was difficult to get an overview of changes in the medication. (...)You ´open´ [a window for a] patient, who has been at the hospital for a few days, and have no idea about what has happened to the patient" (Resident 1)

This issue was discovered in the usability test, but became more salient when the system was deployed. From the observational study we found that physicians often review medication and examination information simultaneously.

Context of use: whether the different modes of use, user roles or usage situations are paid attention.

"The user interface was predominantly designed for nurses performing administration" (Resident 2)

Stopping a medication for a short period was only possible in the medicine administration interface (not used by physicians). Results from the observational study show that the physicians use the chart in a wide variety of clinical situations,

Interaction: whether the user interface is sufficient in ease of use and functionality.

"We are used to have a sheet of paper which states the patient's medication. It is not necessarily the right or the best solution, but it works to get a quick overview of the medications the patient has taken. If you have to move back and forth in four computer windows before you find the information, then you become unfocused. -- At least I do." (Nurse)

Work processes: whether variation, or uniformity, mishaps and deviation can be handled by the system.

The new chart functionality only supported medication prescription and administration, but no other tasks supported by the paper chart.

"You only understand the diagnosis when you see the paper chart. That overview was not possible in the IT system" (Resident 1)

This issue was identified in the usability test, but became a more obvious problem after system deployment. Data from the observational study show that physicians and nurses review medications and other information in the chart before prescribing and administration respectively.

In addition to these issues, other important issues identified in the analysis are related to temporality, work content, and collaboration

Could the misfortune of the patient chart have been avoided?

In this study both the usability test and the observational study indicated some of the major issues experienced after system deployment. Many of the problems pointed out in the interviews were indicated from test and observation findings. The findings from the observational study reflect the complexity of clinical work. In particular, they show how the patient chart is used in various clinical situations and contexts, and that the physicians use the chart for several other purposes than the nurses. It was therefore not a surprise that the physicians were less satisfied with the new system than the nurses, who mainly use the chart for medication administration. The usability test revealed the importance of getting an overview of the patients´ medications, which was also supported by the observational study.

The problems related to medication delivery and logistics issues were not identifiable in our studies, as they could only have been revealed by extensive testing of the entire system chain in the hospital.

Conclusions

Both studies presented in this paper pointed out crucial issues that, if they had been taken into account, could have increased the chance of successful deployment of the patient chart system. Usability laboratory tests reveal important and possibly problematic issues related to the user interface of the new system, while structured observations allow focused and quantitative grounding of use-cases, role models and stakeholder analysis. A combination of such methods is able to detect and elaborate on challenges, problems and discrepancies in a way that no single method can do.

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A Usability Study of Patient-friendly Terminology in an EMR System

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Abstract

Misunderstandings due to terminology differences between health care providers and consumers may cause communication problems and adversely affect consumer access to health information, resulting in poor satisfaction for patients and providers. To investigate the usage patterns of consumer health vocabulary and evaluate controlled terminologies used in electronic medical records, we *conducted a usability study of patient-friendly terms used in an ambulatory electronic medical record (EMR) and associated patient web portal. After identifying 340 unique diagnosis term / patient- friendly term pairs, we mapped the term pairs determined by UMLS to be pairs of synonyms, near-synonyms, or closely-related terms to the keywords of search queries extracted from a consumer health information web portal to learn the comparative frequency of use of members of each pair by consumers. We found out that use of patient-friendly terms could help to bridge the language gap between providers and consumers but not always. In some cases the professional diagnosis terms were used more frequently than their patient-friendly counterparts, typically in cases where the professional terms were more simple or common than the patient-friendly terms.*

Keywords:

Terminology, Medical records, Internet, Patient access to records, Unified Medical Language System.

Introduction

There is a language gap between health care providers and consumers. Providers may not always familiar with medical terminology used by consumers. Likewise, consumers may not know the terminology used by providers. Misunderstandings due to terminology differences may cause communication problems and adversely affect consumer access to health information, resulting in poor satisfaction for patients and providers.

The differences between patients' and providers' expressions of medical concepts have long been recognized and studied [1-5]. The language gap between health care providers and consumers affecting health information retrieval has been studied in the fields of informatics [6-9]. Previous studies have demonstrated needs and efforts for bridging the language gap by developing consumer-friendly terminologies [10-18].

Zeng's research group has developed an open access and collaborative consumer health vocabulary initiative project. They identified 753 consumer terms and found the logistic regression model to be highly effective for term identification in strings derived from query logs of a consumer health site. In Zeng's logistic regression model, frequency of occurrence, string length, word count and number, frequency and termhood status, and nested strings are primarily used as variables, and the master vote as outcome[19]. In their previous study, Zeng's group developed a systematic methodology using corpus-based text analysis followed by human review to assign "consumer-friendly display names" to medical concepts from the UMLS Metathesaurus [20].

Plovnick and Zeng investigated the effect of reformulating consumer health queries using professional terminology [21]. They further developed a query suggestion tool called Health Information Query Assistant system to help consumers search for online health information. The system suggests alternative/additional query terms related to the user's initial query that can be used as building blocks to construct a better, more specific query [22].

Zhang and other researchers used a multidimensional scaling information visualization approach to examine user log files from a consumer health information web portal HealthLink. They investigated query searching behaviors and visually revealed groups of frequently used medical terms, and provided insight into semantic relationships among them [23]. Zhang's research group further employed an information visualization technique Self-Organizing Map (SOM) in combination with a new U-matrix algorithm to analyze health subject clusters through the HealthLink transaction log, which leads to a better understanding of the health-related topics and terminology from the users' traversal perspective [24]. While previous studies examined consumer-professional terminology difference either in health information retrieval or in the medical record, in our study we have explored the influences of the language gap in both areas and focused on the use of consumer terminology in an ambulatory EMR.

Since 2004, Froedtert Hospital and the Medical College of Wisconsin (MCW) have implemented an ambulatory electronic medical record EpicCare Ambulatory (Epic Systems Corporation, Madison WI). In 2008, an associated patient web portal MyChart® was implemented. MyChart® is the shared patient electronic health record integrated with the EpicCare Ambula-

tory EMR used by the healthcare team at Froedtert & MCW clinics. It gives patients controlled access to portions of their electronic medical record.

The EpicCare Ambulatory EMR incorporates a third-party medical vocabulary lexicon called Problem (IT)™ (Intelligent Medical Objects (IMO), Chicago, IL) Problem (IT)™ is a clinical diagnosis and problem list vocabulary containing specialized terms for clinicians, coders, and patients that links to ICD-9-CM. This lexicon enables an ICD-9-based controlled vocabulary to represent the descriptions that clinicians use when documenting diagnoses on the problems lists, or past medical history. Patient-friendly terms incorporated into Problem (IT) ™ are specifically designed for patient web portals like MyChart®. For example, a clinician may enter the clinical term 'Otorrhea' on a patients' problem list without needing to know the exact ICD-9 term or code (Unspecified Otorrhea 388.60). Likewise, a coder familiar with the ICD-9 code or term can specify either and locate the correct diagnosis. In EpicCare, providers can review and update the patients' problem list with clinical terms mapped via the IMO Lexicon. In MyChart®, patients see the patient-friendly terms associated with the diagnosis. In the previous example, when a clinician adds 'Otorrhea' to the problem list, the patient will see the associated patient-friendly terminology 'Drainage from the ear' in MyChart®. Quite often, the clinical term on the problem list is different than the patient-friendly terminology. These differences can lead to misinterpretations and confusion for both the patient and the provider, and can affect the quality of physician-patient interaction.

To investigate the usage patterns of consumer health vocabulary and evaluate controlled terminologies used in electronic medical records, we conducted a usability study of patient-friendly terms used in the EpicCare Ambulatory and MyChart®.

The study is significant because it:

1. Explores the different ways health care providers and consumers apprehend and express health concepts;
2. May improve communication between health care providers and consumers, assists consumers to better understand their health issues and helps them to find health information more efficiently with well-designed consumer-friendly terms;
3. May lead to a better understanding of health consumer information seeking behavior in terms of frequently used medical terms and associated terms;
4. May provide health information professionals with useful and first hand information that can be used to update and revise consumer health vocabularies.

Methods

First, we randomly chose fifty de-identified active MyChart® patients and analyzed the terminology differences between diagnosis terms on EpicCare and patient-friendly terms on MyChart® with same patient's health issues. Table 1 shows an example of the terminology differences.

Second, after removing duplicates, we identified 340 unique pairs of diagnosis term / patient-friendly term from the problem lists of fifty selected patients. We then employed UMLS to verify if the term pairs are exact match, synonyms, partial match or not match. We categorized those term pairs that are broader and narrower terms, related and possibly synonymous to be partial match. Of the 340 unique pairs, 18% diagnosis term / patient-friendly term pairs exactly match with each other, 28% are synonyms, 34% match partially, and 20% do not match with each other. Figure 1 shows the matching result of diagnosis term / patient-friendly term pairs.

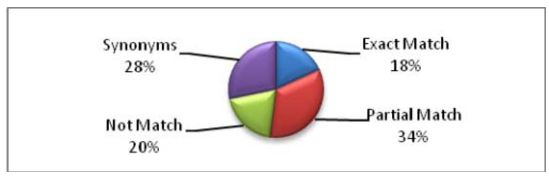

Figure 1 - Diagnosis term / patient-friendly term pairs matching result

Table 1 – Terminology Differences between Diagnosis Terms on EpicCare Problem List and Patient-Friendly Terms on MyChart® Health Issues List

Providers see this screen on EpicCare:	Patients see this screen on MyChart:
Diagnosis	DISORDER OF SWEAT GLAND
Eczema, Dyshidrotic	MENTAL DISORDER
Symptomatic Menopausal or Female Climacteric States	NONALLOPATHIC LESION OF ABDOMEN
Family History of Malignant Neoplasm of Ovary	BREAST ENLARGEMENT
Raynaud's Syndrome	CLOT IN THE LEGS
Globus Sensation	SYPHILIS OF CENTRAL NERVOUS SYSTEM
Somatoform Autonomic Dysfunction	GERD (GASTROESOPHAGEAL REFLUX DISEASE)
Breast Lobule Hyperplasia	HAY FEVER
DVT	PRESSURE-RELATED EAR PAIN
Charcot Joint	MENOPAUSE
Esophageal Reflux	FAMILY HISTORY OF OVARIAN CANCER
Allergic Rhinitis, Cause Unspecified	DECREASED CIRCULATION IN FINGERS OR TOES
Barotrauma, Otitic	

Third, we manually mapped the term pairs that are not exact matches to UMLS to determine their relationship (synonym, near-synonym, closely-related, not-closely-related). For example, we mapped the diagnosis term / patient-friendly term pair "lateral epicondylitis of elbow / tennis elbow" to UMLS and determined they are synonyms in that they are assigned to the same concept unique identifier (CUI) "C0039516".

Forth, after excluding 67 pairs of not-closely-related terms, we mapped the remaining term pairs determined to be synonyms, near-synonyms, or closely-related terms to the keywords of search queries extracted from HealthLink transaction logs to determine the frequency of use by consumers.

HealthLink was an online consumer health resources dedicated to providing consumers with accurate and reliable health information. From 1998-2009, the HealthLink website provided current medical information in straightforward language that explains complex health issues in clear terms. The search terms from the HealthLink transaction log were used to determine the consumer-friendliness for either diagnosis terms or patient-friendly terms in Problem (IT) ™ in this study. These terms from the HealthLink transaction log were not indexing terms employed to index web pages in the HealthLink web portal. Instead, these terms were extracted from the queries submitted from consumers and were used to express a wide variety of customers' health information needs which include those raised from patient records and diagnoses.

Notice that there may be differences between patient-friendly terms in MyChart® and the search terms from the HealthLink transaction log. The primary purpose of patient-friendly terms in MyChart® is to help consumers understand the diagnoses described by these patient-friendly terms. It is natural to use these terms coming directly from consumers to measure the consumer-friendliness of either diagnosis terms or patient-friendly terms in Problem (IT) ™.

We expected that the more frequently the terms have been used for search, the more consumer-friendly the terms are. We chose synonyms, near-synonyms, and closely-related terms for analysis in order to focus on the different ways that health care providers and consumer express the same or similar medical concepts.

To do the mapping, we processed the raw web logs and extracted 3,091,980 search queries from three month's HealthLink transaction logs (October - December, 2008).

Results

Through UMLS, we identified 191 patient-friendly terms as synonyms, near-synonyms, or closely-related terms and their associated diagnosis terms.

Among 93 patient-friendly terms that are synonyms of their associated professional diagnosis terms, 19 of them were used more than 1,000 times in searches within HealthLink queries. 74 of them were searched less than 1,000 times. Table 2 shows the grouped frequency distribution of 93 searched patient-friendly terms that are synonyms of associated diagnosis terms. Among 98 patient-friendly terms that are nearly-synonyms and closely-related terms, 30 of them were used more than 100 times in HealthLink queries and 18 of them were used more than 1,000 times in three months.

Table 2 – Grouped frequency distribution of searched patient-friendly terms that are synonyms of diagnosis terms

Searching frequency	Occurring search terms	Percentage (%)
0-999	74	79.57
1000-1999	8	8.6
2000-2999	3	3.22
3000-3999	1	1.08
4000-4999	3	3.22
5000-5999	0	0
6000-6999	0	0
7000-7999	2	2.15
8000-8999	1	1.08
9000-9999	0	0
10000-11999	0	0
12000-12999	1	1.08
Total	93	100

For each pair of terms, we said that the term used more frequently than the second was more consumer-friendly. In most cases, patient-friendly terms received more searches and were thus more consumer-friendly. However, some diagnosis terms are more consumer-friendly than their associated patient-friendly terms. For example, "lipoma" received 2,166 searches while its associated patient-friendly term "fatty tumor" only got 16 searches. Meanwhile, the diagnosis term "allergy" received 5,601 searches and the assigned patient-friendly term "allergic reaction" only got 1,892 searches.

The most frequently searched patient-friendly term "obesity" was used 12,965 times in search queries over three months, while the associated diagnosis term "obese" was used only 982 times. 86 patiently-friendly terms were not used to search during the three months.

Table 3 shows the most frequently searched patient-friendly terms and their associated synonymous diagnosis terms. Table 4 shows the most frequently searched diagnosis terms and their associated synonymous patient-friendly terms.

These results show that the most frequently searched terms are usually single words or common words. Unlike health care providers who tend to use formal medical terms to describe health concepts, consumers use more simple words or "everyday language" to express those concepts. Sometimes, the professional terms are common enough to express health concepts, which are more frequently searched than so-called patient-friendly terms.

We found that the percentage of both synonyms (28%) and exact match (18%) is less than 50%. The low accuracy rate of the investigated vocabulary system (patient-friendly terms incorporated into Problem (IT) ™) suggests that these patient-friendly terms are not always helpful to narrow the terminology gap between the providers and patients. It shows that a further usability study is necessary and indispensable.

Table 3 - Most frequently searched patient-friendly terms and their associated diagnosis terms

Patient-Friendly Term	Frequency of HealthLink query	Diagnosis Term	Frequency of HealthLink query
obesity	12965	obese	982
diabetes	8447	diabetes mellitus	37
constipation	7445	unspecified constipation	0
high blood pressure	7189	hypertension	2902
urinary tract infection	5534	recurrent uti	23
rash	5005	rash and other nonspecific skin eruption	0
menopause	4984	asymptomatic postmenopausal status (age-related) (natural)	0
depression	4940	depressive disorder, not elsewhere classified	0
stroke	4406	cerebral vascular accident	0
kidney stone	4210	calculus of kidney	0
anemia	4003	unspecified anemia	0
heart disease	3851	unspecified heart disease	0
plantar fasciitis	2995	plantar fascial fibromatosis	0
epilepsy	2568	seizure disorder	97
asthma	2536	unspecified asthma	0
fatigue	2035	malaise and fatigue	0
allergic reaction	1892	allergy	5601
skin cancer	1825	basal cell carcinoma of skin	0
anxiety	1573	anxiety state, unspecified	0
migraine	1503	unspecified migraine without mention of intractable migraine	0

Table 4 - Most frequently searched diagnosis terms and their associated patient-friendly terms

Diagnosis Term	Frequency of HealthLink query	Patient-Friendly Term	Frequency of HealthLink query
gallstone	7766	gall stone	676
allergy	5601	allergic reaction	1892
lipoma	2166	fatty tumor	16
hypothyroid	1556	underactive thyroid	83
osteopenia	1393	bone disorder	0
neuropathy	1150	disorder of a single nerve	0
bph	700	enlarged prostate	0
edema	578	generalized swelling	0
lymphoma	535	malignant lymphoma	0
esophageal reflux	509	gastroesophageal reflux disease	346
hernia	452	abdominal hernia	0
coronary artery disease	403	heart disease due to blocked artery	0
eczema	342	allergic dermatitis	0
osteomalacia, unspecified	322	bone softening	0
varicose vein	197	varicose veins of legs	0
vocal cord paralysis	192	paralysis of vocal cords	3
ovarian cyst	174	cyst of ovary	0
attention deficit hyperactivity disorder	166	attention deficit disorder with hyperactivity	0
periodic limb movement disorder	153	periodic limb movement sleep disorder	0
sacroiliitis	90	sacroiliac inflammation	0

The findings of this study are based on 340 terms from the fifty de-identified patients' records from MyChart®. When the patient sample size increases, the number of the extracted terms will increase accordingly. As a result, the findings might be different. Notice that structure and coverage of a patient database also play a role in the final findings. If the same research method were applied to a different patient database, the results might be also different.

Conclusions

Health care professionals and consumers use different vocabularies to express health concepts. The use of patient-friendly terms could help to bridge the language gap but not always. If the professional terms are more simple or common than the assigned patient-friendly terms, they are more consumer-friendly. In this case, we should choose the same terms that professionals use instead of displaying the terms that are not really patient-friendly in order to avoid increased misunderstandings.

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A Conceptual Framework for Analyzing How Canadian Physicians are Using Electronic Medical Records in Clinical Care

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Abstract

Our electronic medical record (EMR) case study research pursued a set of questions to provide Canadian physicians with practical information on best practices and lessons learned regarding implementation and use of EMRs in ambulatory clinical care. The study's conceptual framework included an EMR System and Use Assessment Survey, interview guide, transcription codes, observation guide and case study report template. The common message that emerged was that no clinic would return to paper-based charts after experiencing the benefits of EMR. In seeking to corroborate our findings with success factors in an EMR implementation meta-framework, we further investigated the role of information incentives as a key factor in sustainable EMR implementations. The sections of our conceptual framework that best enabled us to capture information incentives were the 12 survey questions about information quality, EMR adoption questions in the interview guide and a subset of 26 items from our transcription coding scheme that were linked to physicians quotations about knowing more about the patient when using the EMR than when using paper.

Keywords:

Electronic medical records, Case studies, Motivation, Knowledge transfer, Boundary objects

Introduction

In our EMR study, clinics were invited to participate in case study research being conducted by researchers from across Canada. Participating clinics were selected on the basis of using their EMR as the sole clinical record, that is, as the computerized legal record of patient encounters. The study was sponsored by the Canadian Medical Association and was financially supported by Canada Health Infoway, a not-for-profit organization whose mandate is to accelerate the implementation of electronic health records across the country. These case studies represent the first time in Canada that a structured approach has been taken to examine the benefits of EMRs to primary care delivery.

The EHR Impact Study showed that an easy to operationalize concept of an electronic health record (EHR) system did not exist and a conceptual framework was needed to ensure comparability between different impact measures [1]. An EHR extends the concept of an EMR to include data sharing.

A conceptual framework was the common point of reference for the nine members of the research team who represented the different perspectives of clinician and health informatician. Content analysis in case study research requires methods and procedures that will increase the credibility and transferability of the knowledge that rises from using the conceptual framework. The framework served as a boundary object for building greater shared understanding. Boundary objects are artifacts that enable a common point of reference that can be shared by individuals with different perspectives (i.e. clinicians and health informaticians) [2].

When attempting to corroborate research results, one must reshape the data in ways that make it fit all the frameworks involved. According to an EMR implementation meta-framework analysis [3], the success-failure odds ratio for information incentives properly executed is 69.75 [4]. In seeking to corroborate our findings with this odds ratio, we start with our conceptual framework and determine which dimensions capture the information incentives that come "from the ability to know more about the patient when using the EMR than when using paper" [4, p.113].

Methods

The aim of this research study was to provide physicians with practical information on best practices and lessons learned regarding implementation and use of EMRs in ambulatory

clinical practices. To do this, we developed three primary research questions:

1. How are EMRs implemented?
2. How are EMRs used in clinical practice?
3. How can EMR adoption be increased and sustained?

The research consisted of two stages: the EMR System and Use Survey, which was used to tailor the subsequent interview; and a site visit comprising a one-hour interview with the lead physician and a series of one-hour observations of how the physician, nurse and office staff interacted with their EMR.

Conceptual Framework

The conceptual framework for the study included an EMR System and Use Assessment Survey, interview guide, transcription codes, observation guide and case study report template.

The 7-page EMR System and Use Assessment Survey posed 30 questions asking about overall user satisfaction: 8 questions asking about system quality; 12 questions asking about information quality; 7 questions asking about service quality; 6 questions that were population health specific; 9 questions asking about system usage; open-ended questions regarding EMR systems; and, 3 questions for demographic information.

The interview guide was designed to prompt for responses on implementation, managerial and organizational impact, EMR capabilities and use, EMR and patient care, EMR adoption, practice culture, patient feedback/experience, EMR cost/benefit and other comments. The consent form for the face-to-face interview sought permission for audio recording. The transcription of interview audio recordings was undertaken by an external transcription company. Interviews were conducted in English and French, and the French transcripts were sent to an external service for translation to English.

The 89-item transcription coding scheme was developed based on the research questions and the data. Each transcript was analyzed by two researchers: one was the interviewer; the second was another member of the research team. We used Atlas.ti, a qualitative analysis software program, to code transcribed data to concept categories. The two codings of each interview were done independently. Then the interviewer compared the two analyses and incorporated both perspectives to achieve the final coded interview [5].

The observation guide was used by the researcher to focus on the interactions with the EMR when shadowing the different members of the clinic staff. A set of questions were to be kept in mind: Who is using the EMR? When is the EMR used? What functions of the EMR are being used? Where is the EMR? How is the physician interacting with the patient while using the EMR? What are the strengths and weaknesses?

The researcher who completed the interview wrote up the case study report according to the case study report template. This template contained the following sections: executive summary, introduction, methodology, limitations and challenges of research, EMR capabilities and use, workflow and process changes, organizational impact (with subsections on workflow and clinical practice), key success factors, lessons learned, future plans, and, discussion and conclusions. Each case study report included a clinic sketch to show the physical configuration for encounters that involved patient, physician and computer screen [6].

Data Collection

The unit of analysis for these case studies was the clinical practice setting, rather than individuals, organizations, or the EMR system. Data was gathered from 20 clinics using previsit surveys, key informant interviews and observations.

Thematic Analysis

Using qualitative methods, we undertook a thematic analysis of data gathered from the site visits to answer our three research questions [7].

Filtering Conceptual Framework for Knowledge Transfer

We sought to corroborate specific findings from the EMR implementation meta-framework analysis [3,4] with our study as a means for knowledge transfer around the third question: How can EMR adoption be increased and sustained? The specific success factor chosen for a more in depth analysis was information incentives. This was chosen because the common message that emerged from our research was that no clinic would return to paper-based charts after experiencing the benefits of EMR.

The sections of our conceptual framework that best enabled us to capture information incentives were the 12 questions posed in the survey about information quality, questions in the interview guide on EMR adoption and a subset of 26 items from our 89-item transcription coding scheme that were linked to quotations that expressed how physicians were able to know more about the patient when using the EMR than when using paper

Results

Our nine member research team represented the different perspectives of clinician and health informatician. From a boundary object perspective, the conceptual framework provided a meeting ground among perspectives held by different participants in collaborative research. The only change to the conceptual framework after the research was underway was the addition of the concept of time to the transcription coding scheme.

Transcript coding analysis revealed variation in the application of the codes but convergence was achieved for common messages. Each interview was analyzed by two researchers to code transcribed data to a coding scheme based on 89 concept categories. Codes were developed based on the research questions and the data, and agreed upon by the research team. In total, researchers coded 3749 quotations from physician interviews for 20 EMR case studies.

The thematic analysis generated 20 themes loosely based on those pre-identified in the interview and observation guides [5]. These themes are listed in Table 1.

Table 1 – Themes across case studies

Theme	Theme
Clinic culture and leadership	Patient safety
Motivation	Key success factors and lessons learned
EMR capabilities and use	Barriers to EMR adoption
Technical issues	Benefits of EMR
Scanning	Facilitators of EMR adoption
Workflow and process change; Organization impact	Quality of care
Implementation strategy	Costs versus benefits
Productivity	Efficiency
Impact on patients	Lessons learned
Patient perspectives	Future plans

Success Factors

Clinics believed that their perceived time savings and improved patient record-keeping had improved the quality of care and patient safety by providing more complete information. These clinics used an integrated suite that contains clinical data as well as administrative data, rather than having separate business (back office) and clinical systems. This integration of clinical and administrative workflow is considered to be a key success factor.

Additional success factor topics in our study were categorized as: personal leadership and commitment to EMR; funding; change management and ability to re-engineer; payment model; and collaborative culture [5].

Classifications Across Two Conceptual Frameworks

We know from boundary object theory that classifications have their consequences [8]. When comparing our success factors with other literature we recognized a need to filter our conceptual framework to identify common concepts.

Keshavjee [4] used a different classification scheme to capture success factors in EMR implementation. These were expressed as governance; project leadership; involve stakeholders; choose software; sell benefits; pre-load/integration; tech usability; early planning; workflow redesign; implementation assistance; training; privacy & confidentiality; feedback and dialogue; support; user groups; incentives; and business continuity.

Our conceptual framework had to be adapted to enable us to corroborate what we revealed as success factors against Keshavjee's categories. The success-failure odds ratio is a metric that measures the importance of a factor in sustainable EMR implementations. As an example, incentives, which were primarily information incentives, had a success-failure odds ratio of 69.75.

We selected the concept of information incentives as a common concept worthy of further study. The definition of information incentives is the ability to know more about the patient using the EMR system than by using a paper-based system [4]. This concept can be conveyed in multiple ways. We explored how it was conveyed in the different components of our conceptual framework.

There were 14 items in the EMR System and Use Assessment Survey that explicitly addressed information quality. Improvement in information quality was reported in all clinics (12 strongly agree, 8 moderately agree). Most clinics felt that their EMR enabled the capture/recording of information that is accurate, consistent, complete, reliable, and with low risk of error to the patient. There was some disagreement on the completeness of the information recorded; this reflects the lack of interoperability with other systems. All clinics were content with the way in which their EMR presented information [5].

Of the 89 concept categories, we consider 26 as useful for capturing data on the information incentives, and give the number of quotations associated with the code in parentheses (Table 2). A review of associated quotes for the three most frequently used codes revealed the following ratios of positive to negative quotes: access to data 102:27; quality of care 94:4; interoperability 32:66.

Table 2 – Codes associated with information incentives

Item	Item
access to data (129)	patient education (55)
chronic disease management (62)	patient safety (33)
communicating patient information (63)	population health (33)
data mining (8)	practice management (39)
decision making (51)	productivity (41)
EHR (19)	professional development (28)
Email (8)	quality of care (98)
information flow (56)	recalls (21)
information resources (28)	referrals (27)
internal communication (33)	remote access (37)
interoperability (96)	requests for information (3)
motivation (60)	secondary analysis (4)
organization of data (41)	stewardship of data (14)

Information Incentives as a Success Factor

Respondents cited a set of benefits that outweighed the costs of EMRs. These included efficiency gains associated with EMR prescribing features; the ability to generate referrals; confidence in information and data; lab results; and accuracy. Those with electronic receipt of lab data believe that this feature in itself immediately improves patient care. Other improvements in quality of care arise from the simple fact that the chart is now legible, and the information can be used in

terms of proactive and preventative care. The EMR empowers physicians to provide quality care, because information is more easily available and the information is correct.

The following illustrative quotes came from physicians.

> *"Clinical notes that are legible, prescriptions that are integrated, alerts for drug interactions, renewal made easier, electronic receiving of labs that is very quick, in the minutes following its production, whereas before it could take up to two days to have access, when it was on paper, it's easier when a colleague is on maternity leave or sick leave, it's easier to communicate with other colleagues. When I have a note and I want to advise him, I send it in the internal messaging system and he receives the note in his inbox. That's what it's made easier, yes."*

> *"Clinics feel comfortable with their information — that it is always there, never lost, and most of all, always legible."*

> *"You can be confident in the information you're seeing. Not only is the note legible, another thing that improves care is that the notes — when you dictate notes, or when you're doing the notes firsthand, when you're right there with a patient — you put little nuances and implications into your notes that actually improve the care. Because you understand what you were thinking before, or you can understand what the other physician was thinking."*

> *"I believe it gives better patient care… I definitely think it's the way to practice. It's organized, it's neat, it's legible, and it facilitates communication with your office staff."*

> *"We use the Drug Interaction module. There's Clinical Support Decision Tools like Chronic Disease Management Guidelines and things like that."*

Information Incentives and Potential for Improvement

A few EMR functions were dependent on interoperability with external systems in hospitals, labs and other health providers. Insufficient interoperability was shown to be a significant roadblock to successful implementation. Policy makers would be wise to address interoperability issues in order to increase EMR adoption and sustainability.

> *"The lack of integration. The lack of big-picture vision of what electronic records are going to look like in …, and move systematically toward a big-picture integrated, functional system that it should be, given the day and age of IT."*

> *"One of the biggest issues right now is the continuing frustration that because of regulatory issues and readiness I can't just push out a prescription to the pharmacist. I have to print it and give it to the patient. I can't just message outside of my system very well."*

> *"It's an EMR practice in a paper-based system."*

The usability of EMR functions also impacts information incentives as a success factor.

> *"The main advantage of having an EMR is precisely that it integrates the clinical with the administrative. Because if you buy two different systems, I don't think it's necessarily a very bad decision, but you lose the advantages linked to integrating things together. But there are suites that have modules that are not as good — like the system we currently have, the scheduling, it's not as good as the one I had before. I gained on other things, I lost on some others".*

Many of the clinics have staff exclusively scanning paper documents received from other health care providers. This distracts from much of the potential cost savings predicted by many EMR vendors.

> *"I would say that we may even have more staff than we would if we weren't electronic just because we receive so much in paper copy and we're trying to get it into electronic form."*

Discussion

A conceptual framework was required for a diverse team of researchers to collaborate on case study research. The Canadian EMR Case Studies conceptual framework ensured that the research was conducted in a way that enabled the team to observe a number of commonalities across case studies.

The coding system designed for a particular set of research questions worked well for cross-case analysis, but required some pooling of concepts for comparison of research findings with another EMR implementation analysis study based on a different conceptual framework.

Complex behaviour change interventions, such as EMR implementation, require the use of consistent terminology to support meta-analyses and dissemination of scientific results [9]. The commonalities across the 20 case studies in our research identified the following success factors: personal leadership and commitment to EMR; funding; change management and ability to re-engineer; payment model; and collaborative culture [5]. Keshavjee's factors for EMR implementation success in his meta-analysis were: governance; project leadership; involve stakeholders; choose software; sell benefits; preload/integration; technology usability; early planning; workflow redesign; implementation assistance; training; privacy and confidentiality; feedback and dialogue; support; user groups; incentives; and business continuity [4].

The investigation into one specific success factor, information incentives, illustrated how issues around data organization and indexing need to be addressed to improve knowledge transfer. One resource that could help inform methods for head-to-head comparison of frameworks is the Rx for Change Interventions Database. It organizes its information according to the intervention classification scheme of the Effective Practice and Organisation of Care (EPOC) Review Group in the Cochrane Collaboration [10].

Conclusion

The common message that emerged from the research into how Canadian physicians are using EMRs in primary care delivery was that no clinic would return to paper-based charts after experiencing the benefits of EMR [5]. The attainment of a common message illustrates that the perspectives of the two decision-making cultures in EMR implementation—the clinician and the health informatician—converged. The conceptual framework served as a boundary object and enabled the research team to achieve a shared ground.

The vocabulary used to express success factors varied across studies and illustrated difficulties that could arise in pooling data across research studies. Further work is required to make commensurable the different ways that success factors are categorized in different studies.

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Towards Automating the Initial Screening Phase of a Systematic Review

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Abstract

Systematic review authors synthesize research to guide clinicians in their practice of evidence-based medicine. Teammates independently identify provisionally eligible studies by reading the same set of hundreds and sometimes thousands of citations during an initial screening phase. We investigated whether supervised machine learning methods can potentially reduce their workload. We also extended earlier research by including observational studies of a rare condition. To build training and test sets, we used annotated citations from a search conducted for an in-progress Cochrane systematic review. We extracted features from titles, abstracts, and metadata, then trained, optimized, and tested several classifiers with respect to mean performance based on 10-fold cross-validations. In the training condition, the evolutionary support vector machine (EvoSVM) with an Epanechnikov or radial kernel is the best classifier: mean recall=100%; mean precision=48% and 41%, respectively. In the test condition, EvoSVM performance degrades: mean recall=77%, mean precision ranges from 26% to 37%. Because near-perfect recall is essential in this context, we conclude that supervised machine learning methods may be useful for reducing workload under certain conditions.

***Keywords*:**

Artificial intelligence, Machine learning, Review literature as topic, Systematic review, Study characteristics [publication type], Cochrane Oral Health Group

Introduction

We conducted this study to test the hypothesis that supervised machine learning methods can potentially reduce the workload of systematic reviewers during the initial screening phase of citations. In this phase, teammates independently identify provisionally eligible studies by reading the same set of hundreds and sometimes thousands of titles and abstracts (TIABS). This bottleneck slows the production of quality systematic reviews meant to synthesize research to guide clinicians in their practice of evidence-based medicine.

Additionally, we extended the work of Aphinyanophongs *et al.* [1], Cohen *et al.* [2], and Kilicoglu *et al.* [3] who sought to find rigorous clinical research using supervised machine learning methods. Based on the work of Haynes and colleagues (e.g., see [4]), rigor was presumed if trials comparing treatments were randomized and controlled.

To classify studies with respect to rigor or quality, each research group constructed a reference collection or 'gold standard' of positive cases. Aphinyaphongs and colleagues [1] used MEDLINE records for articles abstracted by the *ACP Journal Club*, which is a respected meta-journal that abstracts or cites evidence-based research in internal medicine for clinicians. Cohen *et al.* [2] used citations for randomized controlled trials (RCTs) included in 15 systematic reviews of drug therapies conducted by an Evidence-based Practice Center (EPC) funded by the US Agency for Healthcare Research and Quality. (The EPC files are publicly available at http://medir.ohsu.edu/~cohenaa/_systematic-drug-class-review-data.html.) Kilicoglu *et al.* [3] used a large subset of manually annotated citations for documents that were used to develop the clinical query filters in PubMed [4]. They selected rigorous studies relevant to human healthcare with a treatment or prevention focus as a gold standard.

Because randomized and quasi-randomized controlled trials (RCTs) tend to be less biased relative to nonrandomized and observational studies, review authors prefer to include RCTs and quasi-RCTs in their systematic reviews. However, it is sometimes necessary to include studies with weaker designs when RCTs are unlikely or unethical. For example, nonrandomized and observational studies are common for studies of: exposure to environmental hazards; invasive surgery compared to no surgery; risk factors for patients with chronic conditions; outcomes associated with patient-selected devices or over-the-counter drugs; diagnostic accuracy; and rare disorders. Thus, to meet the need for synthesized evidence for these kinds of questions, classification methods for studies with weaker designs should be developed along with those for RCTs.

The challenges are significant. Consider, for example, that abstracts with potentially informative words and phrases regarding trial or study design were unavailable in MEDLINE

for most articles published before 1976. Moreover, few terms for designs were available in the MeSH Thesaurus before the 1990s [5 (p. 131)]. Since then, terms have been added or modified to index designs, including weaker ones. For example, the term 'study characteristics [publication type]' includes narrower terms for 'case reports,' 'comparative study,' and 'evaluation studies.' Nevertheless, according to the Cochrane Non-Randomised Studies Methods Group, (1) authors of primary studies inconsistently describe the designs of their studies; (2) bibliographic databases do not reliably index designs; and (3) good filters for nonrandomized or observational studies do not yet exist [6]. In fact, when the latter are eligible for inclusion in a review, authors are enjoined to *not* include design terms in their search filters unless the retrieval set is so large that the review becomes impractical. Thus, the initial screening phase is typically labor intensive when both randomized trials and nonrandomized studies are eligible.

Methods

We used a recently approved search strategy for a Cochrane systematic review about ameloblastomas, which are rare odontogenic tumors of the jaws [7]. This strategy combines a topic filter with the Cochrane highly sensitive filter for identifying randomized controlled trials (see Box 6.4.c in [5]), and a modified SIGN filter for observational studies [8]. (Without terms for designs, the size of the initial retrieval set would have forestalled the review.) The combined filter is designed to find studies that compare surgical resection to any other treatment of ameloblastomas. The editors of the Cochrane Oral Health Group acknowledged the probable low incidence of ameloblastomas and therefore approved inclusion of case-control and patient registry studies. Because the primary outcome is recurrence of the tumor, Bekhuis and colleagues modified the SIGN filter by excluding cross-sectional studies and by including terms for registry studies [7].

The Cochrane Oral Health Group Trials Search Coordinator conducted the search, which yielded 1774 citations from four databases: MEDLINE, EMBASE, the Cochrane Central Register of Controlled Trials (CENTRAL), and the Cochrane Oral Health Group Trials Register. We also retrieved 41 citations from two systematic reviews [9, 10]. After de-duplication, the total number of citations was 1814. We sorted the corpus by publication date in descending order. Even though indexing may be inadequate with respect to design, the sorting reflects our belief that observational studies published after 2007 may be better described in titles and abstracts. This is partly because of the increasing adoption of the STROBE statement for reporting observational studies [11] by biomedical journals, including *Annals of Internal Medicine, Lancet,* and *PLoS,* among others. (See a list of journals at http://www.strobe-statement.org.) In the STROBE checklist, one of several recommendations for writing a good report states that authors should "indicate the study's design with a commonly used term in the title or the abstract." The checklist is available at http://www.strobe-statement.org/index.php?id=checklists.

We built training and test sets by selecting the most recent citations from the initial retrieval set and then proportionately distributed citations from the systematic reviews. Citations in the test set (n=100) and training set (n=300) were labeled with respect to eligibility status in accordance with the consensus decisions of the Cochrane review team [7]. Thus, citations pointing to provisionally eligible studies were labeled as 'include' and those pointing to ineligible studies as 'exclude.' Thirteen percent of studies (13%) were provisionally eligible in both the training and test sets.

We used EndNote to manage citations, to record eligibility decisions of the review team, and to export a text file of 400 citations which was then 'chunked' into separate files (one per citation) using Perl. We used RapidMiner [12], a software package for machine learning and data mining, to which we added a plug-in to process text (available at http://wvtool.sourceforge.net).

Features were extracted from TIABS and metadata using a bag-of-words approach. Pre-processing text involved string tokenizing, converting to lower case, filtering out Medline [13] or English stop words, filtering out tokens with length less than 3, and Porter stemming. Feature vectors were weighted with term frequencies (TF) or the product of TF and inverse document frequencies (TFIDF); vectors were pruned of terms that occurred in at most 3 citations. Features were selected for information gain.

Broadly, we followed the following steps: (1) We trained several classifiers using processed feature sets; (2) compared mean performance of classifiers based on 10-fold cross-validations, where performance measures were mean recall, mean precision, and the harmonic mean of equally-weighted precision and recall (F_1); (3) used grid optimization to find the kernel type that minimized absolute error for the evolutionary support vector machine (EvoSVM) classifier [14]; (4) investigated the impact of training set size on performance; and (5) compared the performance of EvoSVM configurations on the held-out test set.

Results

In early analyses, naïve Bayes and support vector machines (SVMs)—distinct from EvoSVMs—failed as classifiers, even though many researchers have used these algorithms to successfully classify documents [15]. Instead, we compared the following RapidMiner classifiers: DecisionTree, EvoSVM, and weightily averaged one-dependence estimator (WAODE) [16], focusing on EvoSVM in later analyses. To train the WAODE classifier, we first discretized features using the minimal entropy partitioning operator. Selected training results are presented in Table 1.

Analyses not presented compared the performance of each classifier by varying the weights (TF vs TFIDF) for the feature vectors. With the exception of the DecisionTree classifier, performance was better when using TFIDF weights. English stop words instead of MEDLINE stop words were used when pre-processing text for all classifiers because recall was higher when using the former in early analyses.

Table 1–Mean training performance of selected classifiers over 10-fold cross-validations

	Performance		
Classifier	**Mean Recall (%)**	**Mean Precision (%)**	**F_1**
DecisionTree (TF)			
MEDLINE Stop words	25.83	42.83	0.305
English Stop words	30.83	45.83	0.355
EvoSVM (TFIDF)			
Radial	100.00	41.47	0.578
Polynomial Degree 3	66.67	72.83	0.660
Polynomial Degree 4	65.83	73.50	0.676
Epanechnikov Degree 3	95.00	60.20	0.714
Epanechnikov Degree 4	100.00	48.29	0.648
WAODE (TFIDF)	65.83	72.33	0.677

In the training condition, recall is perfect for the EvoSVM classifier with a radial or Epanechnikov (degree 4) kernel, although precision is modest. F_1 is highest for the EvoSVM classifier with an Epanechnikov (degree 3) kernel (see Table 1).

Four EvoSVM kernel types (radial, Epanechnikov, Gaussian-combination, and multiquadric) were compared using a grid parameter optimization algorithm with 3 iterations over 10-fold cross-validations. The EvoSVM classifier with a radial kernel outperforms other configurations when considering absolute error, mean recall, and mean precision (see Table 2).

Table 2–Grid parameter optimization of EvoSVM kernel type (Complexity=1; sigma 1=10; TFIDF)

	Performance		
EvoSVM Kernel	**Absolute Error**	**Mean Recall (%)**	**Mean Precision (%)**
Radial	0.253	92.3	75.0
Epanechnikov	0.265	90.4	72.2
Gaussian-Combination	0.535	28.8	39.5
Multiquadric	0.393	50.0	43.3

When we trained the EvoSVM classifier with an Epanechnikov kernel (degree 4) on 150 citations instead of 300, mean recall degraded considerably, but precision and F_1 improved: mean recall=70.00%, mean precision=76.47% and F_1=0.72.

To understand the impact of training set size, we compared the corresponding feature set size for n_{train}=300, 250, 200, 150, and 100 (see Figure 1). We used stratified sampling to preserve the proportion of provisionally eligible studies in each sample.

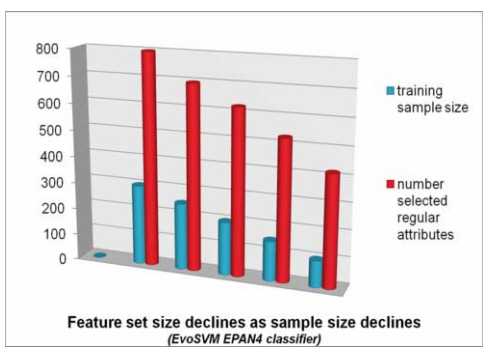

Figure 1–Feature set size is related to the number of citations in the training set.

We further investigated the relationship between performance of the EvoSVM classifier (Epanechnikov kernel, c=1, sigma1=10, TFIDF) and training set size. Training sets were again stratified. Mean recall degrades as the size of the training set decreases, dropping markedly when n_{train} =100; precision peaks when n_{train} =200 (see Figure 2).

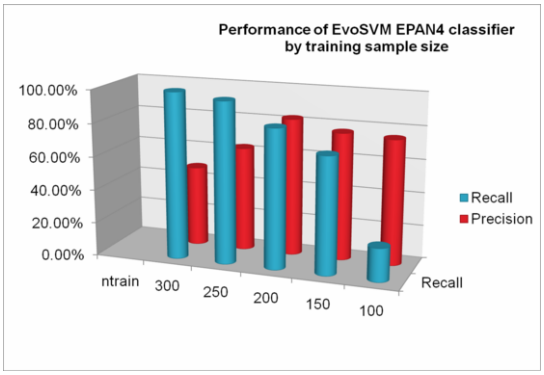

Figure 2–Performance of the EvoSVM classifier is related to the number of citations in the training set.

When we tested the EvoSVM classifier on the held-out test set of citations, performance degraded. Mean recall is equivalent for three configurations (77%), mean precision ranges from 26% to 37%, and F_1 from 0.39 to 0.50 (see Table 3).

Table 3–Performance of the EvoSVM classifier on the held-out test set of citations

	Performance		
EvoSVM Kernel	**Mean Recall (%)**	**Mean Precision (%)**	**F_1**
Radial	76.92	26.32	0.392
Epanechnikov Degree 3	76.92	37.04	0.500
Epanechnikov Degree 4	76.92	29.41	0.426

Note. Further analyses were conducted and the results are available upon request.

Discussion

It is important to realize that recall must be optimal for any machine learning approach meant to aid systematic review authors. For example, the Cochrane Collaboration strongly recommends broad and sensitive search strategies with high recall so that relevant research is not overlooked. In addition, review authors must make good-faith efforts to locate research missed by electronic searches. Thus, they handsearch journals, scan reference lists, contact subject experts, and more. This is why attaining very high recall is our primary goal. Boosting precision is a secondary goal even though modest precision is not as problematic as one might think when the percentage of provisionally eligible studies is relatively low. However, it may be a problem when the percentage is relatively high. Consider the following scenarios.

1. Assume that 2000 citations are retrieved, *10% point to provisionally eligible studies*, recall is perfect (100%), and precision is modest (50%). The classifier will correctly include 200 citations and incorrectly include another 200. The second review author of a two-member review team has to read 400 TIABS instead of 2000, which reduces her workload by 80%.
2. Same assumptions as before, except that *40% point to provisionally eligible studies*. The classifier will correctly include 800 citations and incorrectly include another 800. The second review author has to read 1600 citations, which reduces her workload by 20%.

Nevertheless, the absolute reduction of workload is probably more important to a human than the percent reduction. Consider, for example, that in the second scenario just posed, the review author is spared reading 400 TIABS even though her workload is reduced by just 20%.

Classifiers

In early analyses, the failure of naïve Bayes and support vector machine (SVM) classifiers—distinct from EvoSVMs—may have been due to violations of statistical assumptions. For example, naïve Bayes assumes independence of features and positional independence, and SVM assumes linearly separable classes. Because WAODE [16] and EvoSVM [14] classifiers relax these assumptions, they are more appropriate for these data. (The WAODE classifier differentially weights tree-augmented naïve Bayes models according to how informative each attribute is when set as the root of a tree. The EvoSVM classifier finds an optimal nonlinear hyperplane to classify data that are not linearly separable.)

Although we attained perfect recall with the EvoSVM classifier in the training condition and very high recall for EvoSVM with optimization, over fitting is still a concern. This concern was borne out in the held-out test condition when recall degraded. Nevertheless, the results are promising and suggest that EvoSVM with a radial or Epanechnikov kernel may be an appropriate classifier when observational studies are eligible for inclusion in a systematic review.

Limitations

This study has serious limitations. First, the extracted features may not have been representative of the domain because of the small size of the training set. This could account for the degradation of performance on the held-out test set. In the future, more than 1800 labeled citations from the initial screening phase of a Cochrane review [7] will be available. We expect that performance will improve when the classifiers are trained on a much larger set of citations than was the case for this study. Second, the bag-of-words approach—although affording an appropriate baseline—ignores important phrases, such as *case report, case series, literature review,* and *ameloblastomas of the jaws.* In the future, we will explore various feature sets to improve classification in the held-out testing phase. This will entail annotating citations for relevant terms and phrases, including design features and possibly affiliation and journal. Third, we know that stacking (a method of weighting several classifiers) is a promising approach [3, 17]. However, stacking probably works best with diverse feature sets and is therefore a method more appropriate for a

larger study. Finally, future evaluation of classifier performance needs to be statistically rigorous.

Conclusion

The evidence suggests that supervised machine learning methods can potentially reduce the workload of systematic review authors during the initial screening phase when (1) observational studies of treatments for a rare condition are eligible for inclusion in the review, (2) the proportion of provisionally eligible studies is relatively small, and (3) the number of citations is large enough to capture representative features.

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Balancing centralised and decentralised EHR approaches to manage standardisation

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Abstract

Balancing regional and national electronic health record (EHR) approaches requires cooperation between clinical and technical experts at different organisational levels. Bridging is necessary to achieve interoperability between regional EHR systems, without neglecting the clinical usefulness. This study has investigated the approaches chosen in modelling the clinical content of EHRs in two out of five regions in Denmark. Based on the knowledge obtained in these studies a 'clinical content format' was developed to facilitate the work of the regions, where the clinical content of EHR systems is modelled. The objective of the clinical content format is to enable share and reuse across organisations, furthermore an objective is to gradually introduce standards. The results of the first iteration of a 'clinical content format' are presented and future adjustments are discussed based on the results.

Keywords:

Computerized Medical Record Systems/standards, Computerized Medical Record Systems/administration and organisation

Introduction

In research communities, semantic interoperability is seen as a key to solving the problem of availability and timeliness of relevant clinical data. Semantic interoperability should make it possible to support shared care seamlessly [1] and reduce repeated data entry [2]. In order to achieve semantic interoperability in health care, several standardisation organisations, such as HL7, CEN, ISO, openEHR and IHTSDO, have formulated standardised information models and reference terminologies.[3] The vision of semantic interoperability, however, can not be achieved without a coordinated implementation of standards in nationwide and local eHealth initiatives.

A coordinated approach faces numerous obstacles. A 2007 EU Commission report was reviewing the eHealth status of eight European countries, Australia, Canada and USA. Here it was pointed out, that in all countries there was limited progress towards full semantic interoperability and a growing realisation that implementation of interoperable eHealth solutions will require years to set up. Also at the organisational level, the report concludes that the different national levels of centralisation and decentralisation should be taken into account. To help in coordination efforts, all countries have established or are planning to establish eHealth bodies. [4]

As illustrated in Figure 1, a national eHealth body task is the formulation of standards and strategies. The standards and strategies should be generic in order to support nationwide implementation, and should possibly be coordinated internationally. In decentralised eHealth initiatives, commercial applications are purchased and implemented. In the decentralised setup the priority is to keep the initiatives manageable. Thus, there is a contradiction between different organisational levels involved in e-health development.

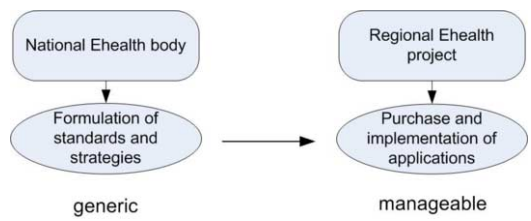

Figure 1 - National eHealth body and regional eHealth projects

In order to further explore the different organisational levels of eHealth, initiatives having both national and regional attention should be studied. Here we have chosen to focus on clinical content modelling in Danish EHR projects, since the scenario presented in Figure 1 is a reality.

National initiatives concerning the structure of EHR content are ongoing in auspices of the Danish eHealth body, Connected Digital Health in Denmark (Connected Health). The initiatives include:

- SNOMED CT has been translated to Danish, which is an important prerequisite in achieving semantic interoperability.
- Several times a year national workshops are held, where regional level actors, who implements the wishes and demands from users in EHR systems, meet. The purpose is to set the framework for exchange of experience early in development.

These are ambitious national initiatives in a small country. However, the initiatives are not trivial to implement since there

is a wide diversity of EHR systems and related IT-systems in the five Danish regions. When the regions implement EHR systems, they prioritise fast solutions that involve users' demands, and the national need to share information across regions becomes secondary. Thus, in the future it will be beneficial to implement standards in regional solutions, but right now specific regional business needs are lacking. Therefore this study addresses how to motivate implementation of national standards such as SNOMED CT in regional EHR projects.

Formalisation of clinical content in EHR projects

Clinical content is defined as the clinical knowledge built into EHR systems, expressed as domain-specific terms, rules and structures.[5]

Clinical content has several objectives:

- To define the interface terminology and relation between interface terminology and a standardised clinical terminology, such as SNOMED CT.
- To define the constraints in the input to EHR systems; e.g., to define a diastolic blood pressure as a number within a certain range.
- To structure the GUI of EHR systems, in order to support a certain clinical workflow.

Clinical content modelling is quite similar to the term 'knowledge level modelling' as described by Beale. Beale describes a two-level modelling approach, where the knowledge level requires its own formalism and structure, and is the level where the numerous, volatile concepts of most domains are expressed.[6] However, clinical content does not have a nationally agreed upon formalism and structure; therefore, and as a result of the decentralisation of EHR implementation, there are variations in the way clinical content is modelled. Thus, it becomes problematic to share and re-use clinical content across organisational borders. This causes each regional unit to commence its own clinical content projects from scratch, a process which is time-consuming and costly. National standardisation could possibly help to solve the problem. This study examines how a structure and formalism for clinical content, called a 'clinical content format', could be developed so as to support standardisation and manageability in a regional context.

Materials and Methods

Given the growing realisation that interoperability can not be rushed, iteratively improving a clinical content format in terms of standardisation could be part of a solution. The basic idea of the proposed method is that standardisation should be gradually introduced to ensure regional manageability.

Method overview

The method is inspired by Hevner et al., whose approach involves both analysis of business needs and knowledge resulting from research to develop innovative solution in the field of information system research. [7] The method developed is illustrated in Figure 2.

The analysis consists of two activities. The first is that of identifying the 'granulation level' in the current clinical content projects. Granulation level refers to the granulation of the material currently used to specify Clinical Content e.g. how entry names, formal representation for data-types and setup parameters of the EHR are defined. An analysis of the granulation level should ensure that the clinical content format is recognisable to the users, that it meets their needs and is manageable enough so that it can be used in practice. Granulation level analysis corresponds to Hevner et al.'s analysis of business needs.[7]

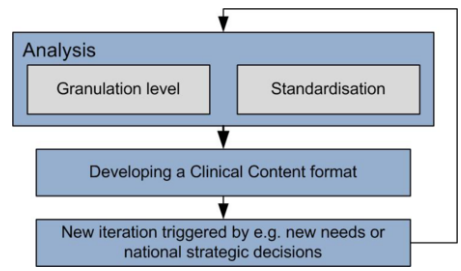

Figure 2 - Method used to develop a clinical content format.

The second activity, Analysis of standardisation, comprises identification of relevant EHR standards and selecting a subset of these based on available strategic decisions and the possibility of articulating clear gains for users. The chosen standardisation approach is integrated into the clinical content format. Analysis of standardisation corresponds to Hevner et al.'s examination of available knowledge resulting from research. [7] Whether standardisation belongs to the research base is an open question, but we regard it as such, since standardisation is widely discussed in the EHR research field. Thus, in the analysis regional needs and national goals of standardisation are balanced.

Based on the analysis, the clinical content format can be developed. Since the field of EHR projects and the standards are constantly changing, the clinical content format should be updated based on results of evaluation, new needs or national strategic decisions. Parallels can be drawn to Hevner et al., who include a number of 'assess' and 'refine' steps to iteratively improve developed solutions.[7]

The method is applied to clinical content modelling in Danish EHR projects as described in the introduction. Details are described in the next section.

Application of method

Granulation level analysis was conducted by examining clinical content projects in two out of the five Danish regions. The analysis included a study of public available information and semi-structured interviews with personnel in the organisations. The Capital Regions clinical content project[1] and the EHR implementation project at Odense University Hospital[2], were chosen as cases based on years of experience with clinical content modelling. The interviews were conducted according to the

[1] http://www.regionh.dk/menu/sundhedOghospitaler/SFI/
[2] http://www.epj.dk/wm122413

method described by Kvale [8]. Three OUH representatives and four Capital Region representatives were interviewed, resulting in 4 hours of recorded data, which was subsequently transcribed.

Relevant EHR standards in a clinical content context were identified by studying research literature (e.g. [3]). The subset to implement in the clinical content format was chosen on the basis of published Danish strategic decisions. Furthermore the possibility of regional adoption of the chosen standards were analysed based on afore mentioned interviews.

After defining the granulation level and the standardisation, the clinical content format was developed using UML class diagrams. The format was visualised in a Mock-Up GUI for developing clinical content, as the Mock-Up GUI provides an intuitive impression of possibilities and limitations of the clinical content format.

The clinical content format was evaluated by means of a presentation for a collection of regional and national actors in the field of clinical content under Connected Health auspices and followed up by an interview with a central Connected Health representative. The application of the method did not include the 'new iteration' step, but the discussion includes ideas about future use of the method as well as the developed clinical content format.

Results

This section consists of the results of the analysis, identifying the clinical content granulation level in the Capital Region and Odense University Hospital (OUH) and the results regarding standardisation. This is followed by a presentation of the developed clinical content format.

Analysis of granulation level

At OUH, the clinical content is modelled in order to enable configuration of the local EHR system, Cambio COSMIC™.[3] The clinical content is modelled through a cooperative arrangement between the hospital departments and a specialised team in the IT-department. The result is visualised in Word-templates. These are used when configuring the EHR system. From the OUH Word-templates, the clinical content granulation level can be deduced. The documentation (input) is most notable at OUH, since overviews of patient data (output) are system-dependent. The hospital departments started using the EHR system in practice as soon as the clinical content was implemented. In the Capital Region, formulation of clinical content is centralised in order to harmonise important documentation and overviews of patient data. The data structure is modelled using an openEHR archetype editor, without modelling real openEHR archetypes, since formal requirements of generic max-datasets are not satisfied. In addition, Mock-Up GUIs are produced in order to visualise both input and output screens. Free text descriptions are also included. These three clinical content information sources are vendor-independent. At present, however, the clinical content is implemented in Opus Arbejdsplads™ from CSC Scandihealth.[4] The implemented clinical content is not yet in routine use in any of the 14 hospitals in the Capital Region.

On the basis of an analysis of the Clinical Content in OUH and the Capitol Region the granulation level of the Clinical Content appears compatible. In short, the result can be expressed in following statements, defining the clinical content format:

- Input is described with setup parameters; e.g., a numeric field has the setup parameter 'unit'.
- Output is described with setup parameters; e.g., a description of the data source.
- The structure of a GUI using the clinical content is defined by an ordering of input and output fields.

Based on these observations the clinical content format can define a delimited and ordered collection of input and output fields with intended use in a specified clinical context. This granulation level limits the possible amount of information provided by the clinical content format since advanced functionality such as decision support cannot be implemented in this simple model. The simplicity reflects the current needs and support manageability, since the details that are defined are limited to those that are currently needed.

Analysis of standardisation

Standardisation of EHR system models and terminology is identified as prerequisites to obtain semantic interoperability.[9]

In Denmark, a strategic decision has been made to use SNOMED CT as common terminology. It is likely that users of the clinical content format could be convinced to map to SNOMED CT to avoid that each organisation is inventing its own terminology, for the GUIs for example. Regardless of whether standardised EHR system models are implemented in the future or message-based interoperability is continued, a prerequisite for sharing data is that the terminology is unambiguous. For the clinical content format, we analysed, that it would be manageable to use SNOMED CT for classification and indexing purposes. Indexing refers to labelling an input or output field with a SNOMED CT code, while classification refers to the selection of one code from a SNOMED CT subset. This simple implementation of the terminology will not facilitate all the possible applications of SNOMED CT. For example, free text is not translated into SNOMED CT concepts. As for the analysis of granulation level, this means that defined details are limited to those that are currently needed

When identifying standardised EHR system models, our conclusion was that since HL7 v. 3 and openEHR/ CEN16303 standards included a dual modelling approach[3], these could be feasible in the definition of clinical content. The clear gains for users of the Clinical Content format, however, remain unclear, since the EHR systems in use are based upon proprietary information models. In Denmark, no strategic decisions are made regarding use of any of these international standards.

[3] http://www.cambiosys.com/

[4] http://www.scandihealth.dk/

Therefore, the use of these standards is not explored in this first iteration on a clinical content format.

Clinical content format

The clinical content format, suggested based on the two cases, is illustrated in a simplified model in Figure 3. The *Specification* class contains the ID of a clinical content specification, e.g., the purpose, such as nutrition screening and the organisation, for example OUH. A *Specification* contains a *Structure Element* for each input and output field. The *hierarchy* attribute defines the placement of the field on the GUI. A *Structure Element* can be either an *Input* or an *Output* field, with added *setup* parameters. A *Structure Element* also contains *Terminology* that allows each field to be indexed using SNOMED CT. A specialisation of the *Input* class is *List.* The list allows the user to choose between several alternatives, when connected to the *Terminology* class. This allows for the use of SNOMED CT for classification purposes.

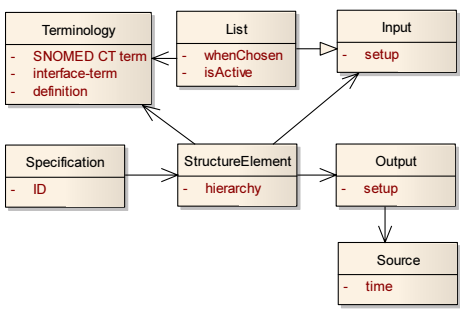

Figure 3 - Simplified clinical content format.

A detailed definition of the format is formulated but not described in this paper. The format is visualised by a Mock-Up GUI for developing clinical content. This is presented in Figure 4. The general idea is that input and output elements from the right side of the GUI can be brought into a hierarchy denoted by 1 and 2. Here interface terminology, SNOMED CT codes and field definition can be added.

When presenting this clinical content development tool, for potential users under Connected Health auspices, it was found that the overall objective of both meeting user's needs and introducing standardisation was considered complex and unexplored. The complexity is discussed in the next section.

Discussion

This study illustrates how a national clinical content format can be developed that balances both regional needs and national goals of standardisation. Hence, the developed approach can be used to facilitate share and re-use of clinical content. As described in the section on Method, future development and iterations of the clinical content format are intended to gradually introduce standardisation to enable a higher degree of interoperability. The complexity of this task, however, should not be underestimated, since factors other than clinical content modelling should be taken into account.

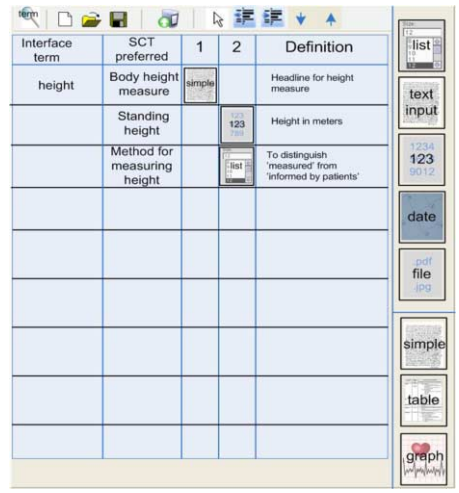

Figure 4- GUI presenting the possibilities of the clinical content format

In Figure 5, clinical content is bridging the technologically-oriented and clinically-oriented aspects. Clinical content should reflect clinical practice; for example, it should support the workflows and support clinical documentation. The long-term goal, however, is clinical standardisation. The purpose of clinical standardisation is to support evidence-based guidelines, to have standardised terminology and practice across organisational boundaries and to be able to document the clinical quality. Another aspect to be taken into account is the status of the currently available models and systems. The existing models and systems impose limits on the kind of clinical content that can be configured and the potential degree of interoperability. The long-term goal is to implement international EHR standards including reference terminologies, hereby enabling fully semantic interoperability. To improve health care delivery, cooperation is needed and multiple aspects should be taken into account; this is illustrated in the following example.

'At hospital A, they have improved the diabetes care by reviewing the clinical guidelines and incorporating them into their practice. While doing this, clinical content modelling was included. A national clinical content format was used as well as the proprietary format of the local EHR system. Expression of the clinical content in the national format enables hospital B to start a similar diabetes care. Thus, A and B carry out the same treatment and collect the same data; therefore they could compare the quality of their respective care or conduct clinical research. However, their vendors should make exchange of relevant data possible which is solved by introducing technical standardisation. After a while A and B decide, that they want to improve the structure of their documentation in order to enhance the documented quality of care. This leads to another

cycle of implementing clinical content, further refinement and improvement of the technical standardisation and so on.'

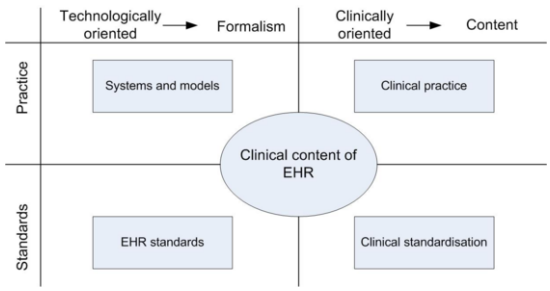

Figure 5- Factors contributing to the complexity of modelling clinical content of EHR systems.

The need for integration of the clinical and technical fields, as described in the above example, is a challenge that has also been identified in the international literature. In some studies, the focus has been on sharing experiences of how to manage EHR systems so that they support clinical practice. In [10], the modelling is done by a proprietary and simple XML-based model, without following a specific standard. This means that, in order to make the model clinically useful, technical standardisation is under-prioritised. In other studies, focus is on using an international EHR standard to model a clinical setting. In [2], openEHR archetypes were modeled, but they were not considered comprehensive and general enough to represent the maximum dataset because they were tailored to local needs. Since maximum datasets are a prerequisite for something to be considered an openEHR archetype, the newly modeled archetypes could not be fed back to the openEHR organisation directly. This means that experience regarding clinical aspects may be lost or delayed because the selected standard is not completely followed.

The method that we have introduced, inspired by Hevner et al., could be a tool to bridge standardisation and user needs in contrast to the above examples, where either technical standardisation or clinical usefulness is chosen. However, the method needs to be evaluated more thoroughly and to include more empirical work in order to ensure cooperation between relevant regional and national organisations. These organisations would include not only regional EHR projects and national eHealth bodies, but also clinical personnel, medical societies, EHR standardisation organisations and vendors of EHR systems so as to reflect the complexity of balancing regional and national approaches and achieving interoperability.

Conclusion

Coordination of regional EHR projects and national or international standardisation approaches is a prerequisite for achieving semantic interoperability. In this study, a method is proposed that makes standardisation manageable in a regional context. However, the complexity of balancing regional and national approaches and achieving interoperability should not be underestimated. Cooperation is needed between regional EHR projects, national eHealth bodies, clinical personnel, medical societies, EHR standardisation organisations and vendors of EHR systems in order to fully accomplish the task. Future work will include studying the feasibility of a clinical content format, by implementing a tool to develop and share clinical content in a specific Danish region and systematically acquire results in a longer time span.

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We would like to thank the clinical content organisations in the Capital Region and Odense University Hospital for interview. Connected Digital Health in Denmark has also been most helpful in completing the study.

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Towards iconic language for patient records, drug monographs, guidelines and medical search engines

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Abstract

Practicing physicians have limited time for consulting medical knowledge and records. We have previously shown that using icons instead of text to present drug monographs may allow contraindications and adverse effects to be identified more rapidly and more accurately. These findings were based on the use of an iconic language designed for drug knowledge, providing icons for many medical concepts, including diseases, antecedents, drug classes and tests. In this paper, we describe a new project aimed at extending this iconic language, and exploring the possible applications of these icons in medicine. Based on evaluators' comments, focus groups of physicians and opinions of academic, industrial and associative partners, we propose iconic applications related to patient records, for example summarizing patient conditions, searching for specific clinical documents and helping to code structured data. Other applications involve the presentation of clinical practice guidelines and improving the interface of medical search engines. These new applications could use the same iconic language that was designed for drug knowledge, with a few additional items that respect the logic of the language.

Keywords:

Iconic languages, Nonverbal communication, Computerized medical records systems, Practice guideline, Documentation.

Introduction

During consultations, physicians frequently need to refer to medical knowledge; however they have very little time to do so, and the amount of knowledge available to them is becoming increasingly vast. It has been shown that, when trying to find the answer to a clinical question, physicians give up after a short time, usually less than two minutes [1]. A possible solution to this problem is to display medical texts in a graphical form. We previously [2, 3] developed VCM (*Visualisation des Connaissances Médicales*, medical knowledge visualization), an iconic language for drug monographs, and we have shown that these icons can help physicians to search for contraindications, cautions for use or adverse effects.

Although initially developed for drug knowledge, the VCM iconic language contains icons that represent most general medical concepts, including diseases, antecedents, risk factors, drug classes, tests and procedures. VCM could thus potentially be used in many other applications outside the initial scope. Drug monographs only represent a small part of the vast amount of medical information and knowledge required by physicians during consultations. Medical knowledge also includes clinical practice guidelines that provide recommendations related to specific diseases. Patient records present physicians with certain challenges, whether looking for specific information or to obtain an overview of the patient. Physicians also need to use search engines efficiently to navigate and search the large number of existing medical documents.

These considerations prompted us to start the L3IM (*Langages Iconiques et Interfaces Interactives pour la Médecine*, iconic language and interactive interface for medicine) project [4], financed by the French National Research Agency in the program TecSan (ICT in Health). This project aims to explore the potential use of VCM for other medical applications, and to identify the icons that are lacking in VCM but that are needed for an iconic language that covers the whole medical domain. The objective of this paper is to investigate the potential of iconic approaches for patient records, clinical practice guidelines and medical search engines.

We firstly briefly describe the VCM iconic language and its use for drug monographs. We then describe the methods used for identifying new areas of potential application of VCM. In the results section, we describe these applications and the new icons that will be required in addition to the existing icons in VCM. Before concluding, we discuss the limitations of our

study and the advantages and disadvantages of using iconic languages.

Background: the VCM iconic language and "Mister VCM"

Drug monographs are texts describing drug properties, such as contraindications and adverse effects. Our previous work involved the creation of VCM [2], an iconic language for drug monographs, including a set of graphical primitives (about 100 pictograms, shapes and colors), and a few rules for combining the primitives to create icons for the major patient states, diseases, antecedents, risk factors, drug classes and follow-up procedures (Figure 1). For instance, the heart, kidney or lung pictograms can be combined with insufficiency, pain or bacterial infection shape to create icons for heart failure, renal failure, pulmonary infection,... and colors are used for distinguishing past, current and potential future diseases. The design of the iconic language took into account findings from cognitive sciences studies, in particular for the graphical representation of *is-a* relations. Consequently, when a physician visually searches for icons meaning "cardiac diseases", he will also find icons meaning "angor" or "cardiac failure".

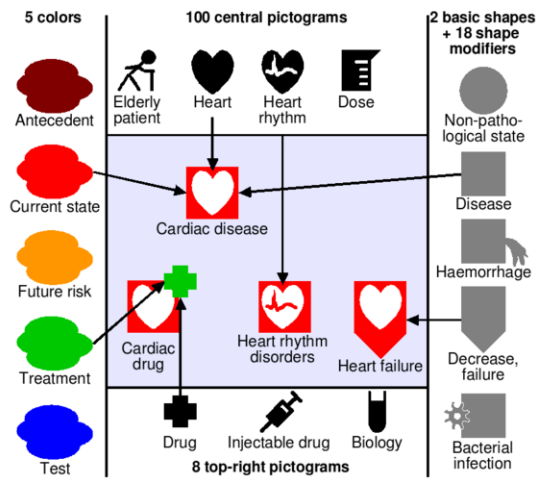

Figure 1 - Examples of VCM icons, created by combining pictograms, shapes and colors

Drug monographs are far too precise for the entire text to be replaced by icons. These texts also serve as legal references. However, icons may still facilitate the comprehension of the text, help to find a specific information, and provide an easy-to-memorize summary. Thus, we designed "Mister VCM" (Figure 2), an iconic interface for conveying information on the drug properties described in drug monograph to a physician during consultation [3]. VCM icons were used to represent contra-indications, cautions for use or adverse effects of a drug. These icons were displayed in a schematic diagram, based on anatomy and etiology. Rules were defined for combining icons when several of them apply to the same case on the diagram, using icons' *is-a* relations. When the physician clicks on an icon, the corresponding textual paragraph from the drug monograph is displayed. "Mister VCM" uses grey icons to indicate the absence of contraindication or caution for use related to a given anatomical system or etiology. This allows the physician to quickly view, for example, that a drug has no renal contraindication, whereas in the drug monograph text, he must read the entire contraindication section.

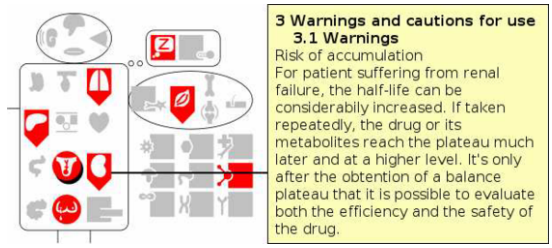

Figure 2 - "Mister VCM" displaying the contraindications of zolpidem, after the clicking on the renal failure icon

Evaluation in a controlled environment showed that with "Mister VCM", physicians briefly trained in VCM identified drug properties twice as quickly as when using a textual interface, and made significantly fewer errors [3]. The physicians were enthusiastic about using VCM, asking for such icons in their software.

Materials and Methods

The various potential applications of VCM that may be of use to physicians were identified through several steps. The use of "Mister VCM" to obtain information about drugs knowledge was firstly evaluated and followed by a focus group; during the discussion, the participating physicians suggested a few uses for, such as the use of "Mister VCM" for displaying information contained in patient records. We then carried out some preliminary investigation, involving master students. This led us to set up the L3IM project [4], involving eight academic, industrial and associative partners. The project design process also entailed some individual reflection.

During the first six months of the project, several focus groups containing GPs or hospital physicians were set up (for a total of 20 physicians). An initial set of focus groups, formed before presenting VCM to the physicians, was aimed at determining the problems they encountered in the use of the existent medical software. A second set was formed after the physicians learned VCM. These groups were dedicated to determining possible applications for VCM. All discussions during the focus group meetings were recorded and analyzed.

Results

Possible applications for VCM

At least three areas for the applications of VCM were identified: patient records, clinical guidelines and search engines.

The use of VCM for patient records

During consultation, physicians often have difficulties obtaining a clear overview of a patient's state, or finding a specific document relating to the patient, such as a hospital discharge summary. This is particularly true for patients with a long history of chronic diseases, or who are not regularly seen, for example for a patient followed by a doctor replacing a colleague on holidays.

Patient records contain patients' information including antecedents, current diseases and treatments, risk factors, biological test results... Patient records also contain clinical documents, such as radiographies, post-operative reports or discharge summaries, particularly for patients in hospital. We identified three possible uses of VCM to help the interpretation of patient records.

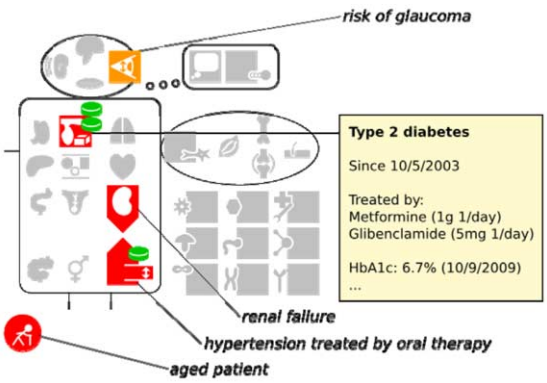

Figure 3 - Example of the use of "Mister VCM" for presenting a summary of a patient's conditions. Labels have been added to explain the meaning of the VCM icons.

- Icons can be used to summarize and to give a quick overview of the patient's conditions, possibly using a "Mister VCM"-like diagram. Figure 3 shows an example for an elderly diabetic patient, with hypertension and renal complications, and a risk of glaucoma. It displays a summary of the patient's current clinical conditions (diabetes, renal failure, hypertension) and risks (glaucoma), organized as a function of anatomy and etiology on a schematic human silhouette. Additional patient characteristics, such as age classes, are indicated below the silhouette. The icons also provide some information about treatments (*e.g.* oral bitherapy for diabetes). This iconic summary could be useful when reading medical knowledge such as contraindications, and may help to prevent an element being forgotten in the follow-up of the patient. Additionally, further information, such as related biological test results or prescription details, could be displayed by clicking on the icons.
- Icons can help physicians to search the various documents attached to a given patient. Documents could be placed within "Mister VCM" as a function of the various hospital services they come from, which are usually associated to an anatomical system or a particular etiology, *e.g.* cardiology or infectiology. Documents can also be characterized by other attributes, such as the type of the document (for example discharge summaries) or the author; this information could be added to the icons.
- Icons could help physicians to add structured data into patient records, for example the ICD10 (International Classification of Disease) code I10 instead of simply writing "hypertension" in plain text. Terminology browsers used for coding patient antecedents could be enhanced by adding icons in addition to, or in place of, the term's textual labels. Given that many terminologies are based on anatomy and etiology, "Mister VCM" could also be used to display the first level of the terminology, *e.g.* ICD10 chapters. Terms could also be searched for by composing the corresponding VCM icon, *i.e.* combining a color, a shape and a pictogram.

Applications in clinical practice guidelines

As for drug monographs, clinical practice guidelines are long texts that are difficult for the physician to read during a consultation. They often include many paragraphs applying only to certain patients, such as the elderly or patients with renal failure. Two applications were considered:

- Icons can be used by the physician to find the paragraphs that apply to the patient. This can be achieved by adding icons in the margin of the text, the icons indicating the various categories of patients addressed (Figure 4). Icons could also indicate the associated recommendations such as recommended prescriptions. Another possible application is the use of "Mister VCM" to summarize the various conditions, displaying the relevant paragraphs on demand.
- Icons can also be used to summarize the decision process recommended by the guideline, possibly using a decision-tree structure. Such a diagram could indicate the disease covered by the guideline, the various patient conditions and the associated recommended treatments or tests to be performed. The diagram could be used as a quick summary of the guideline, but also as an interactive table of contents, *i.e.* by clicking on the icons the physician could navigate through the text of the guideline.

Applications in search engines

Several search engines are dedicated to medical documents, such as Pubmeb for research articles or CISMeF [5] for French medical documents, including guidelines and medical

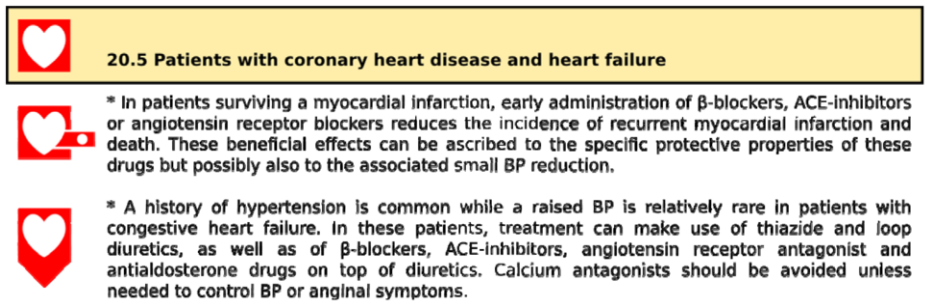

Figure 4 - An excerpt from the European Hypertension Guidelines 2007, tagged with icons inspired from the VCM iconic language. Icons tag the patient conditions addressed by the paragraphs.

courses. However, searching for medical documents is not easy, because the request can be complex and difficult to phrase. Additionally, the list of documents returned by the engine can be long, making it difficult to find the relevant documents, especially if the documents themselves are long, involving several topics like epidemiology, diagnosis, therapy... as it is often the case for guidelines.

Two different applications of VCM icons to facilitate the use of search engines were considered:

- Iconic interfaces could be used to help to formulate a query in a search engine, possibly using a "Mister-VCM"-like interface for choosing the icons on an anatomical and etiological basis. The use of icons eliminates language-related problems, such as synonymy, for example by using the same icon for angor and angina pectoris. However, since icons are not as precise as text, text may be required to refine the query.
- Icons can improve the list of documents resulting from the search. Documents in the list can be tagged by icons, according to their corresponding keywords. The use of a "Mister-VCM"-like diagram for this purpose would not be practical, as each document may involve many anatomic locations and etiologies.

In search engines, resources are indexed with various terminologies, for example MeSH (Medical Subject Headings) terms for CISMeF. Therefore, if these terminologies are mapped to VCM icons, icons could be easily associated with each resource.

Additional icons required for the new applications

In the previous section, we have described several new applications for the VCM iconic language. Given that VCM was initially developed for drug knowledge, some of these applications would require the language to be complemented with new icons, representing additional medical concepts. We have identified the following possible new icons:

- Icons for the different categories of health professionals. These icons could be used to identify the authors of documents attached to patient records. Existing anatomical pictograms could be reused to design icons that represent many different specialists, *e.g.* heart for cardiologists. Other health professionals, such as GPs, pharmacists, nurses,..., would require new pictograms, as well as would some other specialists, such as radiologists.
- Icons for representing document types. Two categories can be considered: documents attached to patient records, such as medical imaging document, post-operative reports or discharge summaries, and documents indexed in a search engine, including clinical guidelines, medical courses and patient leaflets. Within the second category of documents, it would be of interest to distinguish guidelines supported by national or local authorities, from foreign guidelines.
- Icons for representing social aspects of the patient, for example whether the patient lives alone or has low health literacy. These icons would be helpful in patient records, but could also be used in some clinical practice guidelines.
- Icons for diseases need to be extended, to incorporate additional elements representing the severity of the disease, or its evolution: aggravation, stabilization, improvement,... These icons could be used in clinical guidelines, since the recommendations given in guidelines are frequently dependent on the progression of the disease.

These new icons can be added to the VCM iconic language without modifying the existing icons and combinatory rules.

Discussion

In the results section, we have described seven applications for the VCM language, relating to patient records, guidelines and search engines. These new applications would use the already existent VCM icons for patient conditions, drug treatments,... and eventually new icons requiring a few additional elements to be incorporated into the VCM language. These elements must be added taking care that the language remains coherent. We considered new icons for distinguishing between different pharmaceutical classes, such as beta-blocking agents or angio-

tensin converting enzyme inhibitors for antihypertensive drugs, which may be useful for clinical practice guidelines. However, these new icons were not retained due to the limited empty space available on VCM drug class icons, and because pharmaceutical targets are difficult to represent by pictograms without adding textual abbreviations such as "ACE". The implementation of the new applications we described would be facilitated by mapping VCM icons to standard medical terminologies, which is an undergoing work.

These new applications for VCM need to be properly evaluated, possibly using a method similar to the one used to evaluate VCM application for drug knowledge. It would also be interesting to evaluate the successive use of VCM in various applications, such as in the following scenario: a physician searches for a guidelines document using a VCM-powered search engine, then views a VCM-annotated copy of this document, at the same time looking for information in a patient records featuring a "Mister VCM" summary. In particular, it would be important to determine whether the successive use of the same iconic language has a synergetic effect, or whether it is likely to cause confusion.

The use of icons has two main advantages over text (including short abbreviations, *e.g.* HbA1c for glycosylated haemoglobin): icons can be visually searched very quickly, and they are (at least partly) independent of native languages. However, icons may not be easily visualized for certain individuals, such as people with daltonism. Another inconvenient is that iconic languages such as VCM require a short training phase before being able to understand all icons of the language. For VCM, the learning phase is short, and was estimated to about four hours [2].

A few other uses of icons for presenting medical knowledge can be found in the literature, mostly for giving instructions to patients [6- 9], but also for helping medical students to understand physiopathology [10] or for summarizing the solubility and stability of injectable drugs for hospital pharmacists and nurses [11]. However, these icons are limited to the specific application they were designed for, and most of them are simple sets of pre-defined icons without compositional rules for creating new icons.

The new applications that we identified for VCM were focused on use by physician. Other applications could be identified for other groups of individuals, in particular medical students, pharmacists and nurses. However, VCM is probably not appropriate for patients. Indeed, the VCM language was designed taking into account the medical knowledge acquired by health professionals, especially anatomy, whereas patients have only limited knowledge in this domain [12].

In conclusion, iconic languages have many possible applications in medicine. In order to avoid health professionals having to learn several icon systems, and to prevent the potential confusion between icons developed for different applications, a single, coherent and standardized iconic language should be used across the various applications. In this paper, we have shown that, with the addition of a few new icons, VCM could be this iconic language.

Acknowledgments

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Building a Logical EHR architecture based on ISO 13606 standard and Semantic Web Technologies

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Abstract

Among the existing patterns of EHR interoperability, the ISO 13606 standard is an important consideration. It is believed that the use of this norm, in conjunction with semantic technologies, may aid in the construction of a robust architecture, keeping in mind the challenges of semantic interoperability. The objective of this paper is to present a proposal for an EHR architecture, based on ISO 13606 and on the utilization of semantic technologies, for a real EHR scenario. In order to accomplish that, a real EHR scenario is described, as well as its main interoperability requirements and a candidate architecture is proposed to solve the presented challenges of interoperability. The ability of the ISO 13606 EHR reference model to accommodate the scenario was highlighted, together with the support provided by the use of the ontology specification languages – RDF and OWL – in respect to the maintenance of a controlled vocabulary.

Keywords:

Electronic Health Records, Semantic Interoperability, ISO 13606 standard, Two-level Modelling, Archetypes, EHR Service Architecture

Introduction

The issue of interoperability between EHR systems has become, in recent years, a theme of great relevance for the international clinical and informatics communities. The realization that the construction of an integrated EHR system will always involve, at some level, interoperation between different systems, underlines the relevance of interoperability patterns and of semantic technologies in the current context.

In order to understand this assertion, let us consider the creation of an integrated EHR service for a city, state or country. Although it is possible to develop a single EHR system, which fulfills the needs of every health institution in a city, this system will need to be integrated with those of other cities, which will then form the EHR service at the state or regional level. Likewise, it is possible to have a single EHR system for a given state, that will in turn be integrated to those of other states, in order to obtain as EHR service for the country. The same reasoning applies in the case of the obtainment of an EHR service in a global scale.

In this paper the name Logical EHR is given to this arrangement of different EHR systems capable of interoperating so as to offer an integrated service, preserving the existing semantics in the knowledge domain, updating clinical data for every patient in a consistent way, rather than ambiguously, all in accordance with the legal ethical regulations and obligations, following the safety and confidentiality patterns of information. The basic premises for the creation of a Logical EHR are the existence of interoperability patterns and the utilization of semantic technologies.

An example interoperability pattern, which may enable the creation of a logical EHR, is the ISO 13606 standard. It is an international standard published by ISO that specifies the information models and vocabularies needed for the interoperability of EHR systems. Initially developed by the European Committee for Standardization (CEN), with the denomination EN 13606 (*Electronic Health Record Communication*), and is a subset of the architecture proposed by the *openEHR*[1] Foundation [8][9][5]. In summary, it proposes a model of EHR statements that represents the complete or partial information of a patient's health record, extracted from an EHR system, for the purpose of communication to another EHR system or other requesting system.

Concerning semantic technologies, one might observe that, although the Internet offers sufficient flexibility and space in terms of connectivity for reaching interoperability, the techniques traditionally used for integration and interoperability at the application level involve only the use of data exchange formats whose success in terms of semantic has not been very significant. However, the use of semantic technologies in order to facilitate the integration and interoperability of EHR systems may bring significant benefits [4].

[1] The *openEHR* approach is a comprehensive open specifications for EHR systems originally based on the results of the European Union's GEHR-Project in the early 1990s http://www.openehr.org

This paper aims at presenting a proposal for an EHR architecture, based on the ISO 13606 standard and on the utilization of semantic technologies, for a real EHR scenario.

ISO 13606 standard

The ISO 13606 standard was developed by the Technical Committee ISO/TC 215, Health Informatics, and conceived from practical experience obtained during the implementation of the European precursor pre-standard, ENV 13606. It is a subset of the reference model proposed by *openEHR*. Based on the two-level modeling approach, it defines an information architecture to communicate part or the entire electronic health record of a given patient: preserving the original clinical meaning intended by the author; and reflecting the confidentiality of each data as intended by both author and patient [8].

The *two-level modelling* approach is based on the separation of knowledge and information levels in information systems [1][2]. The Information level represented by the reference model that are statements which apply to all entities of a class [1].The Knowledge level is represented by clinical archetypes that are statements about specific entities.

The reference model represents the global characteristics of components of an EHR, how they are assembled, and the information context required to meet the ethical, legal and originality requirements. It defines the following containers: *EHR_Extract* – the electronic health Record for one person; *Folder* – high-level organization of the EHR; *Composition* – Clinical care session, encounter or document; *Section* – clinical headings reflecting the workflow and consultation process; *Entry* – Clinical "statements" about observations, evaluations, etc; *Cluster* – Nested multi-part data structures; *Element* – Leaf nodes with single data values.

This reference model is complemented by clinical data structure definitions, known as archetypes, which represent the clinical concepts agreed upon within a community, with the objective of guaranteeing interoperability, consistency and data quality. An archetype is a formal definition of prescribed combinations of basic classes in the reference model for a specific clinical domain or for organizations, expressed in the form of data restriction. In the ISO 13606 standard they are defined in Part 2, supported by Part 1 but not mandatory [7].

The following may be quoted as benefits of the use of archetypes [6].

- Enable the formal definition of clinical content by domain experts without the need for technical understanding;
- Preserve the meaning of data by explicitly specified and well structured clinical content;
- Can safely evolve and thus deal with ever-changing health knowledge using a two-level approach;
- Can simplify the use of clinical terminologies.

Definitively the ISO 13606 contributes to the Logical EHR approach, as we can see at the Figure 1.

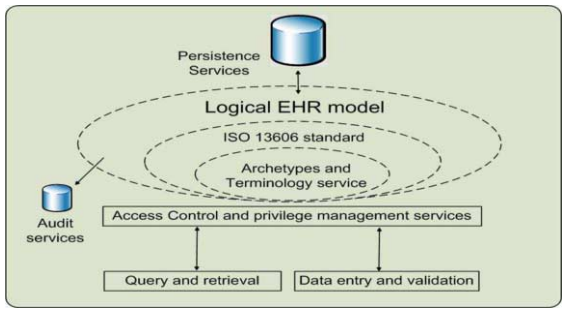

Figure 1 – Logical EHR architectural components

Semantic Technologies

"The Semantic Web is an extension of the current web in which information is given well-defined meaning, better enabling computers and people to work in cooperation"[12].

The initiatives in the field of Semantic Web establish a set of protocols and technologies which promise to improve data categorization and association through an increase in the ability to create relationships and to generate inferences between systems and data. Adding intelligence to the traditional services offered by the web – based on Service Oriented Architecture (SOA) – and make stored data accessible by a set of semantic technologies [13].

In a typical interoperability scenario based on the SOA architecture, systems interact via Web Services using XML and SOAP messages on top of an HTTP network protocol [11]. The challenge of this architecture is to enable heterogeneous web applications, written in different platforms, to be integrated, exchanging data in a user-transparent way. This approach handles messages in an efficient way, but it does not consider the compatibility of the vocabulary being used and does not guarantee that the message recipient is able to comprehend its content [13]. This difficulty has led to W3C's[2] efforts to incorporate semantic technologies as part of its Semantic Web Services initiative.

Two W3C specifications are highlighted on the Semantic Technologies: Resource Description Framework (RDF) and Ontology Web Language (OWL). The RDF provides a framework to establish relationships among data elements, and the OWL improves the RDF with an ability to make constraints on different data elements and their relations with others. RDF and OWL can operate together depending on the scenario. Another important W3C specification is the Web Ontology Language Service specification (OWL-S) that provides a flexible framework for describing and initiating web services [13].

[2] World Wide Web Consortium – http://www.w3c.org

Materials and Methods

This study was carried out at the Department of Health for the State of Minas Gerais (SES-MG[3]), specifically within the scope of the electronic records of the Family Health Program. The Project was begun in the last quarter of 2008 and the main development phase to continue to 2011. Based on the results of grade tests which took place previously [10], the ISO 13606 standard was used as a starting point for the construction of the EHR statements and modeling of the archetypes for the central repository. The proposed architecture was developed from the direct participation of the author in the technical team of SES-MG and PRODEMGE and it was officially accepted in August 2009.

Firstly, the analysis of requirements for interoperability for the EHR project was performed. These were identified by means of brainstorm meetings and specific interviews involving the clinical team at the SES-MG – composed of ten members – at least fifteen technical visits to the health units in the state and research of previous projects and inside documents. These activities were undertaken in the initial 6 months of the project. At the same time, three members of the clinical team ran workshops with the clinical area participants of SES-MG in order to identify the data elements that should be part of the Patient Clinical Summary. After the architecture's approval, the archetype modeling process commenced. The archetypes were developed with the help of editor *linkEHR*[4] and the terminologies to be part of the terminology service were identified while modeling each of the archetypes.

Through an analysis of interoperability requirements and research on the utilization of semantic technologies for the creation of a terminology service, it was possible to elaborate the candidate architecture presented here.

Electronic Health Record Scenario

The Department of Health for the State of Minas Gerais, interested in the benefits brought about by the use of integrated clinical information, intends to create a state-wide EHR repository, with the objective of consolidating each citizen's demographic data and clinical summary. Initially the scope of the project will include only primary care centers in the Family Health Program. However, the objective of the government is to create the foundation for the inclusion of secondary and tertiary care units in the EHR repository.

The State of Minas Gerais is the largest in the country in number of cities, totaling, according to the Brazilian Institute of Geography and Statistics (IBGE[5]), 853 cities. For delivering primary care services, the State has over 5000 health units distributed among its cities, according to information from the SES-MG. The government's proposal is not to develop a single EHR system for the State to be imposed on the cities, conversely, it is to create macroregions and deploy EHR system contracted from the market to service each one. The solution is based on the creation of a central repository and on the creation of a message infra-structure aiming at the interoperability of the EHR systems to be contracted. The repository shall contain the demographic data and a clinical summary of the patients, necessary to support to the Family Health Program.

Each of the afore mentioned macroregions, composed of several health units, will use its own choice of EHR system and will have its own datacenter. The architecture must clearly establish the rules of data exchange so that the solutions access and provide data updates to the central repository, as well as prioritize the utilization of a controlled vocabulary.

Interoperability requirements

As a result from the data survey done with members of the SES-MG, a series of interoperability requirements were identified. A summary of the key requirements is outlined below.

A set of general requirements:

- The central repository should centralize the demographic data and each patient's clinical summary ;
- The EHR systems should feed the central repository and not interoperate directly with each other – EHR system integration should always occur via the central repository;
- Every time clinical data is recorded in the EHR system, the central repository should be updated;
- Before a patient is entered in the EHR system, the central repository should be checked. If the citizen already exists in the central repository, the centrally-held data should be copied to the requesting EHR system.

A set of specific requirements for the central repository:

- It should allow for the structuring of its data elements through a standardised reference model and archetypes;
- It should provide a mechanism which enables the recording and retrieval of each patient's clinical information;
- It should provide a mechanism which enables the recording and retrieval of each patient's demographic information;
- It should provide the EHR system with an authentication mechanism for the identification of the system and its operators;
- It should provide a repository of terminology services, which would serve as basis for the creation of the common vocabulary for the exchange of information with the EHR systems;
- It should provide auditing and reporting services.

[3] Department of Health for the State of Minas Gerais http://www.saude.mg.gov.br

[4] LinkEHR was developed by the Biomedical Informatics Group at the Technical University of Valencia, Spain. http://www.linkEHR.com

[5] Brazilian Institute of Geography and Statistics http://www.ibge.gov.br

Set of requirements for each EHR system:

- It should implement mechanisms for clinical and demographic data exchange with the central repository;
- It should implement mechanisms for the authentication and data security to ensure the data communication with the central repository;
- It should be able to exchange data with the central repository according to the terminology predicted by the terminology service;
- It should be able to exchange data with the central repository, respecting the restrictions defined by the archetypes, which represent the data elements from the central repository;
- It should be able to supply information for audits of any nature.

These requirements served as the basis for the design of the central repository and established key elements for the construction of the service architecture presented below.

EHR Services Architecture

The proposed architecture uses archetypes for the representation of its data elements and was designed with four basic services: clinical data services, demographic data services, archetype services and terminology services. See Figure 2.

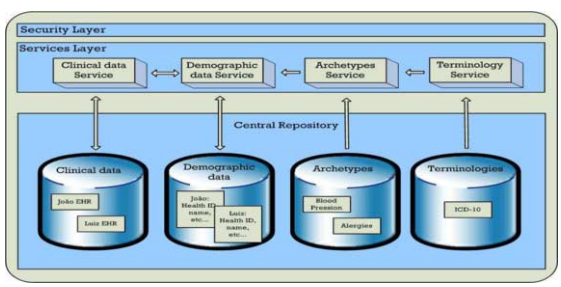

Figure 2 – EHR Services Architecture

Demographic data services are divided into: Demographic data inclusion service, alteration of demographic data service, user deactivation service, service of user consultation by code and service of user consultation with parameters. The Brazilian government has a published standard for sending and receiving data from the national health card. It was decided to utilize this standard, which is based on the utilization of Web Services, for exchanging messages in XML language.

The clinical data services were designed considering the utilization of EHR statements constructed from the reference model of the ISO 13606 standard and *datatypes* specified by the CEN/TS 14796 [3]. Two services were proposed: one for sending data to the central repository and another for enabling the retrieval of data from the central repository.

For sending data to the central repository, the EHR systems will have daily to generate the clinical statements (within *Compositions)* which took place for each patient at the health units, and update the central repository overnight. For that, they will have to consult the archetype structure through the archetype service available, and research the *Sections, Entries* and *Cluster/Elements* that will make up each *Composition.* For the update of the central repository, the statements shall be compacted according to a compacting algorithm yet to be established, and sent via FTP protocol. Since the architecture specifies the utilization of a repository with EHR version control, every time there is a correction or deletion in the clinical data, the EHR system shall send an update statement with the altered data, according to standard established by the ISO 13606 standard.

With regard to the retrieval of clinical data, this will only occur whenever a patient moves from one macroregion to another, or when the EHR system needs, for whatever reason, to update its local database. For that, the EHR system shall send a request to the central repository, and receive an XML file online with the current version of the Patient Clinical Summary (within a *Composition*). For this reason the architecture includes the design of two clinical databases: Patient Clinical Summary database and Clinical History database. The archetypes will include the rules to keep the each data element up to date at the Patient Clinical Summary database. Keeping these databases it will be possible also retrieve all *Compositions* of a Patient from the Clinical History database if it is required. In both cases, because of the version control process, only the most recent version of each object will be considered (if there have been corrections made to an original version).

The terminology service was designed to make it possible that all of the vocabulary content to be used by the EHR systems for integration with the central repository is made available through a unified source. Terminology such as ICD-10, procedure tables, medications, laboratory exams and terminology internal to the SES/MG will be available. The idea is to facilitate access to the terminology by the EHR system, promoting the development of the Logical EHR environment expected by the State. Furthermore, whenever the central repository receives EHR statements from the EHR software, there will be the need to perform syntax and semantic validations on the statement. Within this context, the use of semantic technologies, through the encoding of terminology in ontology representation languages such as RDF(s) and OWL will be a point of great relevance for the project. All terminology will be made available through the same service.

The archetype service was designed to make it possible for contracted EHR systems to request the versions of published archetypes. This is a critical point, for it will enable the gradual publication of new versions of archetypes, facilitating the deployment of the central repository in its initial phase. It will also facilitate the implementation of concepts which will be used later for other health care settings such as public hospitals.

Discussion

The utilization of a unified terminology server, based on the use of semantic technology, in conjunction with the single reference model published by the ISO 13606 standard will enable the establishment of a Logical EHR for the State. But that the work undertaken to date has shown that the architecture alone would not be sufficient to guarantee that the semantics present in the knowledge domain be, in fact, homogeneous. There will be the need for introduction of descriptive terminologies (e.g. SNOMED[6]) and monitoring on the part of the State's clinical team, in terms of audits focusing on the quality of information recorded in the central repository.

Despite the fact that the central repository is based on a reference model and on archetypes - which will allow for a robust and yet adaptable setting for the establishment of a Logical EHR environment and greater flexibility for the introduction of new concepts in the repository - the architecture needs to anticipate the participation of EHR systems that do not use the archetype approach. The EHR system need to, at least, be able to:

- identify the restrictions to which each data element must be submitted, through formal representation in ADL;
- create and interpret messages in XML according to the pattern presented by ISO 13606;
- validate the data elements to be sent to the central repository using the terminology service, by means of RDF and OWL schemes.

It is believed that the frequency of publication of new archetype versions by the SES-MG might be able to sparkle the interest of software suppliers in automatically interpreting the formal specifications predicted in the archetypes. This way, they might be able to obtain a cost reduction in the process of updating new clinical concepts and the terminology adoption in their EHR system.

Conclusion

This paper has made evident the importance of the Logical EHR concept, since the scenario of EHR systems utilization normally involves the integration between different software applications. It was possible to observe the adjustment of the two-level modeling approach, which was the basis for the construction of the proposed architecture, regarding the level of information represented by the reference model, as well as the level of knowledge represented by the archetypes. These allowed for the mapping of all the data elements that constitute the central repository and provided a greater flexibility to the proposed architecture. From the terminologies point of view, the semantics technologies propitiated a favorable setting for the use of a controlled vocabulary, increasing the chances of preserving the semantics of the knowledge domain. It was verified that the reference model for the ISO 13606 standard was appropriate for fulfilling the requirements of interoperability of the case researched, and its statement (*Entry*) model was enough to fulfill the EHR specificities of a Brazilian State. Furthermore, it allowed the participation of EHR systems that do not use the archetype approach.

[6] SNOMED CT (Systematized Nomenclature of Medicine-Clinical Terms) http://www.ihtsdo.org/snomed-ct/

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Chapter 3.

Clinical Information Systems

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Case Study: Analysis of End-User Requests on Electronic Medical Record and Computerized Physician Order Entry System of Seoul National University Hospital in Korea

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Abstract

Seoul National University Hospital (SNUH) in Korea has utilized the full Electronic Medical Record (EMR) system since October 2004. Unlike other countries, most EMR systems in Korean teaching and general hospitals are in-house development systems. Therefore, we can actively respond to user requests on EMR. Here, based on 5 years of experience in EMR system operation, we analyzed 2,339 SNUH EMR user requests from 2006 to 2008 for improvement of EMR system operation and management. We classify user requests into 9 criteria based on guidelines from the SNUH medical information management team. In conclusion, the most common requests (73 %) are for improvement of improving quality of care. However, requests associated with hospital enterprise, public policy, and customer service are gradually increased every year. Therefore, we suggest that suitable EMR management criteria are necessary for reliable EMR operation and management.

Keywords:

Computerized patient record, Computerized physician order entry, Management information systems

Introduction

Seoul National University Hospital (SNUH) is the first modern hospital in Korea since 1885. It now has 1,754 beds, with 563,712 inpatients and 1,850,473 outpatients per year. As one of Korea's largest teaching and general hospitals, SNUH received the Korea Brand Power Index Award for 9 consecutive years [1] and was ranked first in the 2004 National Hospital Evaluation Program by the Korean Ministry for Health and Welfare. SNUH is also the first hospital in Korea to adopt an electronic medical record (EMR) system in all hospital units. The computerized physician order entry (CPOE) system was launched in 1999, and the EMR system in 2004. Representative goals of EMR and CPOE in SNUH include saving space and time, integrating management of medical information, improving quality of medical records, supporting diverse data formats, data recombination, clinical decision support, information exchange among medical persons or hospitals, and better communication. Consequently, SNUH is able to obtain significant outcomes using the EMR system [2], these include qualified medical products, prominent clinical research results, excellent medical evaluation rating, and good education guidance.

Active acceptance & application of end-user requests can result in achievement of these outcomes. 'End-user request' means requirements based on direct needs of medical and nursing users' on EMR. The requests can be actualized by EMR programming(including changing, improving, editing or supporting, etc.). Since most EMR and CPOE systems in Korea's teaching and general hospitals are in-house development systems, we can easily respond to user requests and implement them into the hospital information system (HIS). Besides the characteristics of system development, the reason that we actively collect end-user requests is to promote EMR ownership and participation. Adoption of the CPOE was relatively easy, due to its diverse and attractive merits. However, since SNUH has a long history of paper medical records, many hospital personnel were reluctant to use electronic medical records, in spite of the advantages of such as system.

In order to collect and reflect end-user requests, we set 'user-friendly' policy as a major HIS management policy at SNUH. 'User friendly' policy means that anyone who uses EMR or CPOE can meet his or her own requirements through diverse routes. In detail, there are three steps. The first step is to open diverse channels for acceptance of user requests, i.e. telephone call, bulletin boards, e-mail, and so on. This is important for encouraging active user participation. The second step is active and positive acceptance after discussion of requests through EMR system board members and end-users. At SNUH, the EMR system board member is composed of doctors, nurses, IT specialists, and programmers. The last step is suitable coordination. The EMR and CPOE systems are very complicated and are interconnected to each EMR program component. Therefore, the process of coordination with program developers and medical personnel is essential.

In this paper, we analyzed end-user requests for the three previous years for review in our study of 'user-friendly' policy. Based on 11 years of experience with the CPOE system and 5

years with the EMR system, we can propose a promising method for operation and implementation of a good quality HIS.

Materials and Methods

SNUH launched its CPOE system in October 1999 and its EMR system in October 2004. SNUH improved its CPOE and EMR systems with two major upgrades in 2005 and 2006.

We first collected SNUH end-user requests from 2006 to 2008, including requests for a second major upgrade in 2006 [3]. Unfortunately, no data on end-user requests was documented before 2006. The total number of requests for the previous three years was 2,339. We then classified the collected requests into 9 categories, which were defined by the SNUH medical information operation team on the authority of practical & political demands in SNUH. The categories are shown in Table 1. Detailed subcategories of each category are also shown in the table.

Table 1- Categories for EMR users' requests

Category	Sub-categories
Improving Quality of Care	Medical process optimization
	Newly established department
	Medical persons communication
	Program management
	Decision support
	Authority
	Device interface
Evaluation of Clinical Quality	Clinical quality index
	Hospital accreditation process
Service for Customer	Patient information privacy
	Patient safety
Government Regulation	National health insurance regulation change
	National health management policy change
Hospital Enterprise	Hospital process innovation
	Quality assurance
Statistics	Statistics of operation, admission, and discharge
Education	System for medical students
	Updating manuals
Clinical Research	EMR modification for clinical research supports
Miscellany	

Analysis Results

Table 2 summarizes user requests. The most frequent request category is "Improving Quality of Care," with a proportion of 73%. We can easily understand this result, since one of the most important purposes of using the EMR and CPOE systems is improvement of the quality of clinical care. The categories include "Evaluation of Clinical Quality" (12%), "Service for Customers" (5%), "Government Regulation" (4%), and "Hospital Enterprise" (1%). In 2007, the number of requests increased rapidly (from 540 to 913, 69.1%) due to nation-wide hospital accreditation in Korea, which is performed every three years. Therefore, the "Evaluation of Clinical Quality" category increased almost 1,000%. This rapid increase also confirms the importance of the EMR and CPOE systems in hospital management and operation.

Another interesting development is that as system end-users become accustomed to using the EMR system, they make more requests. The total number of requests in 2008 increased 64% compared to 2006. When we investigated user requests in detail, recent requests focus on more specific clinical purposes, rather than general bug fix requests. This means hospital personnel have begun to depend on the EMR or CPOE systems in their routine work.

Table 2- User requests on SNUH EMR

Category	2006	2007	2008	Total
Improving Quality of Care	466	572	674	1712
Evaluation of Clinical Quality	20	222	36	278
Service for Customer	24	27	72	123
Government Regulation	3	35	51	89
Hospital Enterprise	15	29	31	75
Statistics	2	10	9	21
Education	1	2	6	9
Clinical Research	1	6	0	7
Miscellany	8	10	7	25
Total	540	913	886	2339

As shown in Tables 2 and 3, the noticeable categories are "Government Regulation" and "Service for Customer." In government regulation, even though the number of requests is small, any request associated with this category is very complicated. For example, the Korean government pushed hospitals to integrate the real-time drug utilization review (DUR) system into their systems. The adaptation rate of electronic health records in US general hospital is very low [4]; however, the rate in Korea is relatively high [5] and has increased rapidly since 2004. Recently, most Korean general hospitals have

used EMR systems. In contrast to other countries, Korea has only one national health insurance agency, known as the National Health Insurance Corporation. Within this environment, the Korean government has begun to control hospital EMR or CPOE systems in order to promote public health.

Customer service is also important. As in Table 3, this category is almost 100% increased in its ratio (from 4.44% to 8.13%). This implies that EMR is an important tool for increasing the quality of patient service; SNUH is actively trying to utilize the EMR and CPOE systems in this category.

Table 3- Ratio of each EMR user requests category

Category	2006	2007	2008
Improving Quality of Care	86.30%	62.50%	76.07%
Evaluation of Clinical Quality	3.70%	24.32%	4.06%
Service for Customer	4.44%	2.96%	8.13%
Government Regulation	0.56%	3.83%	5.76%
Hospital Enterprise	2.78%	3.18%	3.50%
Statistics	0.37%	1.10%	1.02%
Education	0.19%	0.22%	0.68%
Clinical Research	0.19%	0.66%	0.00%
Miscellany	1.48%	1.10%	0.79%

Although the 'Improving quality of care' category has decreased in its proportion from 86.30% in 2006 to 76.07% in 2008, the number of requests has still increased from 466 in 2006 to 674 in 2008. This means that users have required much more diverse functionality from the EMR system by taking notice of its convenience and practicality, even though the EMR system is improved by reflection of every request.

A 2008 Survey of the HIMSS (Healthcare Information and Management Systems Society) shows results similar to those in Tables 2 and 3 [6]. Figure 8 of [6] shows "Improving Quality of Care," which increased from 56% in 2007 to 69% in 2008 and "Patient (Customer) Satisfaction," which increased from 36% to 55%. Our results show the same trends as mentioned above. Notice that results from the HIMSS survey of the "top business issues facing healthcare" are derived from CIOs or IT managers; however, our results are obtained from end-users. This implies that medical personnel, including doctors and nurses have begun to notice the importance of IT systems in healthcare.

However, there is a pitfall of 'user friendly' policy. Table 4 shows the number of medical user requests, accepted requests, requests implemented on EMR, and requests in progress. The "Accepted requests" category refers to requests approved by EMR board members; "implemented requests" refer to requests implemented on the EMR or CPOE system; "under development" refers to requests still under development after being accepted; and "withdrawal" represents requests that are withdrawn after being accepted.

Table 4- Summary of practically implemented user requests in the case of medical part

	2006	2007	2008
Total Requests(in medical part)	286	783	688
Accepted Requests	143	391	323
Implemented Requests	93	292	214
Under development Requests	48	98	109
Withdrawn Requests	2	29	42
Under development/ Accepted(%)	33.6	25	33.7
Withdrawn/ Total(%)	0.6	3.7	6.1

As in Table 4, the number of requests still in progress has increased. By trying to accept all possible user requests, users begin to rush very individual demands onto the EMR or CPOE system. In addition, users become accustomed to the system; therefore, requests become more complicated and interconnected to other programs. In some cases, users make contradictory requests, due to conflicting interests; or make requests that require a change in the business process. These problems cannot be solved by EMR board members, so increment of withdrawn ratio should be happened.

Since IT resources are limited, it is difficult to implement all accepted requests in time. As in Table 4, the ratio of underdeveloped requests is about 25~34%. This situation(slow implementation of user requests) causes user dissatisfaction. Therefore, IT managers should try to catch essential requests and prioritize them, furthermore, control programmers for building the accepted requests in time.

Discussion

Since implementation of the EMR system at SNUH as the first trial among major Korean teaching and general hospitals, there have been many concerns regarding adoption and implementation of EMR. Therefore, we have chosen a 'user-friendly' policy in order to improve user participation.

Fortunately, results of our analysis confirm that our 'user-friendly' policy is one of the key elements of success in adoption of the HIS system. End-users make more frequent requests as they get used to the system. The total number of requests in 2008 increased 64% compared to 2006; and users made 3.5 requests per business day in 2008. End-users have recently shown a desire to use the EMR and CPOE systems for improving customer service, as well as quality of clinical care. The board of hospital directors has begun to use the EMR and CPOE systems for management of hospital enterprises, including process innovation or simple financial statistics. Moreover, the government has noticed that HIS can be a useful tool for improving public health. In conclusion, EMR and CPOE system must be an essential tool for improvement of the quality of care.

However, 'user-friendly' policy brings other problems. For example, the complexity of the system has increased and the speed of the system has slowed down. Therefore, a balance must be established between 'user-friendly' policy and limited resources.

We must mention that the EMR and CPOE systems at SNUH are in-house development systems. SNUH also has an IT team that includes programmers. Therefore, we can actively collect end-user requests and implement the accepted ones on our HIS system. This can mean a significant difference between the SNUH system and those of other countries. It might be a key element for our successful EMR implementation.

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Does CPOE Actually Disrupt Physicians-Nurses Communications?

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Abstract

This study addresses the question of the respective impact of organizational vs. technical environment variables on the collaborative aspects of healthcare work situations. It analyzes the physicians-nurses communications during the medication use process, according to both the organization of their work and their technical environment. Participant observations, interviews and recording of the dialogs were performed in 4 hospitals functioning with either a CPOE or a Paper based system. The study (i) presents the identification and description of the communications' processes involving doctors-nurses face-to-face communications and the supports that mediate medication information and (ii) focuses on the amount of face-to-face communications depending on the organization of work and the technical system used. The analyses demonstrate that the organizational variables have a larger impact than the technical environment on the quality and quantity of the communications and cooperation activities.

Keywords:

Communication, Medical order entry system, Human activities, Work

Introduction

In many safety critical environments, technical automated systems prove efficient to reduce and prevent errors. In the healthcare domain, the medication use process has been extensively studied under the safety point of view and a huge amount of efforts has been made to support the implementation and adoption of Computerized Physician Order Entry (CPOE) systems to prevent medication errors [1]. Indeed, successfully implemented CPOEs prove efficient to achieve a significant reduction of Adverse Drug Events (ADE) [2]. However, sociotechnical or human factors qualitative studies repeatedly uncover unexpected and unintended negative effects of CPOE systems [3].

In the hospital setting, the work situations are inherently collaborative. The care of patients inevitably involves many different professionals, all needing to share patient information and discuss their management. The medication use process may be characterized as a complex distributed work situation: rather than existing in the mind of any particular individual, the cognition is distributed across the minds of the members of the clinical team and across physical media [4]. In this context, the critical role of doctors-nurses face-to-face communications has been largely demonstrated [5-6]. The professionals actually prefer direct communications for gathering information, more particularly about the medications which is the category of information most frequently sought by the professionals [7]. Moreover, the role of poor communication in generating avoidable error and poor outcomes is now widely discussed [8]. Since the responsibility of doctors and nurses are complementary rather than overlapping, a complete, coherent, and updated knowledge of the patient status requires a direct two-way information flow among team partners.

Some studies have focused on the impact of the implementation of CPOE applications on communications. Enthusiastic implementations of new technologies do not always have the consequences expected of them: most of the studies find that the technical system deteriorates the communication and cooperation activities [9]. This is in part because human communication processes are shaped into a form dictated by the technological system. There are essential differences between what happens in an informal conversation and what happens in a formal information system transaction [10]. But above all, there is a large number of factors that might influence communication behaviors, including the nature of available communication infrastructure, the nature of the work undertaken and the practices that are routinely applied within the organization. The technical environment might not be the most important determinant of the quality of professionals' communications. Doctor-Nurse cooperation and communications are also governed by the organization of their work.

The present study aims at highlighting the critical role of the organizational factors when implementing a CPOE application in the work situations. It analyzes the doctors-nurses communications during the medication prescribing-administration

process, according to both the organization of their work and their technical environment, CPOE vs. Paper. The study (i) presents the identification and description of the communications' processes involving doctors-nurses face-to-face communications and the supports that mediate medication information and (ii) focuses on the amount of face-to-face communications depending on the organization of work and the technical system used.

Context of the study

Sites of the Study

A paper-based situation study was undertaken in a 3000-bed capacity hospital referred to as H1, in three wards: Cardiology, Nephrology and Neurosurgery.

The CPOE situation study was undertaken in two different hospitals running the same IT system:

- a 550-bed hospital, H2 which had been running the CPOE for three years. The analyses were realized in two medical departments: cardiology / gastroenterology and infectious diseases,
- a 825-bed capacity academic hospital, H3 which had also installed the CPOE. The study took place in two pilot sites, the nephrology and immunology wards where the system had been in use for about 6 months.

Overview of the Medication Use Process in the European hospitals

According to national and local regulations, the tasks necessary to carry out the medication ordering and administration procedures are distributed across the physicians, the pharmacists and the nurses. All the physicians attend all the patients and so do the nurses and pharmacists. The physician is in charge of the therapeutic decision making and of ordering the meds. The nurse is not supposed to copy the physician's orders on any support except to validate the administration. She/he has to control the meds before administering them to the patient; she/he must validate the administration and eventually document any unexpected event. The pharmacist is in charge of controlling the prescription and of delivering the medications to the medical unit.

It must be noted that in the vast majority of European hospitals, unit-dose dispensing is limited to a small proportion of drugs. The products are globally dispensed in the wards (drugs for several patients and for several days), the nurses being in charge of storing them in the ward medications' locker. The nominative dispensing (drugs for a given patient for a given period of 24h to several days) has a particular organization with direct delivery of the medications to the nurses in the ward for the involved patient. These organizations of the dispensing necessitate a preparation phase from ward stock before the actual administration to patients. Nurses are in charge of this preparation.

We will describe in this paper some universal characteristics of the organisation for oral route meds and standard schedules.

Description of the two systems (paper-based and CPOE)

In the hospital setting, the therapeutic decision making and ordering tasks take mainly place during the medical rounds, where the physicians visit all the patients of the ward. With the paper-based system (H1), doctors perform the medical round using a wheel cart with the patients' medical files underneath. They write their medication orders on the medical orders' list which is structured with 3 columns dedicated respectively to the entry of the date of the order, its content, and the signature of the provider. Only new prescriptions or prescription changes are entered at each visit at the patient bedside. Nurses then organize the administration of oral routes medications. It is structured by the preparation of pill dispensers usually covering a 24 hours period. At some point in the 24 hours period (night shift, morning, evening), a nurse prepares the pill dispensers for all the patients of the ward. To perform it, the nurse can rely on the information contained in each patient's medication orders' list. She/he translates the prescription into suitable administration times and dosage forms according to their knowledge and the ward routines. During the 24h period covered by the pill dispensers, the physicians visit the patients and place new orders or modify the existing patients' treatments. These modifications require an update of the corresponding pill dispensers by the nurse. This update is executed as soon as the nurse gets a modified medication orders list. The pill dispensers may be stacked on a wheel cart or on a fixed support. Nurses perform "administration rounds" using the wheel cart with the pill dispensers on top and the patients' medical files underneath. During these rounds, the nurse administers the meds to the patient, validates the administration on the MAR (Medication Administration Record), and eventually documents any abnormality. This MAR presents the treatments on a summarized way with a temporal axis which permits to obtain, at a glance, a global, summarized view of the patients' current medication.

In the CPOE situations (H2 and H3) , a laptop on a wheel cart supports physicians order entry at bedside. The CPOE functions require two main screens to enter medication orders. Using the first one, the physician selects the proper drug. With the second one, the physician specifies the dosage. He has to enter the duration, the frequency and either a precise schedule or a global schedule (*e.g.* morning-noon-evening). The system then automatically updates the planning table and sets the specific timing for the administration depending on the organization of the ward (*i.e*. 7 am., 12 am., 6 pm.). For the display of the treatment, doctors get one screen which comes out in the form of a list of detailed orders structured with 5 columns dedicated respectively to the type of meds (oral route or injection), its detailed content, the date the administration should start and the date it should stop, and finally the status of the prescription (current, stopped or suspended). The orders and their exact time for administration appear on the nurses' care plan. As for the paper MAR, the treatments are summarized with a temporal axis which permits to obtain, at a glance, a global view of the patients' current medication. The modalities of the preparation are similar to the paper-based situations. The pill dispensers may be stacked on a wheel cart or on a

fixed support close by the laptop. If the administered drug is different from the prescribed drug, they have to document a "memo", *i.e.* a note for doctors which appears in the form of an exclamation mark in the doctors' screen.

Materials and Methods

HFE Methods

Five observers trained in naturalistic observation in complex settings conducted the observations. A first qualitative analysis of the medication ordering - administration process was undertaken. Naturalistic observation supported by handwritten time-stamped detailed field notes focused on (i) doctors-nurses' face-to-face communications about medication and (ii) interactions with the medication supports (MAR and Orders' List / paper-based and computerized). Interviews were performed with professionals to ensure a good understanding of the events and to eventually complete missing data.

In a second step, quantitative data were collected in the hospitals H1 and H2. For each ward, eight observations have been undertaken. Each observation period started with the arrival of the prescribing physician in the ward and ended with the administration of the meds to the patients. During each period, all the doctors-nurses communications about the care-providing for the inpatients were audio-taped.

Results

Face-to-face communications

The analysis amounted to 55 observations (lasting 3 to 8 hours) and 44 interviews. The observations highlight three main organizations of the doctors-nurses face-to-face communications (Table 1), thus whatever the system (CPOE or paper-based); organizations spontaneously described in the interviews by professionals.

1. The Common Round organization (CR): In the common round organization, the nurses' activities are organized so that they can participate systematically with physician to the medical rounds (one nurse or several nurses). Considering the entire prescription-administration process, the physicians-nurses face-to-face communications occur mainly during this dedicated time of the medical round. There are a two-way communications between physicians and nurses. Physician very often comment aloud their reasoning and therapeutic decision. Nurses summarize the patient's case, provide relevant information to the physicians and, sometimes, participate in the decision when they make suggestions for therapeutic changes. The very rare dialogs off the medical rounds happen only when there are unexpected changes in the situation, *e.g.* in the patient's status.

Table 1 – Percentages of the duration of doctors-nurses face-to-face communications per ward according to the communications' organization (Common Round, Briefing, Opportunistic Exchange) and the system (CPOE, paper-based).

			Scheduled		OE
			CR	B	
CPOE	H2	Card./Gastroent.	92 %	0%	8%
		Infectious disease	0%	89%	11%
	H3	Nephrology	0%	0%	100%
		Immunology	0%	0%	100%
Paper-based	H1	Neurosurgery	98 %	0%	2%
		Nephrology	0%	81%	19%
		Cardiology	0%	0%	100%

2. In the briefing organization (B), dedicated time slots are scheduled before and/or after the medical rounds where physicians and nurses participate in short daily meetings. These briefings are regularly planned at the same time so that doctors and nurses, or the extended clinical staff, can organize their activities to participate. All the patients' cases of the department are reviewed so that physicians and nurses are mutually aware of the patient's case and its evolution. The dialogs may influence the next decision making of the physicians during the medical round. Most often the briefings occur before the medical round and sometimes after, when physicians need notifying new therapeutic changes that have not been addressed during the first briefing. During the prescription-administration process, the doctors-nurses dialogs take mainly place during these dedicated times. During these two-way direct communications, nurses summarize the patient's case and physicians may comment. A few dialogs occur outside the briefing, *e.g.* when a change in the situation occurs (unexpected results, unexpected evolution in the patient's status, etc.).

3. In the opportunistic exchanges organization (OE) no dedicated time slot for physicians-nurses face-to-face communications is scheduled. Therefore, some brief dialogs occur sporadically when physicians or nurses can no longer perform their own activities with the only support of the patient record (paper or computerized): they are compelled to ask their colleague for more information. These informal communications are distributed throughout the time and the space. They are the last resources to compensate weaknesses of the systems (paper vs. computerized). Some of these brief verbal communications are initiated by physicians. They interrupt the medical round to fetch complementary information about the patient, *e.g.* "does he sleep well?" or "How much does he piss?". The information they need is not readily available whatever the technical system. But most of the communications are initiated by the nurses needing additional information to interpret unusual or modified therapeutic orders.

Medication supports

The table 2 presents the differences of each system, differences observed whatever the organization (CR, B or OE).

Table 2 – Differences in the interactions professionals / systems, depending on the type of system

Paper-based system	CPOE system
• New complementary exams or lab results can arrive anytime, professionals have then to constantly check their receipt, thus overloading the professionals • During information gathering in the patient medical record, loose sheets allow doctors to lay out all the necessary information and thus make easier the task • As the MAR is easily accessed at the patient bedside and well structured for information gathering about the current treatment, doctors systematically use it, thus making easier the information gathering • Doctors write their orders as they think them, writing orders into a paper-based system is easier/less restrictive than entering them into a CPOE system	• Alarms notify new complementary exams or lab results availability, thus efficiently guiding professionals • Finding out through the system all the necessary information is tedious (several windows and screens) and makes difficult the information gathering for doctors • To gather information about current treatment, doctors are constrained to use the order list which makes difficult the information gathering (while the MAR exists, it is not readily available to the physicians and thus is very little or not used) • The entering of unusual orders into the system is time consuming

The results show differences in the interactions between the professionals and the systems depending on the type of the system. One of the advantage of the CPOE over the paper one, is information can be updated in real time with the alarm's notifications which is a highly appreciated functionality by both professionals (doctors and nurses). However, the CPOE system fails (i) to provide ready access to a summarized view of the information and (ii) to support a rapid and easy entering of the orders.

The analyses show other differences in the use of each system, but only in one of the organizations, the OE organization (vs. CR and B) (Table 3). In this organization and for the paper-based situation, problems with notifications of changes also concern the medications changes. In the CPOE situations, in addition of being time consuming, the filling in of orders compels the doctor to enter information he doesn't usually deal with, *e.g.* the solvent of an infusion or the precise timing of medication administration, most of the time he prescribes with moments or frequencies, nurses being in charge of translating orders into suitable administration times.

Finally, none of the two systems, whether the paper-based or the CPOE, is able to efficiently support the doctors-nurses communications: in the paper-based conditions a nurse's workaround of the order list is observed and in the CPOE conditions, the "memo" functionality is not satisfying.

The results show an impact of the CPOE system on the doctors-nurses cooperative activities during the medication use process. The introduction of this type of system has the great advantage to give to the professionals an access to legible and updated information in real time as compared with a paper-based system. It has, however, some weaknesses all too frequent in currently available systems, *i.e.* the entering constraints and the failure to provide ready access to information overviews. But on looking closer, these are mainly ergonomics defects of the tool that can be easily solved and controlled.

Table 3 – Differences in the interactions professionals / systems for the Opportunistic Exchanges organization, depending on the type of system

OE/Paper-based	OE/CPOE
• The medical order list is also used by nurses to write some comments. • Doctors mainly prescribe medications during the medical round but also punctually at other times. Nurses are then stressed to miss a change in the treatment and constantly check for changes into the patients medical records • The handwriting of some doctors is illegible for nurses	• It happens that doctors miss a problem with the administration of a med (difference between what have been prescribed and administered). The "memo" is not sufficiently salient and intuitive, doctors consult it very rarely. • Some information that doctors are forced to enter can be confusing for them, *e.g.* they are not used to enter the solvent of an infusion. • The schedule of medications entered by doctors in the system is not always in accordance with nurses routines, nurses also change the timing to correspond to their rounds without checking with doctors which can be dangerous

Whatever the technical system, three main organizations (CR, B, OE) have been identified which features seem to have an impact on the coordination and communication processes. The CR and B organizations have scheduled face-to-face communications which allow each partner to take the time to understand the situation and adjust a common representation of the situation. On the contrary, the partners of the OE organization have no scheduled exchanges and interact mainly by mediated systems (CPOE vs. Paper-based) which turn out to be insufficient to support the exchanges between partners. The differences observed are the consequences of the lack of face-to-face communications; they are not observed in the other organizations (CR and B), whether with paper or CPOE.

Quantitative analysis of the face-to-face communications

The quantitative analyses amounted to approximately the same number of hours in the 5 different departments (from 36h58 to 40h05), meaning that there are no significant differences in the medication use process itself across those departments, F (4, 35) = 1.01, $p > .05$.

Table 4 - Durations of observations and dialogs according to the support of work and the organization.

System	Org.	Duration of observation	Duration of dialogs	Mean durations in minutes (SD)
Paper-based	OE	39h40	0h33	M = 4.12 (4.2)
	CR	37h33	13h10	M = 98.75 (12.2)
	B	40h05	2h15	M = 16.9 (3.3)
CPOE	CR	36h58	16h50	M = 126.25 (20.6)
	B	39h36	2h18	M = 17.25 (2.5)

As expected, there is a marked difference in the duration of the physicians-nurses dialogs according to the organization of their work (Common Rounds / Briefings / Opportunistic Exchanges) while there is no impact of the technical environment *i.e.* CPOE vs. paper-based, $\chi^2(1, N = 40) = 1.66$, $p > .05$. (cf. Table 4).

Discussion

This study addresses the question of the respective impact of organizational variables and technical environment variables on the collective aspects of healthcare work situations. The most important result of the study is the significant impact of the doctors-nurses communications organization in the teamwork. These results confirm the critical role of the face-to-face communications and of their modalities on the teamwork. For the time being the technical environment cannot support efficiently all the doctors-nurses communications. IT systems tend to acquire and present data in a mechanistic way, while conversations are characterized by the fluid and interactive notions of asking and telling, inquiring and explaining [10]. Also only a part of the communications could be replaced by information systems but not the entire communications activities. It is difficult to provide in a formal way all the information needs because they are context dependant. In routine situations, professionals share a common model of the task and so need to communicate less during an exchange. In contrast, in unusual situations a significant portion of the communication may need to be devoted to establishing a common representation of the situation. This means that during the face-to-face exchanges, partners may check with each other repeatedly throughout the exchanges that they indeed understand each other.

Although supporting more effective communication practices may have great impact on the collective activities, there remain enormous gaps in our broad understanding of the role of communication in health care delivery [8]. The great variety of communications' organizations within each hospital complicates the task. It would be interesting to provide the hospitals with a framework or an observation grid supporting the organizational characterization of their various departments before the introduction of a new IT system. The findings of this study on the three organizations need to be generalized. The issue is to identify in the work situations the determinants of the collective activities. One of them is the scheduled of face-to-face communications' slots in the work organization, and also its modalities. Indeed, exchange during the medical round and the decision making process (CR) or rapidly in the nursing room (B) is quite different. In another study, we demonstrate that the quality and extent of nurses' knowledge about the therapeutic care plans and about the drugs management may vary greatly depending on the organization of the physicians-nurses communications [11]. For example, based on the analysis of nurses' activities and confrontation interviews, we could establish that a nurse participating in medical rounds (CR) presents an extended understanding of the medical characteristics of the pathology, an extended knowledge and understanding of the therapeutic care plans and of their underlying medical rationale and finally an extended knowledge of the particular patient's medical case.

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Discuss Now, Document Later: CIS/CPOE Perceived to be a 'Shift Behind' in the ICU

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Abstract

Effective communication is essential to safe and efficient patient care. We aimed to understand the current patterns and perceptions of communication of common goals in the ICU using the distributed cognition and clinical communication space theoretical frameworks. We conducted a focus group and 5 interviews with ICU clinicians and observed 59.5 hours of interdisciplinary ICU morning rounds. Clinicians used a CIS/CPOE system and paper artifacts for documentation; yet, preferred verbal communication as a method of information exchange because they perceived that the documentation was often not updated or efficient for information retrieval. These perceptions that the CIS/CPOE is a "shift behind" may lead to a further reliance on verbal information exchange, which is a valuable clinical communication activity, yet, is subject to information loss. Electronic documentation tools that, in real time, capture information that is currently verbally communicated may increase the effectiveness of communication.

Keywords:

ICU, Communication, Interdisciplinary

Introduction

Evidence linking ineffective communication in the inpatient setting to negative outcomes such as increased length of stay, increased patient harm and increased resource utilization heightens the need to understand patterns and perceptions of clinical information exchange[1-5]. Effective communication in the intensive care unit (ICU) is critical due to complex technologies, therapeutic interventions and high patient acuity [5]. In the United States, the Joint Commission has identified communication failures as the leading cause of sentinel events and listed ineffective shift report as a contributing factor[6].

Stein-Parbury and Liaschenko found that during stressful situations collaboration breaks down and professional boundaries are accentuated regarding who owns what kinds of knowledge and who is responsible for specific kinds of work[7]. The ICU is a stressful environment in which patient care is dependent on many disciplines who must simultaneously work both autonomously and collaboratively[8]. Shift work in the ICU, specifically the frequent hand-off of patient care responsibilities to a different clinician, is known to increase the demand for effective communication[9, 10]. Additionally, division of labor (i.e., distribution of activities and responsibilities), which is utilized by clinicians to increase system efficiency and overall functioning, is dependent on information exchange[8].

The aims of this study were: 1) To describe the ICU activity system in the context of interdisciplinary communication of common goals; and 2) To describe nurses' and physicians' perceptions of interdisciplinary communication of common goals in the ICU.

Background

The theoretical frameworks of distributed cognition and Coiera's clinical communication space were used to better understand clinician patterns and perceptions of the communication of common goals in the ICU (see Figure 1)[11, 12]. In the theoretical framework of distributed cognition the unit of analysis is the *activity system,* which is composed of *individuals* and *artifacts* (e.g., technology). The theory posits that the pattern of *information exchange* can drastically modify the behavior of the activity system and that the behavior of the *activity system* should be described by the patterns of information flow [11]. As opposed to traditional cognitive frameworks that only analyze individual processes, distributed cognition integrates goal directed actions and interactions of *individuals* and *artifacts,* and information exchange within an *activity system*[11].

Communication between nurses and physicians is important in the ICU because these clinicians work closely together to coordinate ICU specific patient care, communicate frequently, and are the primary users of clinical information systems (CIS) and computer provider order entry (CPOE) systems [13]. Coeira's clinical communication space framework describes the communication and information exchange activities between clinicians within the activity system according to the amount of common ground that exists between the communicators[12]. *Goal directed actions*, such as patient care tasks, and *interactions*, such as communication tasks, can be explicitly modeled, and the appropriate communication or information tools can be anticipated using the clinical communication space framework. Baggs describes ICU interdisciplinary collaboration as contingent upon the antecedent conditions of *Being Available* and *Being Receptive* which facilitate the core process of *Working Together* to achieve the outcomes

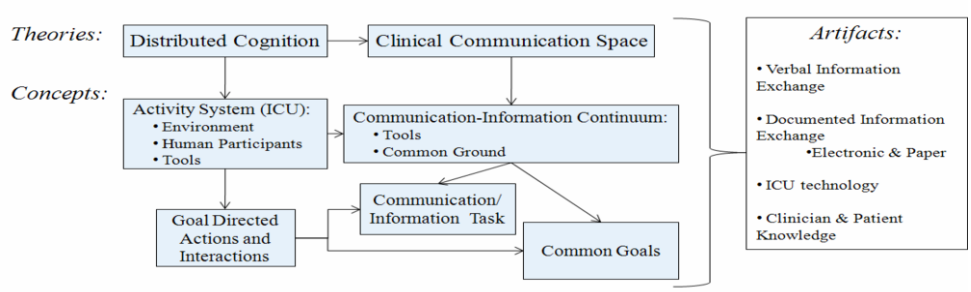

Figure 1 - Integrated Distributed Cognition and Clinical Communication Space Theoretical Frameworks

of *Improved Patient Care*, *Feeling Better on the Job*, and *Controlling Cost[14]*. The key focus of this study is *Working Together* which includes the *Coordination* and *Sharing* of patient care information in a *Patient Focused*, *Team* environment.

Materials and Methods

This descriptive study used ethnographic observation techniques, focus groups and interviews to identify characteristics of information exchange related to common goals in the ICU environment. This study took place at New York Presbyterian Hospital Columbia University Medical Center (NYP-CUMC) on the Neurovascular ICU (NICU), an 18 bed unit that specializes in intensive care for patients with neurovascular injuries. The hospital's vendor-based CIS/CPOE system supports electronic documentation of structured, semi-structured, and free text data for nurses, physicians, and respiratory therapists in the NICU.

Institutional Review Board (IRB) approval was obtained from Columbia University for all activities and informed consent was obtained from participants. The focus group and interviews, which were conducted with ICU clinicians, were held at a convenient time and place on the CUMC campus. All of the participants were compensated with a $10 cash voucher for their time. The focus group and interviews were audio-recorded and transcribed verbatim by a paid transcriptionist. The transcripts were verified against the audio-recordings by the researcher for accuracy. The field notes and interview transcripts were analyzed by the researchers for themes related to information exchange of common goals for patient care. ATLAS.ti™ (GmbH Berlin, Version 5.5.9) software was used.

We observed all clinicians who participated in interdisciplinary NICU morning rounds. During the observations the investigator (SC) observed and recorded handwritten field notes of the interactions of the entire NICU team (i.e., activity system) as defined by the distributed cognition and the clinical communication space theoretical frameworks. These interactions included conversations as well as clinicians' use of documentation artifacts, such as electronic documentation in the CIS/CPOE system and paper-based documentation. Data collection continued until data saturation (i.e., no new themes were identified) was achieved and the observational, interviews, and focus group data were triangulated for consistent themes.

We analyzed the triangulated data using distributed cognition to describe the *activity system* and the *goal directed actions and interactions* within the activity system. We also used the clinical communication space and Baggs' ICU interdisciplinary collaboration coding [14] to describe the communication and information exchange activities within the activity system (see Figure 1). Baggs' coding framework was extended where needed. The results are presented as: 1) the distributed cognition activity system description, and 2) the clinical communication space information exchange description.

Results

Clinicians were observed during NICU interdisciplinary morning rounds for a total of 16 days during the fall 2008 and spring 2009 which equaled fifty-nine and one-half hours. Each observation of NICU rounds lasted between three hours and four and a half hours. We also conducted one focus group that consisted of eight NICU nurses, one interview with an ICU staff nurse, and four interviews with ICU residents.

Distributed Cognition Activity System

Within the NICU's activity system, the individuals who were observed included the following types of clinicians: 1) Physicians (e.g., attendings, fellows, residents, and medical students); 2) Nurses (e.g., charge nurse, staff nurses, and nursing students); 3) Pharmacists; and 4) Respiratory therapists.

The artifacts used by the clinicians as information resources in the NICU were used to provide and capture information during and after ICU interdisciplinary morning rounds. During ICU interdisciplinary morning rounds, the artifacts that provided information to the clinicians were: 1) Computer terminals used by the attending, two residents and a pharmacist to provide access to the hospital's CIS system; and 2) Personal notes. These personal paper-based notes were carried by clinicians and included information written down during hand-off and throughout their shift. Personal notes consisted of the clinicians' to-do lists and the nurses' paper-based vital signs flow-sheet, as well as printed information from the CIS such as the medical administration record (MAR) and the attending's ICU note or the resident's sign-out note. During rounds, two residents sat at computer terminals and, based on the discussion, retrieved laboratory values, clinician notes, vital signs, and radiology results such as x-rays from the CIS.

Additionally, the resident who was presenting information about the patient referred to information that he or she printed

from the CIS/CPOE system as well as personal notes such as to-do lists. The patients themselves also served as an information resource during the moments that the team was in the patient's room during ICU interdisciplinary morning rounds. For example, during a given patient's bedside assessment the team also referred to data from the various therapeutic technologies in the room such as ventilator settings, intravenous medications, intravenous pumps rates, cardiac monitoring, and intracranial pressure monitoring data.

The artifacts for documentation that were used by clinicians to record the information that was discussed during rounds included paper documentation and the electronic CPOE system. The attending physician documented what was discussed by all of the clinicians who were present at rounds on the "Attending ICU note" in the CIS/CPOE system. Additionally, each one of the other clinicians were observed to hand write brief notes on their own personal papers at varying time points. The residents, using the computer terminal, continuously entered discussed orders into the CPOE system during rounds.

In addition to the artifacts that were used during rounds, the CIS/CPOE system included an interdisciplinary plan of care flow sheet. Nurses, respiratory therapists and nutritionists used this structured electronic flow sheet to document care. However, this flow sheet was not talked about or looked at during ICU interdisciplinary morning rounds. The only documents that were looked at during rounds were the "Vital Signs" and the "Intake and Output" flow sheets in the CIS/CPOE system as well as the paper-based vital signs flow sheet used by nurses. A paper-based nursing care plan was available but was not used; the nurses stated that it could be useful, but that they did not want to have to fill out any further documentation or duplicate information that they already documented in the CIS/CPOE system.

Despite documenting vital signs, medications, and fluids in the CIS/CPOE system, the nurses also documented the patient's vital signs and intravenous medications and fluids on the paper-based vital signs flow sheet that they carried around with them. The charge nurse also used a paper-based sheet that was written on and updated by each nurse during nursing rounds. This sheet contained information about each patient's diagnosis, any abnormal vital signs, intravenous lines, and plans for imaging tests (e.g., computed axial tomography, also known as a CAT scan) or surgery. The charge nurse information sheet also contained information about interventions such as the use of a cooling blanket, if Tylenol was given for a fever (a fever is a concern for neurological patients due to a link to poorer outcomes), and if intravenous medications were used to control the patient's blood pressure.

Clinical Communication Space

Clinician perceptions and patterns of interdisciplinary communication and information exchange activities were coded according to Baggs' ICU Interdisciplinary Collaboration coding framework. We found that clinicians preferred verbal discussions as a method of *Sharing* information. Therefore, to explicitly capture the clinical communication space concepts of *communication and information tasks* we added the codes *Verbal* and *Documentation Information Exchange* to the ICU collaboration framework (see Table 1). Both of these categories had positive and negative aspects, therefore, they are each represented by positive and negative clinician quotations.

Verbal Information Exchange

Overall, verbal communication was the preferred method of information exchange in this ICU. The residents used the CIS/CPOE system to retrieve vital signs, the patient's fluid balance and to make sure that orders were entered; the residents verbally asked the nurse for other information related to the nursing assessments, interventions, evaluations and coordination of care for the patient. The residents stated that they place emphasis on entering new orders in the CPOE system, yet the nurses stated the importance of verbally communicating and discussing these orders. The nurses stated that part of sharing goals is making sure everyone knows the reason for why you are making a change. "Whether or not some documentation is updated is variable, but [we try] to always verbally communicated the updates to each other in shift report."

Common goals for the patient were verbally shared by physicians and nurses during morning rounds; yet, the clinicians acknowledged that sometimes a goal was explicitly stated and sometimes it was just implied in a CPOE order or other documentation and may be missed, forgotten or not prioritized as intended. Nurses stated that if they were not present at rounds, due to conflicting patient care responsibilities at that time,

Table 1- Clinician Perceptions of Verbal and Documented Information Exchange

Verbal Information Exchange	(+) *Resident:* It's a lot faster and easier to ask 'Please, just verbally, quickly tell me what's going on.' (-) *Nurse:* It doesn't all get written down [at rounds] and the night nurses don't know, sometimes in the report it gets lost in transition...miscommunication or doesn't get passed on, and you work twelve hours with one eye closed, basically not having all the information with you. (-) *Resident:* A third of the time, usually the event is communicated verbally and the issues or treatment and results are communicated verbally again, but nothing's ever written down.
Documentation Information Exchange	(+) *Resident:* The [beside chart] of the nurse's notes…past medical history and pertinent… a log of what happened. If I know a specific event happened, and I'm trying to get more details, that's where I may go. (+) *Nurse:* Writing things down in succinct manner physically next to the patient is very helpful. Because [then] everyone's very aware of it and people start saying, "Hey, did you see them?" "No, let's call them again." It's very helpful in getting things done and communicating, because it's written down, kind of almost set in stone once something's written down. (-) *Nurse:* The computer system doesn't even remotely match what's going on with the patient. It's ridiculous; there'll be Cardizem hanging [intravenous medication] and no orders for it [in CPOE system].
(+) positive aspect of category, (-) negative aspect of category	

they would piece together the plan and determine the patient's goals from their own assessment, attending note, resident sign-out, nurse shift report, orders and unit standards "that we all know." During the observations, the charge nurse and the fellow (i.e., a physician receiving specialty training) acted as liaisons between the medical and nursing teams. There was no formal team-based meeting after morning rounds to communicate changes in plans between nurses and physicians or to come to consensus about changes in patient goals. As one nurse stated, "sometimes nursing goals and medical goals conflict; however, due to the high amount of verbal communication on the unit they often overlap." The residents and nurses agreed that "if goals are known they are used to guide the day." Therefore, the clinicians expressed that it may be beneficial to provide unified general patient goals, specific tasks and major events of the day in a simple format that is readily accessible and contributed to by everyone.

Documentation Information Exchange

Clinicians emphasized aspects of documentation in the ICU that inhibited their workflow such as patient information contained in multiple disparate sections of the EHR, and information that was not updated to reflect current patient goals. Moreover, nurses commented that orders appear in the CPOE system that were not explicitly related to the nurses perceived understanding of the common goals for the patient. One resident described difficulty in keeping the medication list accurate: "Yes, because I find that it changes frequently, that list, whether it's the drips versus the standing medications."

However, the clinicians also described aspects of the computer-based documentation that enhanced clinical workflow. One resident stated that documenting a plan "can solidify it" to help to ensure that the plan will be carried out and its progress will be evaluated. Nurses commented that 'if someone forgot to tell you the plan in report, it was wonderful if it was written in the computer.'

Our observations identified that the structured documentation in the CIS was typically supplemented by CIS free text notes written by nurses and CIS sign-out notes written by residents at or near the end of their shifts. These notes included information that may have been documented in a structured format in other parts of the CIS, but summarized the structured data and provided additional contextual information in order to "tell the story" of the patient and the patient care that was provided during that shift.

Discussion

Computerized systems may increase the effectiveness of communication within the nursing or medical discipline [15, 9]. However, the integrated distributed cognition and clinical communication space analysis demonstrated the perceived lack of effective and updated electronic documentation artifacts within the ICU activity system that was examined. Limited use of electronic documentation restricts the ability of clinicians to establish common ground through the CIS regarding their *goal directed actions and interactions*, *communication and information tasks*, and *common goals* of patient care. Our analysis suggests that when the CIS does not facilitate clinicians establish common ground they prefer verbal information exchange.

Based on the clinicians' statements during the focus group and interviews, information contained in the CIS is often perceived to be a *shift behind* (e.g., night shift or day shift) and includes only the clinical care that has already been provided to the patient. Therefore, the current structure and content of the documentation tools in the NICU may not be sufficient to capture the information exchange of common goals that occurs during and in between ICU interdisciplinary morning rounds. The perceived lack of updated documentation may increase clinicians' reliance on verbal communication. For instance, if the clinicians perceive that other clinicians are not updating the electronic documentation frequently they may wonder if frequently updating the electronic documentation is an efficient use of their time during their shift in the fast paced and complex ICU environment. These perceptions likely influence clinicians' behavior to electronically document patient information at the end of their shift or to omit information that had been verbally exchanged from the electronic documentation. Kim et al., also found that the restrictions imposed by the CIS developers caused nurses to omit many information layers and data categories that would have represented greater contextual information that was useful for clinical care as well as for data reuse for administrative and research purposes [16].

Clinicians' continued reliance on personal paper-based notes suggests that the CIS may facilitate establishing common ground amongst the clinicians. One of the intended useful roles of a CIS at the point of care is to provide clinicians with access to shared information regardless of constraints such as their location or the time of the day. The sharing of paper based documentation is limited by constraints such as the location of the documentation or the shift worked by the clinician that is in possession of the paper documentation.

Of note, the clinicians that were interviewed appreciated the potential benefits of electronic documentation such as increasing common ground regarding the patient's plan of care, preventing information loss, and increasing the opportunity for information retrieval. However, the continued use of personal paper-based documentation by clinicians and their preference for verbal communication, despite their acknowledgments of the potential benefits of electronic documentation, are evidence that clinicians are ignoring aspects of the CIS/CPOE tools that do not fit into their clinical workflow.

Despite the clinicians' perceived limitations of the CIS/CPOE system to support ICU communication and information exchange activities, the clinicians continued to use the CIS/CPOE system; however, they supplemented the system by implementing verbal information exchange conventions. These verbal conventions were used to verify information that was updated in the CIS/CPOE system in an effort to ensure the quality and safety of patient care. For instance, the nurses stated that CPOE orders may only imply what the related patient goal was; therefore, if a goal related to an order was not previously discussed or documented the nurses' verbal double check may be the only form of verification that the order was entered as intended. In a previous study we found that nurses perform these double checks by determining the physician's rationale for an order as a method to assess the safety and ap-

propriateness of the order [17]. These finding about the clinicians' use of verbal double checks relate to Hazlehurst and colleagues conclusion that multiple representations, or redundancy, of information in the ICU increases robustness of the system and ensured correct functioning [18]. Including contextual clinical information linked to CPOE orders or nursing actions, such as the rationale or an explicit patient goal, may provide the multiple representations that may be sufficient as a double check. Moreover, the clinicians' free text documentation in the CIS provided contextual information and summarization of the interpretation and meaning of the structured data points in various parts of the CIS. Clinicians' discussions may inform the "story of the patient" that is told in the free-text documentation; additionally, a clinician may "tell the story" of the patient in free-text documentation because once his or her shift is over there likely will be no further opportunities to discuss and convey summarized and contextual information about the patient with other clinicians who may care for the patient. According to Coiera's [12] clinical communication space theoretical framework, information that is routinely verbally discussed during rounds or documented in free-text notes that summarizes and contextualizes patient information to "tell the story" of the patient, may be ripe for an automated information tool.

The limitations of this study are that the observations were conducted on one NICU and that all of the clinicians that were interviewed or participated in the focus group were from one hospital. Therefore, some of the findings may not be transferable to different ICUs, different types of patient care settings, or other hospitals. Additionally, we did not conduct any observations during the night shift in the ICU. However, the data saturation and triangulation of the observational, focus group and interview data increase confidence in the discussed themes and conclusions drawn from this study.

Conclusion

The large amount of information that is verbally exchanged amongst clinicians is evidence that clinicians have not harnessed the CIS/CPOE tools available for their maximum use of information exchange. According to the clinicians observed and interviewed, CIS/CPOE documentation is a *shift behind* and information retrieval is not efficient, leading to a further reliance on verbal information exchange. Moreover, verbal information exchange is subject to information loss.

Our data indicate that the current documentation tools in the NICU may not be sufficient to capture the interdisciplinary communication of common goals that occurs during, and in between, ICU interdisciplinary morning rounds. Therefore, future research should aim to further understand and meet the need for CIS/CPOE documentation to support verbal information exchange in the ICU in real time.

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Method for testing a CPOE system in the medication process in a cardiology ward

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Abstract

Medication errors are of major concern in most countries. The European PSIP project aims to identify and prevent medication errors by enabling data mining and designing contextualized decision support functionalities using a human factors engineering approach. To create a basic understanding of the work practice in the medication process members of the staff in a cardiology department in a Danish hospital were asked to take pictures of their workplace. The pictures were used as a memory trigger in a subsequent interview. Furthermore a video based observation of a full day of work was carried out. In this paper the methodological considerations and experiences are presented and discussed.

Keywords:

Adverse drug events, Human computer interaction, Video analysis, CPOE.

Introduction

Adverse Drug Events (ADE) due to medication errors and human factors are a major public health issue. They endanger patient safety and cause considerable extra healthcare costs. Decision support should assist in reducing the incidence of preventable ADE, by providing health care professionals and patients with relevant information and knowledge. The efficiency of the relevant feedback is however impeded by two major drawbacks:

- Lack of reliable knowledge about ADE
- Poor ability of IT solutions to deliver contextualized knowledge focused on the problem at hand, aggravated by a poor consideration of causative human factors

The European project PSIP (Patient Safety through Intelligent Procedures in medication) aims to identify and prevent ADE [1]. Data mining and semantic mining of structured hospital data bases in France and Denmark will give a list of observed ADE with frequencies and probabilities, thereby giving a better understanding of potential risks. The main objective of the project is to develop innovative knowledge based on the mining results and to deliver to professionals and patients contextualized knowledge fitting the local risk parameters in the form of alerts and decision support functions.

To enable the design of alerts and decision support functions in a contextualized form it is essential to have a deep understanding of the medication process as it is performed in daily clinical work. The present study surveys the medication process in a cardiology department in a mid size hospital in the Capital Region in Denmark.

Methods

In earlier work practice analysis it has been shown that there is a fundamental difference between what people say they do, what they think they do, and what they actually do [2]. What the users say and think they do to perform their work tasks can be investigated by interviews [3], but to explore what they really do and how they do it can best be revealed by close observation of their work over a period of time. The combination of interviews and observation studies is a good means of identifying how work tasks are adapted to fit the particular contextual setting [4].

In this study a nurse and a physician were interviewed to investigate how they performed the three stages of the medication process: prescription, dispensing, and administration. Two weeks prior to the interviews the two staff members received a disposable camera and were asked to take pictures of situations from daily works practice they felt important. The semi-structured interviews started with open questions about each phase of the medication process, prescription, dispensing and administration. The two staff members were asked to explain which devices and artifacts they used in each phase, what knowledge they applied, and how the tasks are organized.

Their response (the light post-it notes in Figure 1) were categorized and validated during the interview. These categories correspond to a general technology concept [5]. When they could not think of any further issues under the mentioned categories they were presented with the pictures they had taken with the camera.

The pictures triggered their memory with additional issues (the dark post-it notes in Figure 1). Apart from identifying the elements included in the medication process the nurse and the physician were also asked to explain the actions taken in performing the tasks. Hence the interviews provided a description of how the staff perceives their work practice in the medication process.

To get information on how the medication processes really are performed and the technology involved in the contextual setting we observed two nurses and the physician during a full days work. The observations were recorded on three video cameras.

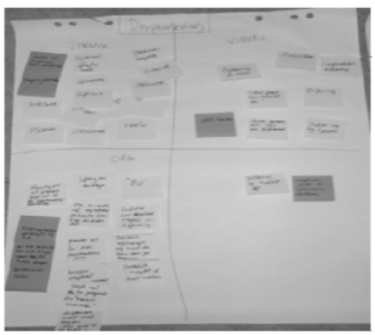

Figure 1 - Categorizing issues mentioned during interview

As a pragmatic validity and reliability check the approximately 18 hours of video was subsequently reduced to 20 minutes representing the most important situations in the prescription, dispensing and administration phases. The 20 minutes video recording has been approved by the staff, as representing this particular day at the cardiology department.

The full length video recordings were organized according to what phase of the medication process it concerned. In particular the physician work practice in the prescription phase was coded using a grounded theory approach. A first attempt to detect situations where decisions were made was given up, because it was impossible to detect precisely when single decisions were made. Instead we could identify when new information was obtained, from what source, and where it happened. Hence the physician's round with seven patients was coded with respect to when information was obtained from:

- a digital artifact
- a paper artifact
- a nurse
- the patient
- another source

The information obtained from coding was used to create a graphical representation to model the health professional's information seeking and processing. This representation graphically depicts over time the location of the health professional, the artifacts involved and the conversions that took place. An excerpt representing the interaction of the physician with a patient on a round is shown in Figure 2.

Results

The photo supplemented interview method and the video observation method for studying work practice in the medication process has been carried out without practical complications. They both produced very rich data as explained in the following.

The summarized results of the interview with the staff nurse are shown in Table 1. Each of the three phases in the medication process--prescription, dispensing and administration are listed in columns. The general technology framework is used to categorize all the issues and elements that came up. The elements that were mentioned during the conversation in the first part of the interview are printed in regular font; whereas the elements that were added after the nurses were presented with the photos they previously had taken with the disposable cameras are printed in italics. In the bottom row of Table 1 the actions taken during each medication phase are described.

The video recordings from the three cameras added up to more than 18 hours and give a very rich picture of what is really happening during a normal day at the department. The raw material has been edited and reduced to 20 minutes that can be used for presentation to external audiences, which has been approved by the staff at the cardiology department.

The video recording has been coded and graphically represented using the diagramming method described above in the Methods (see Figure 2). All the video for the physician has been coded and the video for the nurses in its full length will also be coded to detect and investigate important variables of context determinants. The aim of this analysis is to guide the design of decision support functionalities and their contextualization.

Discussion

When interviews are used as the data collection method voices are typically audio recorded for later transcription. Later the respondents validate the transcriptions, which subsequently are analyzed with respect to specific aspects. In the present study the analysis was performed simultaneously with the dialogue with the respondent, and the validation of the categorization was done at the end of the interview. This allowed us to correct potential misinterpretations during the interview. However, a potential disadvantage is that the respondent starts to respond according to the categories instead of just answering the questions.

The respondents own photos proved to add value to the interview. Nine new elements came up after the pictures were presented to the nurse, and in the description of how they performed in the medication process were remarkably enriched by the presence of the pictures.

The use of video recording for observing work practice differs from other uses of this media in a number of ways [6]:

1) The activity filmed does not happen for the sake of the recording. It has similarities with surveillance, but differs from test situations such as traditional usability evaluation.

2) The actors are aware that they are being filmed. In most cases the actors has been involved in the preparation of the recordings and have agreed to participate, which distinguishes it clearly from surveillance.

3) The actors are not paid or in any way bound to a particular obligation during the recording.

4) The recording happens as a part of a change process to the actors' work practice. In the present case the staff has an obvious interest in contributing to improvement in patient safety and the reduction of ADE's.

The greatest advantage of using video for observations is that this media can catch work practice situations visually as well as recording sound. The video document enables deep analysis because repetitive playbacks facilitate the study of essential details in the work practice – details that were imperceptible at first sight. The video recording is, however, not identical to the authentic situation. It will always be a reduction of the real, and not a completely accurate reproduction. Firstly the video media has a selective view limiting what is possible to observe, and secondly the sound quality can be reduced which means that pieces of information can be lost. Thirdly the space of experience is reduced from 3-D to 2-D. The most significant reduction however is the total absence of smell and atmosphere in the location, which can have significant influence on the interpretation of a communication process.

Table 1 - Result of the interview with the staff nurse

	Prescription	**Dispensing**	**Administration**
Technique	• Paper record • Note in pocket • Telephone • Acute sheet • *ECG curve* • *White board*	• Trolley • Cup • Medicine catalogue • Printer • Computer • Toxin cabinet • Exhaust device • IV-mix equipment • Bar code • PDA's • *Plastic bags* • *Paper record*	• Trolley • Medicine cup • PDA • Patient wristband • IV-rack
Qualification	• Basic nursing • Knowledge from errors • Experience • Older nurses • *CPOE-course*	• Locally acquired skills • Experience • Alert with toxins • Wonder and double check • *CPOE training*	• Locally acquired skills • Experience • *CPOE training*
Organization	• Patient • Other nurses • Physician • Lab technicians • Pathology lab • X-ray • Blood bank	• Asking colleagues • Quietness in medicine room • Dispensing for the whole day depending on time available • *Check off with the mouse instead of bar code*	• Independent work • Planning as the day pass • One patient at a time • Watch the patient take medicine
Outcome	• Information sheet to patients • *Health status improvement for patient*	• Medicine in the cup • Medicine in accordance with prescription	• Medicine administered • Changes recorded in CPOE
Action	Decisions on prescriptions made during • Discussing patients during board round • Collaboration with physician using the CPOE system and other information systems in the office • Communicating with the patient, the physician and other colleagues	• Find the patient in the system • Print out label with patient ID • Identify the medicine • Find it on the shelf • Identify it by the barcode • Dispense the prescribed dose • Check for dispense • Put the glass on trolley	• Log in on PDA • Drive the trolley to the bed room • Find the patient • Read the bar code • Check the identity • Explain the medicine • Watch the patient take the medicine

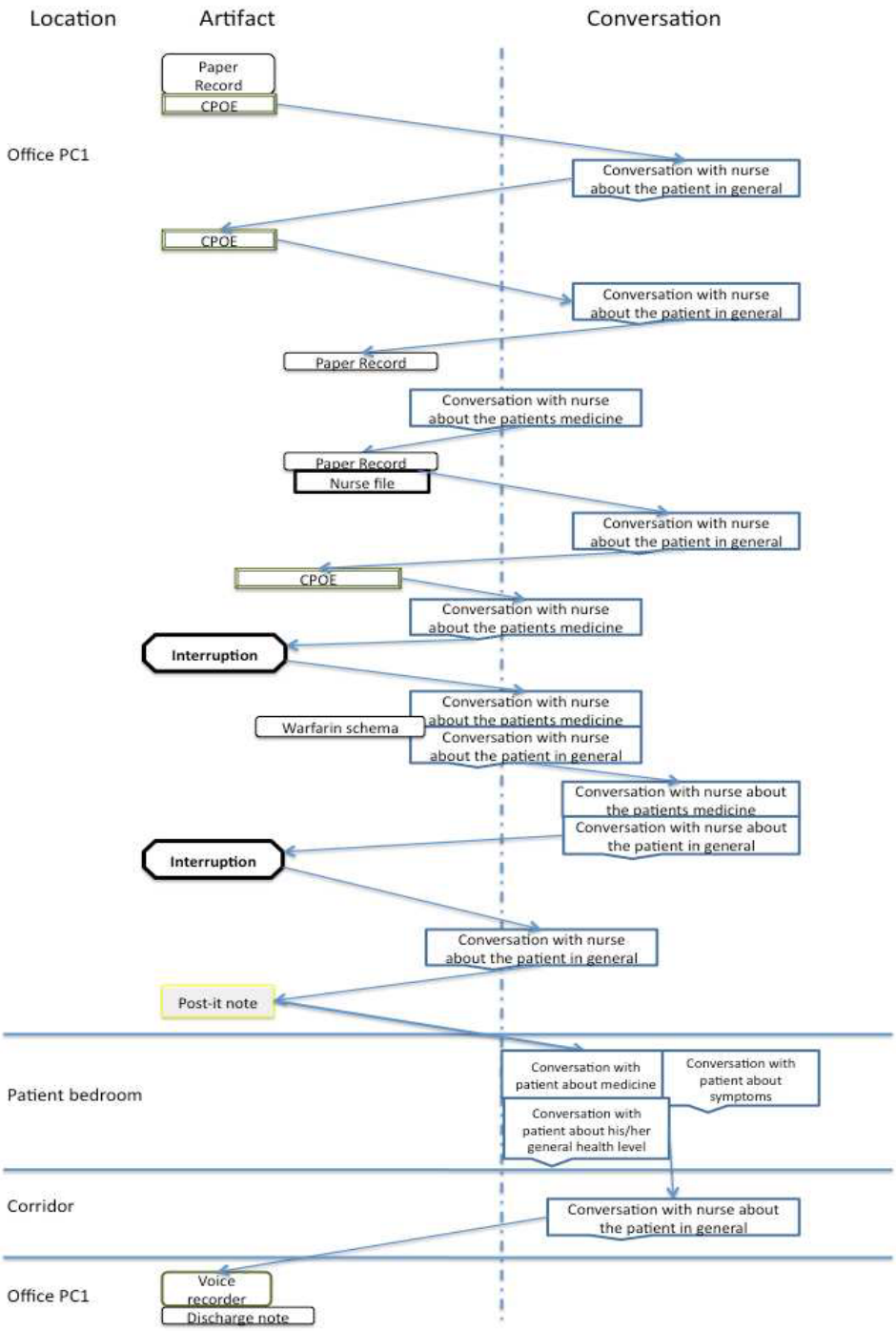

Figure 2-Graphic representation of information seeking with a patient and processing during a round

One of the perils of using video for analyzing work practice is that it can have a seductive effect. This seems to appear in at least three different forms [6]:

1) In the illusion that what you see is objective data.
2) In the risk of viewing it as entertainment.
3) In the temptation to ascribe the actors' motives and feelings.

The seductive effect in terms of objectivity often happens when hours of real time recordings of every day work practice seen through a particular lens are fragmented and analyzed by several independent researchers. They can identify typical work actions, quantify them and compare results. In this situation it is often forgotten that the data has already been edited: positioning of the camera has been determined, timing of the recording and equally important, those who are behind the camera often come out of the same community of practice as the staff being observed.It can sometimes be difficult to yield to the temptation to let unintentionally funny situations slip through the editing process or to focus on such situations in the analysis. It is often the unexpected, the disconfirmation of expected patterns that attracts attention. Particular consideration of ethics is essential to maintain video recording as a scientifically sound methodology [7].

In the present study we asked the physician and the nurses we primarily followed to think aloud. We did not want them to talk to the camera, or explain what they did, but just to say what they were considering in their work. This seemed to work very well, and it appeared to be very easy for them to do because they are used to collaborating in their work tasks (i.e. during the prescription phase the nurse and the physician constantly communicate about diagnoses, development in health condition, observations of patient behavior and things that must be done).

A question often discussed is the degree to which people are influenced by the presence of a camera, and if it makes any difference if there is an operator behind the camera [8]. After all it boils down to an empirical question that must be investigated on each occasion. From viewing the recordings it is clear that we can distinguish when the work performed is influenced by the presence of the camera. Often the observed person starts to talk directly to the camera, when he/she discovers it or abruptly changes behavior. In general however it is our experience that the observed staff members very quickly habituate to the camera, and the presence of the camera does not bias the observations in any significant way.

In the present study it has been clearly demonstrated that the interviews – supported by the respondents' own photos resulted in a clear and detailed description of how the medication process is performed. The descriptions obviously follow the rules for how medication processes are supposed to happen. The nurse describes the process as it is taught at the nursing school. However, from the video recordings of a single day in the department it is clearly shown that the formal medication process is often over-ruled by shortcuts and workarounds. But it is also clearly documented that every case of over ruling is accompanied by a rational argument in terms of efficiency or considerations about quality of care for an individual patient.

Conclusion

Analysis of work practice of medication processes using video in combination with interviews supported by pictures taken by the respondents has proven to be a very powerful tool to obtain an understanding of what is really happening during the medication process. The methodological discussion has also exposed how important it is to be critical in the detailed analysis of the rich and comprehensive data collected.

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Steps towards Single Source - Collecting Data about Quality of Life within Clinical Information Systems

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Abstract

Information about the quality of life from patients being treated in routine medical care is important for the attending physician. This data is also needed in research for example to evaluate the therapy and the course of the disease respectively. Especially skin diseases often negatively affect the quality of life. Therefore we aimed to design a concept to collect such data during treatment and use it for both medical care and research in the setting of dermatology. We performed a workflow analysis and implemented a designated form using the tools of the local clinical information system. Quality of life data is now collected within the clinical information system during treatment and is used for discharge letters, progress overviews as well as research about the treatment and course of disease. This concept which contributes to the single source approach was feasible within dermatology and is ready to be expanded into other domains.

Keywords:

Quality of Life, Pruritus, Single Source, Clinical Information System

Introduction

Medical care and research aim to enhance the quality of life (QoL) of patients. Documenting quality of life in routine healthcare and reusing this information for research should therefore be fundamental. This reuse of routine healthcare data for research purposes, which reduces the documentation workload and enhances the interaction between care and research, is an example of the *single source* approach.

One objective of single source in medical informatics is the rapid innovation transfer between medical care and medical research which implies the joint use of data collected at a single data entry point and the exchange of it respectively [1]. Although data collected during medical care might serve different purposes than data for clinical research [2] the data collected during medical treatment is valuable also for research purposes and vice versa. It should not only be collected for a single purpose especially not only for administrative purposes.

Regarding quality of life this data is not only used for medical care and research but also needed to account for new cost-intensive medical treatments to third party payers. The value and effect of the medical treatment is measured by the related benefits for the patient and one instrument to measure patient welfare as a consequence of medical treatment is QoL [3, 4]. Scores related to QoL therefore provide an instrument to quantify the improvement or impairment of the health of patients through health care interventions.

The analysis of QoL information is relevant for various medical domains. In the medical domain of skin diseases for example many studies related to psoriasis or atopic dermatitis showed that the quality of life is negatively affected [5]. A main symptom which dramatically affects the QoL is pruritus [6]. However vertical data collection about various dermatoses, especially chronic pruritus, and longitudinal data collection about the course of disease and improvement of QoL is still scarce [7].

The "Competence Center for the Diagnosis and Therapy of Pruritus" (in the following simply called pruritus competence center) which is part of the dermatology department at the university hospital of Münster is currently studying how out- and inpatient medical care influence the QoL for patients with chronic pruritus. A common instrument regarding quality of life in this field is the dermatology life quality index (DLQI) [8] which is also used in the course of various studies at the pruritus competence center. For routine medical treatment it was shown by Salek et al. [9] that the systematic assessment of patient QoL is beneficial and should be a routinely measured parameter in dermatology.

The collection of data about QoL however implies technical and organizational challenges. A recent study shows that the routine documentation workload of medical staff already takes about 25% of their total workload [10] and that usually does not include data about QoL. In the pruritus competence center for instance one medical doctor has an average number of 12 patients per day, most of them also being enrolled as study patients for whom the QoL is scored throughout the study period. The data collection will have to be integrated into the

clinical routine workflow and therefore into the clinical information system (CIS). For the medical staff it will need to add value in order to be accepted.

We therefore aimed to develop a single source concept to collect and use data about quality of life and to assess the technical, organizational and clinical feasibility of that concept. As a pilot setting the department of dermatology and the DLQI to score the quality of life were chosen.

Materials and Methods

Workflow Analysis

We analyzed the process of the current documentation concerning users, equipment and forms in the department of dermatology using standard methods of business workflow analysis [11]. The analysis was done through unstructured interviews with doctors, nurses and administrative staff and through on-site observations of the clinical routine workflow. The forms were analyzed with respect to their format, data structure and use. To evaluate user acceptance we applied unstructured interviews and measured the number of used forms.

Pilot Setting

The DLQI, which was developed by A. Finlay, is a questionnaire comprising ten items and is used for ongoing scoring of life quality in dermatology [12]. It was used for various studies in the past and proofed to be adequate to provide reliable data for the quality of life [8]. Therefore we chose this instrument and evaluated it for its use and implementation within the local clinical information system ORBIS® [13]. As pilot department we chose to work with the pruritus competence center as they already have experience using the DLQI.

Implementation of forms within the clinical information system

The electronic form was implemented with the integrated form designing tool of the local clinical information system called ORBIS® Form Designer [13].

The electronic form was designed in the same format as the original paper form and can also be printed for the patient as the corresponding print template is attached.

Querying the results of the electronic form

All data within and attached to the form can be queried with the integrated query tool of the local clinical information system called ORBIS® Report Generator [13]. Using this tool the overview of all patient scores was parameterized by querying data from the completed forms for each patient and displaying date, commentary field, score and meaning of the score (see Figure 1).

In addition the single values for each item can be extracted and the query for all patients can be exported into csv (comma separated value) format in order to be used for further analysis. All query data is pseudonymized before being exported.

Results

The DLQI form and its workflow were analyzed, parameterized and implemented in the productive database of the local CIS within less than a week. The following Table 1 shows the application areas of the DLQI score in the past (Before) and with the integrated electronic form (After). The results are referred to throughout this section and the following discussion section.

Table 1 – Application areas of DLQI Score

Application area	Before	After
Patient inserts data into CIS	No	No
Documentation of QoL for outpatients	Yes	Yes
Documentation of QoL for inpatients	Yes	Yes
Progress overview of QoL over time for outpatients	No	Yes
Progress overview of QoL over time for inpatients	No	Yes
Transfer of QoL information into doctor's letter for outpatients	No	No
Transfer of QoL information into discharge letter for inpatients	No	Yes
Reporting functionality for research purposes	(Yes)	Yes

Application area = Areas in which the DLQI score is used; Before = Available before the implementation; After = Available after the implementation

Past Documentation Workflow

In the course of out- and inpatient medical care QoL by means of the DLQI is scored for every outpatient visit and for inpatients at admission and discharge. Shortly before the consultation the patients receive the paper form of the DLQI and have to answer the 10 questions which relate to how much the skin problems affected their lives in the past seven days.

In the past patients answered the questions on paper forms which were handed to the treating physician during the visit. This paper form was then filed in the paper patient record. The score was calculated manually and entered into a separate excel-based database for research purposes.

New Documentation Workflow

Two doctors of the pruritus competence center were trained as key users to use the form in the pilot phase who then trained other users.

Pat.: [redacted]

Progress Overview DLQI

Date	Status Commentary	Score	Meaning
6.10.2009	after treatment	5	small effect
24.9.2009	at discharge	8	moderate effect
12.9.2009	Status improved	10	moderater Effekt
2.9.2009	at admission	17	very large effect
24.8.2009	during treatment	12	very large effect
9.8.2009	before treatment	15	very large effect

Figure 1- Overview of DLQI Scores for a patient

Date = Date of data collection; Status commentary = Text chosen from a catalogue in the form about the status at the point of data collection; Score = calculated DLQI score; Meaning = Meaning of the score, effect on the quality of life

The treating doctor or medical assistants now insert the completed paper forms received from the patients manually into the electronic form in the CIS for the respective patient. As there are only 10 items in the questionnaire it was decided for the pilot phase to be faster and easier to manually enter the answers instead of implementing a possibility to e.g. scan the completed questionnaire and automatically insert the answers in the electronic form.

Through the implementation of the electronic form the following additional features were added which is also reflected by Table 1:

- The date of the data collection is preset with the date of creating the form but can be changed in case the electronic form is completed at a later stage.
- A catalogue to enter a status was added. Here it is possible to select a commentary about the state of the patient and about the point in time the form was filled in (e.g. At admission, At discharge, Status improved, etc.)
- The score will be calculated automatically but only after all questions are answered. For every question there is the possibility to answer "not relevant" which equals 0.
- Besides the score as a number also the meaning of the score, and thus the effect on patient's life, will be calculated and displayed automatically next to the score. In case the effect is very/extremely large the text is displayed in red to highlight the severity.
- For every form saved in the electronic patient record the reference shows the date of data collection, the score and the meaning of the score.
- Within the form it is possible to open an overview of all previously collected scores for that specific patient with their dates and meanings as shown in Figure 1.
- A text module was created in order to takeover data from the DLQI into the discharge letter or other communication documents.

A query like the extract in Figure 2 showed that in the course of two months the form was used 104 times for 45 inpatient and 59 outpatient cases for a total of 86 patients. The average time needed to complete the form was 1 minute and 10 seconds with a standard deviation of 40 seconds. After 6 months of use more than 650 forms were documented for 139 inpatient and 511 outpatient cases for a total of 460 patients.

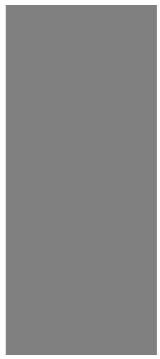
The DLQI score from the same form was used by means of a text module in the discharge letters of 14 patients in the first two months.

The users reported that the overview of all scores for a patient (Figure 1) was looked at frequently however it is not verified through system data because this form does not have the option to be saved in the database.

A report similar to Figure 2 which queried all single items as well as other related patient data was generated and can be looked at directly in the system or exported in csv format. In that way it can also be used in an already existing separate research database at the pruritus competence center for further study purposes. For example DLQI scores for all patients can be imported into the current excel database using a macro.

Whether there are more complete forms now compared to the number of completed forms before the implementation no reliable data was found.

In unstructured interviews the trained doctors were asked about their experience with the electronic form after the first week and the first month of its use and were satisfied with the usability and added functionalities of the implemented solution. After 6 months the form is still used regularly for every patient visit.



14.9.2009	5	inpatient
14.9.2009	7	inpatient
15.9.2009	4	inpatient
15.9.2009	8	inpatient
15.9.2009	4	inpatient
21.9.2009	8	inpatient
22.9.2009	6	inpatient
22.9.2009	23	inpatient
23.9.2009	22	inpatient
24.9.2009	2	outpatient
24.9.2009	3	outpatient
24.9.2009	6	outpatient
24.9.2009	1	outpatient
24.9.2009	8	outpatient
24.9.2009	7	outpatient
24.9.2009	4	outpatient
24.9.2009	1	outpatient

Figure 2- Query of DLQI forms

Patient = Patient Identification (only visible for attending physician); Date = Date of data collection; Score = calculated DLQI score; Case Status = In-/Outpatient status

Discussion

The electronic version of the DLQI is used for the medical care visits in the area of pruritus for out- and inpatients and will provide data for research purposes. The form was easy to implement, had a good acceptance and the added functionality was found to be very useful by the users. The time needed to insert the data from the paper questionnaires was relatively short and well accepted. Besides in the end no additional time was added to the process as the time which was needed before to calculate the score is now used for the manual insertion.

Because of the availability of the score and its meaning through text modules within the CIS this kind of information about quality of life was made available for the first time within the discharge letter. This was found to be very useful as it is now communicated to other treating physicians. Therefore it is planned to use this text module also within other types of communication documents.

The progress overview of all DLQI scores for a patient can now be used during medical care to observe the progress and in retrospective studies for various research questions. In addition the structured availability of quality of life data can serve to proof the need of special treatment towards third party payers.

It is also possible to generate queries that span all patients and include patient/case-related data. By using those queries research findings could be supported with data extracted out of the clinical information system. In addition the export of all queried data in csv format can be used for further research in various studies in which the DLQI is needed as a parameter. Before the implementation of our concept QoL data was only manually inserted in a separate research database whenever it was needed. Therefore in Table 1 the research reporting functionality is shown in brackets. For vertical studies it is planned to implement the form in the whole clinic within the next months in order to collect more data in the different domains of skin diseases.

This shows that a reasonable amount of QoL data will be collected through a simple form implementation, which serves different purposes in medical care and research. Through this prototype in dermatology a common concept is now available to integrate QoL information within routine treatment.

Limitations and future prospects

One limitation is that the patients have to fill in the questionnaires themselves. The DLQI is a patient reported QoL but they do not have access to the CIS and hence another person has to enter the respective data. Table 1 shows that this was neither possible before nor after the implementation of our concept. Therefore another future topic will be an evaluation about other ways to insert data, e.g. through scan mechanisms, digital pens or mobile devices with or without touch screen functionality. The challenges here are firstly that for the patient those applications need to be as simple and easy to use as the paper form. And secondly most CIS vendors ask high prices for interfaces even to such simple applications as the electronic format of a patient questionnaire which not all clinicians are willing to pay. However once a feasible method is found to insert such data into the CIS it might also be possible to link data from other healthcare providers like the general practitioner or transferring hospitals.

The fact that another person has to enter the data into the system also limits the timeliness of the availability of data. It is not possible yet to transfer the QoL data into the doctors' letters of outpatients as shown in Table 1. This is because those letters are written during or directly after the visit and not in all cases the QoL data has already been entered until then. Other mechanisms of timely data entry will have to be analyzed as already stated above.,

We also were not able to find out yet whether there are more complete forms now than before. Although through a plausibility check all forms need to be complete in the electronic form in order to show the score there can still be incomplete paper forms coming from the patients and thus also incomplete forms without a score in the system. However, we did get told that the form is now used regularly for every patient visit which was not the case before.

Within the dermatology department a next step is to implement another scale used during pruritus treatment to score the pruritus intensity. This can then be evaluated against the QoL score. Also the QoL data will have to be integrated with treatment documentation which so far is only done within the paper patient record. This way measuring patient benefits in the course of the therapy can directly be set into relationship with the treatment. Another step towards the integration of routine and research will be made.

To further validate the general concept to collect QoL data during routine medical treatments and use that information for both care and research purposes, we will implement our concept in other medical domains in the coming months. For example the same method of implementation was already applied for other similar scores, e.g. depression scales like Hamilton and Young Mania Rating Scale in psychiatry.

However, in that case the scores were not directly related to quality of life but to monitor the severity changes under treatment. Apart of the other medical domains we will also need to bring this solution into other hospitals with different clinical information systems to proof the generalized solution.

Conclusion

Data about QoL can now be extracted directly from the clinical information system and be used in the routine medical care as well as for research purposes. Thus the collection of QoL information through a single source approach is feasible and well accepted in a university hospital setting.

Competing Interests

The authors declare that they have no competing interests.

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Methodology of integration of a clinical data warehouse with a clinical information system: the HEGP case

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Abstract

Clinical Data Warehouses (CDW) can complement current Clinical Information Systems (CIS) with functions that are not easily implemented by traditional operational database systems. Here, we describe the design and deployment strategy used at the Pompidou University Hospital in southwest Paris. Four realms are described: technological realm, data realm, restitution realm, and administration realm. The corresponding UML use cases and the mapping rules from the shared integrated electronic health records to the five axes of the i2b2 CDW star model are presented. Priority is given to the anonymization and security principles used for the 1.2 million patient records currently stored in the CDW. Exploitation of a CDW by clinicians and investigators can facilitate clinical research, quality evaluations and outcome studies. These indirect benefits are among the reasons for the continuous use of an integrated CIS.

Keywords:

Clinical data warehouse, Clinical information system, Heterogeneous data integration, Data security.

Introduction

Clinical Data Warehouses (CDW) were defined in the early 90s as subject oriented, integrated, time-variant, non volatile collections of data used in support of management decisions [1]. They have been extensively used in the industrial field [2] and much more recently in healthcare. CDW now play an important role when addressing issues related to the integration of heterogeneous databases, considered essential for biomedical research [3]. For example, new types of data, arising from tissue bank management systems [4] or biomedical research [5], need to be integrated with legacy data sources to promote networked or translational research.

Although there are examples of studies demonstrating the benefits of using a CDW for clinical and biomedical researches [6-8], the direct reuse of clinical information systems (CIS) for this purpose is still very rare [9].

Here, we present the methodology used at the Georges Pompidou European Hospital (HEGP) to implement a CDW that is closely integrated with the hospital CIS.

Materials and Methods

The HEGP clinical information system

HEGP is an 890-beds university hospital in southwest Paris, France. The total number of employees is 3,200, with 400 full-time equivalent physicians. The mean number of inpatient admissions/month is 4,700 and of outpatient visits/month is 18,000.

The HEGP CIS is built upon on a component-based approach [10]. The healthcare-related components include the patient ADT, healthcare record (EHR), and act management (CPOE) components from MEDASYS®, and an appointment-resource scheduling component ONECALL© from McKesson®. Healthcare components are integrated through an enterprise application integration platform (EAI) developed by THALES® including a reference manager where the different concepts and their relationships are declared. The CIS is accessed from the 3000 PCs, laptops, and thin clients through a common portal associated with a HL7/CCOW manager and a security component where user access rights are described.

A top down design approach

The deployment of this CDW is a four-year project that started in 2008. One of its objectives is to establish a global methodology for integrating a CDW into comparable French institutions. Using a top-down approach (Table 1), we decided to distinguish four domains or realms (technical, data, restitution and administration) in which we successively: 1) model UML use cases related to the CDW design; 2) analyze compliant technological frameworks, and 3) implement functionalities with selected tools.

This approach is described in detail below.

Table 1- HEGP top-down approach to integrate clinical data warehouse into the clinical information system

	Technical realm	Data realm	Restitution realm	Administration realm
UML use cases	To ensure security and data protection To optimize usability of IT tools To tune data flows and data volumetry	To make source data available To make target data available	To design and broadcast CDW objects	To manage the life cycle of CDW objects
Technological frameworks	French National body for security recommendations; strong reversible encryption algorithm Open source software; collaborative developments Database mirroring	Navigation through database models; business layers analysis Mapping of data sources to target CDW schema; datamart creation	Business intelligence solutions; enterprise content management systems	Help desk system
Implementation tools	Bouncy Castle® java library I2B2® framework ORACLE® utilities	SchemaSpy; SAP®/BO Universes ORACLE® (materialized) views; Talend®/OS ETL jobs; DocuWiki	SAP®/BO reports; KaliTech®/Kalidoc; I2B2 client	Peregrine®/GPS

UML use cases

The technical realm

The technical realm concerns the deployment of CDW hardware and software infrastructures. We have identified three corresponding top-level use cases:

- To ensure security and data protection: we assume that users with high level permissions (physicians for example) are allowed access to all data concerning their patients, but that users with low level permissions (statisticians for example) should only have access to anonymized data. We refined these use case by analyzing each of the recommendations of the French coordinating body for privacy and security (CNIL) and their impact on every CDW activity [11].
- To tune data flows and database volumetry.
- To provide easy-to-use IT tools: one of the main objectives of the CDW project is to facilitate user access to the clinical data. Therefore, the ergonomics and the usability of the IT tools provided are very important. In particular, they must solve the "not enough time" issue [12].

The data realm

The data realm covers the management of the data sources that feed the CDW, including how data are modeled, accessed, and integrated into the CDW. We identified two corresponding top-level use cases:

- To make the source data available: this use case concerns physical access to data, model documentations, potential reverse engineering techniques and cooperation with applications vendors.
- To make the target data available: in this use case, the focus is on the capacity of the CDW model to support data analysis and design of new objects (reports, indicators, etc.), i.e. to move from a storage/access-oriented data model of operational medical applications to the analysis-oriented model of a CDW.

The restitution realm

The restitution is related to the manner in which users have access to the CDW objects and how new information is generated in the CDW. We identified one top-level use case in this realm:

- To design and to broadcast reports.

The administration realm

The administration realm deals with the exploitation (supervision, parameterization, evolution and maintenance) of the CDW objects. From a quality of service point of view, with the objective of managing the activity of the CDW as a service provided by the IT team to the end users, the main use case is:

- To manage the life cycle of the CDW objects

Results

CDW technological frameworks and implementation tools

The technical realm

To fulfill the constraints related to source code accessibility and collaborative development possibilities, we decided to focus on Open Source software components, whenever possible. A CentOS/Linux operating system and the I2B2 [13] framework upon an ORACLE® database for the storage were selected and installed as the core CDW infrastructure.

The first security principle we applied was the anonymization of all data identifying patients, both for structured data or for non structured data (free text reports). In some cases, it is nec-

essary to restitute patient identifiers, so anonymization has to be reversible. All non identifying data (biological results, physician order entries, ICD-10 codes, etc.) are available without restriction. Patient-identifying data are encrypted with a strong reversible cryptographic procedure based on a AES algorithm implemented using the Bouncy Castle java libraries [14]. For experimentation, we are using a 128 bit-long AES key. This encryption function has been integrated into the jobs used for data migration that also use the java language.

For structured data, HIS patient identifiers and hospital stay identifiers are also eligible to anonymization. These two identifiers are used in the CDW as primary keys in the database tables and the encrypted identifiers are bigger (in terms of internal machine representation) than the non-encrypted identifiers. We therefore modified the storage format of some I2B2 tables in the ORACLE® database. We modified the I2B2 client accordingly to manage the new format of patient identifiers.

For non structured data sources (e.g., text reports from in/outpatient stays or surgical interventions), anonymization involves five successive steps:

1. Extraction of Microsoft® WORD-based text reports from the EHR database: a first PHP script using MS ActiveX objects extracts and uncompresses the native WORD-based text reports stored in the DxCare®/Medasys EHR database.
2. Conversion from WORD format into DocBook XML format with the ANTIWORD program.
3. Tagging of identifying data: a NLP tool is used to mark identifying data inside DocBook XML-based reports with new tags.
4. Encrypting of tagged data: the AES algorithm is used to encrypt reversibly tagged data inside XML-based reports with the 128-bit AES key.
5. Integration of encrypted XML-based reports in the CDW database with a second PHP script.

The data realm

As the first milestones of security and data protection were established, we assessed integrating real patient data into the CDW. Data realm implementation consists of three steps.

Step 1 – Identification of data sources

This step requires knowledge and expertise from legacy data sources necessitating close collaboration with the various application vendors.

Step 2 – Mapping of data sources into the target schema

The target schema is the five-axis star schema of I2B2 (PATIENT, PROVIDER, VISIT, CONCEPT and OBSERVATION) [13]. PATIENT, PROVIDER and VISIT related data are easily extracted from the data sources and mapped to the target schema because our CIS components already structure their data according to these axes and the corresponding items can be almost directly integrated into the I2B2 schema.

CONCEPT mapping

The attributes of the data source related to the CONCEPT axis address the issue of the classifications and terminologies used; these are very intimately linked to the business logic with which the data are created. In the I2B2 framework, each classification or terminology must be transformed into a tree structure (i.e. a hierarchy with single inheritance links). Therefore, the initial phase of CONCEPT mapping consists in providing:

1. A name for the new classification used by the data source;
2. A SQL request (r1) that returns a raw dataset including 1) the names of concepts in the new classification; 2) the identifiers for the concepts; 3) the identifiers of the parents for each concept.

Then, each line returned by (r1) must be transformed into I2B2 storage format with the tree structure constraint: the location in the classification is managed by a text field that is calculated as the sequence of the traversed levels from the root of the hierarchy down to the associated CONCEPT. This step can be performed by a second SQL request (r2).

OBSERVATION mapping

The attributes of the source data related to the OBSERVATION axis are the primary data subject to computation and analysis in the CDW. The initial phase of the OBSERVATION mapping is to provide a SQL request (r3) that extracts raw dated facts which comply with the four following constraints:

1. They must be related to a (single) patient.
2. They must be temporally dated: data that are not dated (for example the first name and the last name of a patient) are theoretically not eligible to be stored in the OBSERVATION axis.
3. They must be "generated" within the scope of the healthcare process, with an identified creator or source (the PROVIDER) and with an identified medical event (the VISIT), for example a consultation or a hospitalization.
4. They must be associated with a concept (an anchor in a classification loaded in the CONCEPT mapping step).

Then, as in the case of CONCEPT mapping, each line returned by (r3) must be transformed to meet I2B2 table format constraints (r4).

For each new DATA SOURCE, we have implemented these four different requests with dedicated ORACLE views using copies of the CIS databases (Figure 1). Copies are managed with ORACLE® import/export utilities to prevent direct use of production databases. The views are used in the Open Source Talend® ETL jobs when data are migrated. A master job encapsulates all ETL jobs to provide a single access point for integrating all CDW data at once.

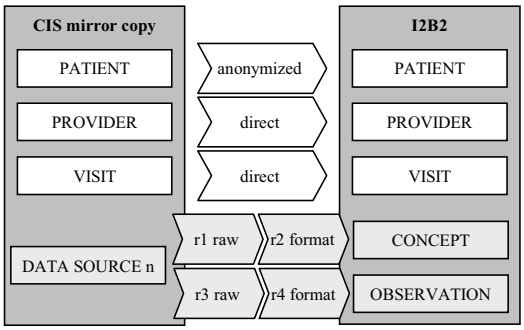

Figure 1 – Overall synopsis of data mapping

Step 3 - Building of dedicated datamarts

An important issue is the availability of data at the relevant level of granularity [15]. In the CDW, data are stored at the lowest possible level of granularity (as observation facts) and this may not be appropriate for users who want highly aggregated data. Hence, when necessary, dedicated datamarts are created for storing aggregated data at a required level with ORACLE materialized views. These materialized views allow specific design and fast access to pre-computed variables.

As concerns the PATIENT, PROVIDER and VISIT axes, the I2B2 database is loaded with 1,214,000 patients, 1,058,000 stays and 975 hospital units stays (as of September 2009); for the CONCEPT and OBSERVATION axes, we have integrated seven main different data sources into the CDW (Table 2).

Table 2 - Data sources currently integrated into the HEGP CDW (September 2009)

Data sources	Number of concepts	Number of observations
Laboratory results	7,291	62,819,471
Drug prescriptions	31,363	1,002,940
Clinical observations from structured forms	5,224	20,842,494
ICD-10 codes	21,356	1,874,639
Medical act codes	10,050	1,775,283
Consultation and hospitalization text reports from the cardiovascular department	39	165,873
DRG codes	3,771	467,281
TOTAL	79,094	88,947,981

The restitution realm

The restitution real analysis involves user interaction and functional integration with other CIS components. The main objective of the CDW is to facilitate access to clinical data for users and these users may have different profiles [12]. We therefore used dedicated tools for each user profile:

- Power users: SchemaSpy (to navigate in database models) and DocuWiki (to maintain technical documentation)
- Standard and occasional users: SAP/Business Objects (to design reports) and KaliTech®/Kalidoc (to integrate reports into the enterprise content management system)
- Searchers: I2B2 dedicated client

The restitution of CDW objects was evaluated through various pilot studies including:

1. EHCR quality management (clinical report exhaustivity for the year 2008)
2. Evaluation of medical prescription practices by studying simultaneous biological prescriptions of ESR and CRP in the hospital (since the year 2003)
3. Evaluation of a rule-based engine dedicated to pharmaceutical validation of drug prescriptions [16].

The administration realm

For the Administration realm, we decided to enlarge the functional perimeter of the Help Desk used in the hospital (Peregrine software®/GPS) to cover CDW functionalities such as "Request for new dashboards". For the two pilot domains, we used the Peregrine®/GPS software to register dashboard creation, and thereby monitor the evolution of these two CDW objects in the future.

Discussion and conclusion

CDW can be used in the health sector with several objectives, including: 1) quality management (for auditing or for outcome studies); 2) identification of best practices; 3) population follow-up (for predictive medicine or disease registries); 4) clinical investigations or case studies; and 5) intervention studies (as in before/after studies or controlled trials). The success of the CDW depends on the preexistence of the CIS producing and storing raw clinical data. The two components evolve in synergy: the CIS is the main source of data for the CDW and the CDW produces data (indicators, reports) that enhance the overall healthcare activity, which is in turn processed by the CIS.

In this paper, we have presented the methodology used for integrating a CDW based on the I2B2 framework into the information system of the Georges Pompidou University Hospital. We were able to initiate a global methodology for integrating heterogeneous databases into an open, community-based framework that allows integration with other HIS components for data restitution.

The open source feature of this framework helps with the adaptation of the core database model to implement our security strategy based on a strong reversible encryption algorithm applied to all patient-identifying data.

The simplicity of the I2B2 star schema model facilitates several tasks:

- Creating generic procedures (either with ORACLE® views or with Talend®/Open Studio jobs) for data integration into the CDW. In the data mapping step (figure 1), View 2 and View 4 are generic, and this accelerates new data source integration.
- Creating dedicated datamarts with ORACLE® materialized views to allow both the design of oriented analysis of new aggregated variables and to accelerate their computation and their integration into users' reports.
- Designing a dedicated SAP®/Business Objects universe layer for building reports and dashboards with raw or aggregated, CDW data.

We have also initiated the use of the Peregrine®/GPS helpdesk system but only in the scope of pilot domains. A specific task of user training is required to encourage the use of this help-desk software in the context of the hospital CDW.

We will continue to deploy a procedure to update the CDW data continuously from the currently integrated data sources, to add new data sources such the hospital bio-bank, and to evaluate the benefits and drawbacks of the CDW in a production environment. An important issue is the usefulness of the CDW for routine selection of candidate patients for clinical research studies. Another is the value of the system for feeding CDISC electronic case report forms (e-CRF), partly or completely, with data stored in the CDW to evaluate research fostering strategies such as those described in [17].

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TEDIS : an Information System Dedicated to Patients with Pervasive Developmental Disorders

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Abstract

Pervasive Development Disorders (PDD) represent a life disorder which significantly affects individuals and families. It requires long term specialized institutions health care, education and social accompaniment. In France, 350,000 to 600,000 patients are estimated to be affected and 5,000 to 8,000 newborns will develop the disorder every year. In 2005, Autism Resource Centres were created in each of the 23 regions in France, to support the PDD hospital reference centres in providing formal clinical assessment for each patient. Such assessments will support the prescription of health care measures, educative and intuitional orientation and accompaniment. An information system called TEDIS was designed to assist the psychiatrists and multidisciplinary medical experts at Necker child-psychiatry hospital, in organizing PDD patients' information and providing ground for improving knowledge about the disorder, its epidemiology and underlying biological mechanisms. The professionals' involvement from the beginning in the development process facilitated TEDIS design and implementation. The results of first experimentations are encouraging. They are described as well as the short term and mid-term deployment planning.

Keyword :

Autism, Pervasive Development Disorder, Information system, Internet, Dynamic web server.

Introduction

The concept of autism was extended since its first description by Kanner in 1943 to Pervasive Developmental Disorder (PDD)*. This latter represents a broad range of disorders characterized by the association of difficulties to communicate (verbal and non verbal communication), impaired social interaction and restricted, repetitive and stereotypes of behaviour patterns (DSM-IV, American Psychiatric Association, 1994 [1]). PDD may be associated or not to a mental delay. The frequent association with other neurological and organic disorders such as Bourneville Tuberous Sclerosis suggests a multifactorial aetiology of PDD.

Estimates of the prevalence of autism and PDD are moving towards increase in rates [2]. Recent studies have consistently provided PDD estimates in the range of 60-70/10,000 being thus one of the most frequent childhood neurodevelopment disorders [3]. In France, 350,000 to 600,000 patients are estimated to present with PDD and 5,000 to 8,000 new-borns will develop the disorder [4].

Diagnosis is based upon a precise behavioural and communication analysis of children about three years old. The treatment consists of life term care: a series of early and individually adapted measures in the domains of education, behaviour and psychology. Treatment compliance, may significantly improve the relational capabilities and social interaction with some degree of autonomy and possibility of language acquisition and non verbal communication.

Therapy costs are not negligible in the PDD context. Comparative direct health care costs studies between children affected with PDD, asthma and diabetes, showed the costs for PDD were two- to threefold higher than for asthma and diabetes ($4,815 vs. $1,469 vs. $2,404 respectively [5]).

PDD represents an important issue in public health as an increasing number of families and individuals seek educational, social and health care services to deal with the large impact of the affection [4, 6]. In France, public health authorities supported, particularly since March 2005, the creation and development of National and regional "Autism Resource Centres"†. They involve a multi-disciplinary team of experts in autism, who collaborate in favour of early PDD diagnosis, promoting research, assistance and providing information, counselling and expertise to the patient' families and to the health care and social professionals [7]. The Autism Resource Centre of the region of Ile-de-France region (11,616,500 inhabitants) coordinates five medical departments to provide clinical assessment expertise in patients affected with PDD.

The department of pedo-psychiatry (child-psychiatry) at Necker Hospital in Paris is among them. It beneficiates from two care units for autism assessment: an outpatient unit where PDD patients are hospitalized for a 3 weeks period and an ambulatory unit where patients are hospitalized during 4 days for checkups. The majority of children evaluated are between 3

* In french : Trouble Envahissant du Développement – (TED)

† In french : Centre de Ressources Autisme - (CRA)

and 6 years old. They undergo evaluation in a variety of domains: clinical assessment of psychological, motor and speech development, consultation in neurology and genetics, as well as specialized para-clinical exams including brain MRI with spectroscopy, contextual EEG, standard and high resolution caryotype, searches for chromosomes alterations by fluorescence in situ hybridization (FISH) and for metabolic disorders. Additional investigations guided by the clinical exam are prescribed as necessary.

A written report is issued at the end of the assessment. It is transmitted to the parents, to the care providers and/or to the institutions involved in the patient care. Formal demands are consequently addressed to specialized institutions to consider patient admission, to the Institution of Handicapped Persons [‡] (MDPH) to qualify the handicap and to the Social Security medical officer to qualify the long term character of the disease [§] (ALD) in order to beneficiate from the medical care cost coverage. For the last five years, about 250 children between 3 and 6 years old who consulted in the Necker child-psychiatry department were diagnosed as affected with PDD. They underwent an exhaustive clinical and para-clinical evaluation. The initial paper-based screening, despite its exhaustivity, contributed to find an aetiology in only 5% of the patients. Besides, it was not adapted to support complementary epidemiological and aetiological researches.

The need for a database system to automatically process patient's clinical information and support the multidisciplinary efforts in characterizing PDD was raised. The database system will focus on prospective patient assessment data in child-psychiatry department and integrates conclusions from genetics, neurology, ophthalmology, ORL, radiology, biochemistry departments. Longitudinal follow-up of PDD patients, will help evaluating the clinical evolution and adjusting prescription of medical, educative and social therapies. The database system will allow evaluating the significance of correlation between PDD phenotypes and genetic and/or biological disorder, and support further research studies. An information system called TEDIS (Troubles Envahissants du Développement – Information System) was designed based on formal cognitive engineering sessions between experts in the child-psychiatry department at Necker Hospital and in Biostatistics and Medical Informatics Department in the same hospital.

In the next sections, we will first present the objective and functional specifications of TEDIS and the database conceptual data model. We will then expose the present experimentation and planned project actions in the short term and the mid-term.

Material and Methods

Related works

Few databases related to autism are found in the literature; none in France dealing with experts' PDD assessment.

Database content: autism

- Daslne [8]: is a database of children with autism spectrum disorder living in north east of England was established in 2003 on a standalone computer in Newcastle University.
- AutDB [9] aims at providing current knowledge on candidate genes linked to Autism Spectrum Disorder. The content of AutDB originates entirely from published scientific literature and is manually annotated by expert biologists.

Production database within a Decision Support System

From the beginning TEDIS was designed to integrate a production database documented by end-users (clinicians) and controlled by psychiatrists into a decision support system. This latter will interact with additional automated internal and external resources, and will support health care decision making, epidemiology and research. There are several such systems in the medical literature. We will remind two of them developed at the Biostatistics and Medical Informatics in Necker Hospital for the proximity of the challenge, the data modelling and system implementation.

- MSIS Multi-Source Information System [10, 11] dedicated to patients with end-stage renal disease. Built on n-tiers architecture, dynamic web-server, with a patient identification server, a production database, a data warehouse and geographic information system.
- CEMARA [12]: covers a broad variety of rare diseases. Built on shared rare-disease data subset and on specific disease data sets.

Knowledge engineering meetings

Twice a month since October 2008, knowledge engineering meeting sessions gather senior and junior medical experts with the knowledge engineer to elicit the PDD' domain information specifications and users application requests.

TEDIS' application interface template was used to organize and represent the PDD domain information. It served as a mediator and supported feedback exchanges with the professionals between engineering sessions. Specific information subsets were validated progressively this way.

TEDIS' Objectives and functional specifications:

Objectives

- Improve PDD patient's health care, educative measures, social counselling and recommendations and support multidisciplinary collaboration;
- Contribute to a better knowledge of the aetiology and epidemiology and support heath care decisions, health care research;
- Contribute to improve systematic PDD patient's data collection in the reference centres, extend the use of the system and promote collaborative national and international research, with the respect of patient data privacy and interoperability standards.

[‡] In french : Maison des Personnes Handicapée (MDPH)
[§] In french : Affection de Longue Durée (ALD)

Database general specifications

The database has to be remotely accessible through secure connection, highly available with rapid response time. It should allow multiple and simultaneous accesses and support transactions. It should be scalable to accept growing data load from additional child-psychiatry reference centres.

TEDIS patient data privacy will be guaranteed through logical and physical processes complying with the national commission of freedom and computing (CNIL) recommendations.

The conceptual data model

Patient database

Nominative patient data are stored in a separate database. This design facilitates managing sensitive information and allows rapid searches for potential duplicates in patient data entries [13]. A sequential unique patient identification number is generated and serves to relate records from multiple database tables to a single patient file. Additional variable keys characterize individual clinical events such as: initial PDD state, expert assessment, multidisciplinary medical experts' decision at first visit / follow-up observation assessment.

Functional specifications

Clinical data: temporal assessment events:

- Initial state: It is a dated event corresponding to the first time the PDD diagnosis was assigned to a patient. It can be anterior to or the same as the first visit date to the child-psychiatry expert centre at Necker hospital. There is one initial state observation per PDD patient file. It includes:
  - Personal and family medical history, with psycho-social environment and context;
  - Pregnancy medical events and the parents' psycho-sociological assessment;
  - Birth reports;
  - 0-3 years period with developmental data concerning motor skills and language acquisition, context of schooling, social environment, major medical events;
  - Patient care, therapeutics, educative and social measures, before formal expert PDD assessment.
- First visit / Follows-up visits: these are also dated events, with a reference date of PDD' assessment in the child-psychiatry department. Follow-up assessments occur after a period of 18 months since last expert assessment. They include information about:
  - Context of visit to the department of child-psychiatry, the description of the objectives, the settings and the context of the patient evaluation;
  - Psychopathology assessment with specific detailed clinical tests of psychological, clinical, speech and motor assessment. For each assessment, a developmental age in comparison with the chronological age is assigned by the clinical expert;
  - Multidisciplinary assessments include: paediatrics, genetics, neurology, hearing and visual consultation and investigations, detailed electro-encephalogram characteristics, cerebral MRI results.
  - Based on the clinical assessment in the child-psychiatry department and in the multidisciplinary team, measures are proposed for school and educative orientations as well as re-educative and therapeutics treatments, in outpatient clinics or in full time care institution. A main medical diagnosis, based on ICD10 codification qualifies the patient disease. It may be documented with three associated medical diagnoses.
  - Multidisciplinary medical expert's staff decision may adjust or confirm the diagnosis or suggest further investigations. The patient case may eventually be included in a research protocol.

Data model

TEDIS relational data model, presented in Figure 1, is organized on individual PDD patient identification file.

The related medical information are stored in separate databases and linked to the patient identification using the patient identification number.

The data model matches the PDD patient organization.

An initial clinical state observation, before expert' assessment, is attached to each patient file.

A dated observation corresponding either to the first visit in the child-psychiatry department or to a follow-up visit (we will refer to both kind of visit as follow-up visit) is affected to the patient file. Follow up visit records are affiliated to the patient file.

To each follow-up observation, dated medical conclusions from experts in other disciplines are attached as well as dated observations of therapy measures and multidisciplinary staff recommendations.

The chronological sequence of observations may be described this way:

A patient identification record is created. An initial state observation, with a reference date: the date of the first time PDD diagnosis is attached to the patient file. An actual (follow-up) assessment observation enhanced with multidisciplinary assessment observations and therapy recommendations are attached to the patient file. Periodic clinical assessments are documented and attached to the patient file. Longitudinal information for a PDD patient cohort may be generated this way.

Additional information related to TEDIS' user profile, medical centres and medical thesauri, administrative data, standard list of professions, geographic locations, are organized in separate databases and used to document each patient record.

Finally, the database system is designed to easily accept PDD patient assessments from additional PDD reference centres.

Dynamic Web server

We implemented TEDIS based on n-tier architecture and thin Internet client through a secured web-interface connection. We used the Java JSP/Servlets technology and the Apache Tomcat Web server to communicate between the client and the MySQL database server. The servers are deployed on Linux environment [14] in tested secure architecture.

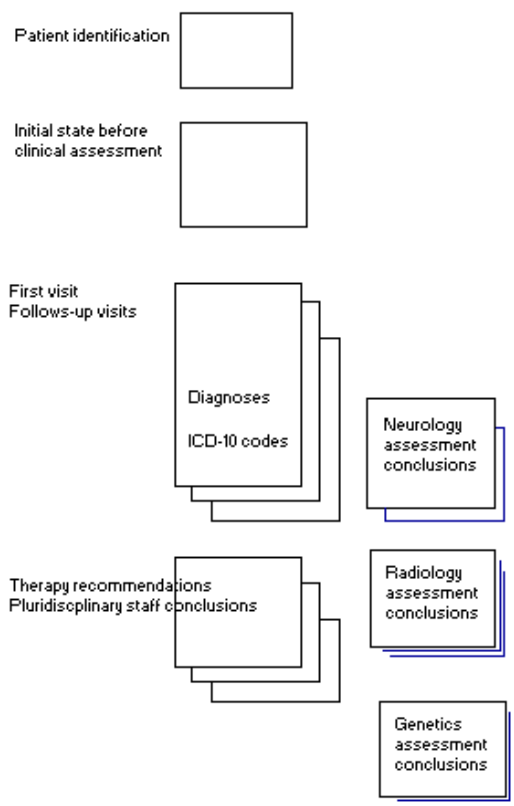

Figure 1 – TEDIS data model: To each patient record are affiliated: an initial state before assessment observation, one or many follow-up visit observation, one or many multidisciplinary assessment observations and one or many multidisciplinary staff therapy recommendations.

Experimentation

The experimentation is organized into phases:

- Current phase consists of testing the paper template forms issued from the TEDIS application interface, to assess its acceptance among a variety of professionals, the easiness of its use, and its completeness according to TEDIS objectives. The impact of data availability for entering retrospective and prospective patient records were evaluated as well as the need of a medical expert to fill or supervise filling which subsets of PDD patient information.
- The application will be deployed current year and the objective is to enter by the end of this year all 2009' PDD expert assessment observations about 50 patient records.
- Besides continuing collecting prospective data in 2010, retrospective patient's observations, about 250 observations, will progressively be entered in the system.
- The deployment and user training will continue in the following period. The ability of TEDIS to support the multidisciplinary staff meetings, based on the data collected will be tested during this period.
- During 2010, major TEDIS functionalities built around the production database and the TEDIS application are supposed to be stabilized and to be able to accept patient's data from additional PDD reference centres.

Results

Actually a minimal patient record of PDD' patients assessment in child-psychiatry and related medical disciplines was made available as the result of collaboration between medical informatics and medical domain experts. It is agreed upon among a large community of health professionals including psychiatrists, psychologists, speech therapists, neurologists, radiologists, geneticists, etc.

According to the professionals among psychiatrists and psychologists who tested the paper forms issued from TEDIS: the application form interface is structured in a way to allow fluid move from specific assessment subsection to a general overview representation of the multidisciplinary assessment. TEDIS forms are easy to fill.

Twenty PDDS' patient records were filled by medical expert of child-psychiatry. This experiment pointed out the difficulty to fill retrospectively patient records because of unavailability of information and the need to make specific searches. It was time consuming and required about 20minutes completing retrospectively a PDD patient record.

A second observation from this experiment concerned the need of a medical expert to fill most of the clinical assessment sections as they required specific test results qualification and integration. Administrative data and event dates such as multidisciplinary assessments dates and clinical authors may be completed by non medical staff members.

Discussion

Existing PDD database systems are either too specific in comparison with TEDIS' focus (e.g. evolving medical expert assessment) or complementary in the domain of autism and PDD. In contrast with existing database systems, where patient associations primarily influenced the database design [8],

TEDIS was designed with medical experts in child psychiatry, to respond to their demand to organize growing patient's data.

TEDIS is dedicated to PDD patient expert assessments for a better knowledge of the demand of care and for adapting and coordinating the multiple care issues and resources. The accumulation of quality data of prevalent and incidents patients will provide valuable resources for assessing early diagnosis, enhancing therapy measures, developing epidemiological analyses and supporting research in particular in relating genetics and biological processes to clinical phenotypes of PDD.

The design of TEDIS' database system opened to extend data input from multiple child-psychiatry medical centres, offers the perspective of improving systematic PDD patient's data collection in the reference centres and promoting collaborative work between child-psychiatry centres as well as international research, respecting patients' data privacy and interoperability standards.

Challenges of interoperability, epidemiology data analysis and researches in genetics and biology correlations will characterize future developments of TEDIS.

Conclusion

Modelling medical domains remains a challenging and a continuing task. It has to fit with the health care community needs for a better knowledge of the care demand and for a better planning of the offer of care. Implementation of the data model has to support the professionals' patient data management in daily use and favour collaborative multidisciplinary team work. Integration into a decision system will support research and enhance decision making.

The data collection process has to be opened and favour collaborative work between domain expert teams and decision makers. It has to profit from advances in technologies and rely on interoperability standards. TEDIS is dedicated to patients with PDD, was designed to meet with these challenges.

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Developing a User-centered Voluntary Medical Incident Reporting System

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Abstract

Medical errors are one of leading causes of death among adults in the United States[1]. According to the Institute of Medicine, reporting of medical incidents could be a cornerstone to learn from errors and to improve patient safety, if incident data are collected in a properly structured format which is useful for the detection of patterns, discovery of underlying factors, and generation of solutions. Globally, a number of medical incident reporting systems were deployed for collecting observable incident data in care delivery organizations (CDO) over the past several years. However, few researches delved into design of user-centered reporting system for improving completeness and accuracy of medical incident collection, let alone design models created for other institutes to follow. In this paper, we introduce the problems identified in a current using voluntary reporting system and our effort is being made towards complete, accurate and useful user-centered new reporting system through a usability engineering process

Keywords:

Patient Safety, Incident Reporting, Usability, Task analysis, heuristic evaluation

Introduction

The University of Missouri Health System has implemented a web-based medical incident reporting system called Patient Safety Network (PSN) since 2002. In the previous study [2] on one year dataset of medical incidents, 2,919 cases out of total 5,654 reports were finally extracted as non-duplicated and valid data after cross checking consistency and completeness. Among them, 958 cases (32.8%) were labeled with "miscellaneous", which was too blurry to be analyzed in-depth even after laborious manual data pre-processing. In addition, the rest of dataset still face challenges due to chunks of descriptive incident data in free text format.

The completeness and accuracy of reported incidents are core attributes for meaningful use and iterative improvement of voluntary medical incident reporting system. According to the previous researches, plenty of conceptual blurs were existed in the process of medical incident reporting. For example, how to break down the "miscellaneous" dataset into distinct subclass; how to build a comprehensive hierarchy to precisely express incident classes such as "fall", "medication/IVs"; how to approach a rating scale system of harm score for reporter to evaluate incident severity with less uncertainty; and how to improve reporting process for meaningful description of medical incidents. These are the questions asking for higher quality of data entry. On the other hand, system utilityb[3] perceived by levels of users could either accelerate or impede the enhancement of such application, which depends on system feedback. For instance, the comprehensive summary and analysis results of incident data generated by system is a foundation to develop collaboration for system using among the stakeholders such as reporters, analyzers (designer) and CDO leadership. That feedback cycle could effectively and efficiently assist designers in interpreting and working out the problems that arise during use, and in return, different level of users can quickly perceive improvement in person. Consequently, a sustained development process of user-centered voluntary medical incident reporting system could be established. However, all supposed achievements above heavily rely on quality data.

For this purpose, we are redesigning a voluntary medical incident reporting system with user-centered concerns. In contrast, the current PSN system has a variety of usability weakness and heuristic violations in aspects of site structure, navigation, scanability and flexibility, according to Nielsen's guide book[4] for web design. Therefore, usability is regarded as a standing point of user-centered reporting system design at the initial stage of our study.

Previously, usability was proved as one of most influential human factorsb[5] to usefulness and ease of use in this kind of system. From recent published literatures [6-7], it comes to the fore that the ultimate accept or reject of such system largely relies on the degree of system usability [8]. By far, due to time pressure and immature theories of engineering method, the usability studies were rarely conducted in the process of existed medical incident reporting system design and development system. However, it is believed that the usability issues are included from the beginning of the development process not only the iterative design cycle may shorten, more importantly new insights might be acquired on general system design aspects that might potentially lead to errors in healthcare. So in the entire project, we combine usability engineering as an initial part of development cycle for a user-centered medical incident reporting system.

Methods

The user-centered design framework [9] requires analysis at the user, task, function and representation level for effective design and evaluation of an information system. In a prototyping process, we started with a dominant type of users (nurse)

and employed a horizontal dimension prototyping method [3] to keep the features yet eliminate the depth of functionality.

Focusing on the functionality of reporting, firstly we conducted a task analysis inspecting the PSN interface to measure several fixed factors that might influence usage of system and set a series of goals for improving identified weakness. Secondly, we developed a new web-based interface using JavaScript, PHP and ExtJS library with new features on technology and content management such as Ajax and procedure based question-answer. And then executing task analysis again on the new interface aimed to confirm achievements of new design. Meanwhile, we conducted a heuristic evaluation to identify severe usability violations and use the results to improve the overall user-friendliness.

Task analysis

Referring to Nielsen's book of usability engineering [3], a task analysis is to study how users approach the task, their information requirements and how they deal with exceptional circumstance, identify points where users fail to achieve goals, spend excessive time, or feel uncomfortable. The analysis generates a list of all the information users will need to achieve goals, the steps that need to be performed and the criteria used to determine the quality and acceptance of results. In this case, we set three variables as inspected objects: mouse click, key stroke and memory load. By emulating a typical user's operation in reporting a patient fall incident, the step counting on these three aspects were summarized and grouped into four sections: initial questions, event common questions, event details and summary & others, as it shown in Table 1. The improvement of system on such concerns is believed to visibly reduce the operational and mnemonic workload in the process of incident reporting. What make these three factors interest us is they can be measurable and improvable by interface re-engineering.

Concretely, we went through the PSN and new interface with the same scenario of patient fall, which requires largest number of questions in all existed eight types of event. They are including blood/blood products, skin impairment, medication reaction, equipment/device, medication/IVs, fall, procedure/treatment and miscellaneous. The number of mouse click and free text input was calculated and summarized for same steps of each interface. Simultaneously, the analysis of memory requirements was conducted for each section (a granularity defined above) of two designs to measure memory requirements of reporting system questions. In the end, all summarized outcomes on mouse click, key stroke and memory load were listed into a tabular format for comparing differences of two systems. This spreadsheet can intuitively illustrate the progress in usability issues between the two interfaces.

Heuristic Evaluation

Heuristic evaluation is a usability inspection method effective in uncovering design problems, which is considered to yield the most serious problems with the least amount of effort [10]. For this discount evaluation method, 3-5 usability experts are recruited to inspect interface design problems, and then they are requested to summarize and report heuristic violations as a basis for usability improving.

For resource limitations in terms of time and finance, we eventually enrolled three doctoral students majored in computer science with proper training on heuristic evaluation method. They were asked to use the 14 usability heuristics developed by Zhang et al. [11]. The 14 categories refer to: Consistency; Visibility; Match; Minimalist; Memory; Feedback; Flexibility; Message; Error; Closure; Undo; Language; Control; Document.

Table 1-The requirements at the Key Stroke, Mouse Click and Memory Load level of two interfaces

Sec	Task		PSN(A) Prototype(B) Both(S)	Key stroke	Click	Memory Load
Answer Initial Questions	Anonymous Report	A	RadioGroup check(Y/N)		1	Recall the title of health profession, facilities where incidents occurred and level of patient involvement
		B	Checkbox(default:uncheck)		0~1	
	Health Profession	A	Pulldown list		2	
		B	Has default value, auto-complete entry	Initial letters	0/2	
	Involvement	S	RadioGroup for facility and patient involvement		2	
Event Common Questions	Demographic	S	Name,Birthday and Gender	Patient name entry	10~11	Patient ID or name; When the incident happened and what date is that day; patient home unit and related doctors
	Event Date	A	Time pickup widge		2~3	
		B	Add with default value, two shortcut buttons		0~3	
	Address & clincians	A	pulldown list,text field		7	
		B	Add with auto-complete	Initial letters	7	
Event Details	Type & Harm Score	S	Both are RadioGroup check widgets		2	Recall entire process of incident and compare them with page quesitons in mind, then make a precise or
	A series of questions to depict cases,e.g."fall"	A	Single & Multiple textfields, RadioGroup, Checkbox, Dropdown list	up to 6,000 free text input	6+	
		B	Procedure based question-answering radio groups	Specify in short for unlisted items	4~11+	
Summary Other	Review info; save,submit, delete	A	Review but cannot modify info		1	memorize which question and which page this question is in
		B	Can modify most of info		1	
	Page flips	A	Button for backing to previous page		9	
		B	Navigational bar takes page flips		9	
Total		A		very much	42~44+	
		B		a few	35~49+	

Three experts were asked to conduct an on-site evaluation as a group. The entire process took about 60 minutes. The first 15 minutes were spent to explain background of evaluation, hand out an evaluation stepwise description and make a brief demonstration of interface operating. Then the experts did the evaluation as a group but individually, due to the timely evaluation for the first version of prototype. One of them played the interface as an incident reporter according to stepwise task description. At the meantime, the rest observed operations and inspected system features and feedbacks. They were asked to go through the interface together several times with following 14 usability principles (14 usability heuristics) and developed pertinent discussions. The group of evaluators jotted down usability violations and solutions suggested, and then rated a severity score for each usability violation based on the following scale:

- 0 - Not a usability problem at all;
- 1 - Cosmetic problem, need not be fixed unless extra time is available on the project;
- 2 - Minor usability problem, low priority to fix;
- 3 - Major usability problem, important to fix, so should be given high priority; and
- 4 - Usability catastrophe, imperative to fix before product can be released.

In the end, such results organized in Excel format were sent back to us as a feedback. The entire process was audio-taped and later reviewed several times to find out missing parts and remove duplicates (same meaning in different expressions). All of our modifications were emailed back to each evaluator for verification purposes.

Results

As a result of task analysis, Table 1 exhibits the detailed combination of two analyses. It manifests the interface testing outcomes in terms of mouse click, keyboard stroke and the retrieval of mnemonic information. The four sections of tasks were investigated, including initial questions, event common questions, event details and summary/other. The number of mouse clicks varys, which depends on if default value applies or not (e.g. 0/2 means that selecting "Health Profession" require 0 or 2 mouse clicks) and if a question has multiple values (e.g. 4~11+ means that depicting a fall event requires 4 to 11 plus mouse clicks to answer questions in format of radio button and checkbox). The column of key stroke argues the reasons of text inputting for each interface. And the last column elaborates the requirements of mnemonic data to each section. In total, the new design has a large range of mouse click counting number, 35~49+ clicks based upon a typical case used for testing; whereas, the PSN has 42~44+ clicks. But for requirements of key stroke and memory load, the new design requires much lower.

The changes above came with the following technical progresses we made in the new interface.

- Set default values with statistical evidences. E.g. our analysis shows nearly 70% of reporters are residential nurse and nearly70% medical incidents were reported within two days after occurrence. Therefore, setting "RN" as default value and creating two shortcut buttons for picking up today's date and yesterday can facilitate data entering.
- Present accurate and meaningful prompts at the appropriate position. E.g. replace a chunk of static instructions with over-the-cursor button tips and show concrete date on today's date button
- Shortcuts for data entry and adjustment. E.g. easy page flips, can edit almost all entered data at summary page
- Using closed-ended questions to substitute open-ended ones.
- Procedure based ("if-then" rules) process combined with closed-ended questions for collecting event details. Using standardized multiple choice questions to substitute open-ended questions in formats of multi-lines text field, single-line text field, checkbox, etc.

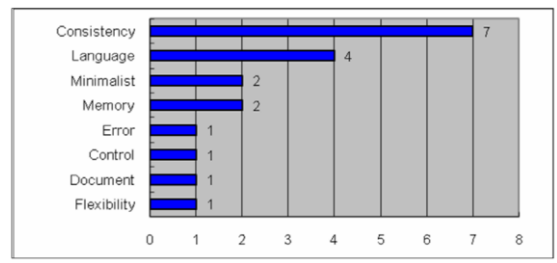

Figure 1-The categorical distribution of identified 19 usability violations

By heuristic evaluation, 19 usability violations were identified, which belong to 8 heuristic categories. Consistency and Language were the two heuristics most frequently violated in the new user interface. These two categories alone accounted for nearly 60% (11/19) of all the identified usability violations. The specific distribution of heuristics violated in this step is presented in Figure 1.

The concrete descriptions of result were organized into a tabular spreadsheet, which is a list of 19 usability problems found through the interface as well as hints for features to support successful user strategies. There are total six sections, including five sections of date reporting (initial info, event common info, event details, summary and harm score), as well as one section for general problems. The severity scores rated by three evaluators are averaged and the narrative texts are reorganized into proper categories. The Table 2 is an excerpt from all identified violations with severity score over 2.5 (major and catastrophic violations). In this table, the sections are consistent with them in Table 1.

Discussion

This study demonstrated the initial employed strategy for usability engineering a voluntary medical incident reporting system. First of all, the two dimensions of prototyping methods were introduced to decompose the entire system development into vertical and horizontal levels. Then, at the vertical level, we did research on reporting functionality of the current PSN and new interface to discover variables influencing usage of system through task analysis.

Table 2-An excerpt from major and catastrophic usability violations

Sec.		Problem Ddescription (P) Recommended Solution (S)	Heuristics Violations	Severity Rating
Initial Questions	P	No explanation to red asterisks for required questions	Document	4
	S	Explain at the first place where red asterisks appeared		
	P	Layout of two radio group widgets	Consistency	2.66
	S	Indent the options of these two widgets, use shaded block to highlight them		
Event Details	P	The name of button which triggers a reset of start over the event details question	Language	3
	S	Change button text ""restart"" changes into ""reload this page"" or ""clear""		
	P	Use "check one" to be a alert for radio group that only can check one option	Minimalist	3
	S	Remove "check one"		
	P	User is maypossible to forget to rate for event harm score	Consistency	3
	S	A better reminder or put it event harm score section into one a separate page to instead of on the navigational bar		

And at the horizontal level, we started a heuristic evaluation on the new interface with improved factors mentioned above. Such an iterative analysis, development and evaluation process will be continuing until all issues such as user types, tasks, functionality and data representation are completed at the both vertical and horizontal levels. This is our usability engineering method for system prototyping.

There are two reasons for us to follow the PSN system and develop the new system framework and data entry process. One is because some of changes made to solve certain problems may cause new problems. Another reason is about learnability. A substantial modification could make system new to current users and break down their previous convention and understanding of reporting a medical incident. The relearning could cause frustration to expert users and be time consuming for both novice and expert users.

In task analysis, three factors were identified to largely affect users' performance of reporting. They are memory load, key stroke and mouse click. Comparing the two analysis results on existing and new incident reporting, the memory requirements of new one for manipulating interface and incident recalling were decreased largely. An impressive enhancement achieved is for answering event details. In the PSN system, it used many different widgets for such data collection including 2 single text fields, 2 multiple text fields, 4 pull-down lists, 10 radio/checkbox groups and 7 buttons. All of them laid out in a two screen high (screen resolution is 640x480 pixels) page. The users have to scroll the page back and forth and leap blindly among the confusing questions which are considered heavy burdens of memory load per cognitive theories. Furthermore, those two multiple text fields allowing up to 6,000 characters free text input can frustrate reporters and results in various levels of details of reporting. On the contrary, the counterpart of new design followed the Common Formats of AHRQ and set up less than 11 causal related questions in closed-ended format meeting the same goal. Such improvements not only lower the memory burden, but also can remarkably decrease the number of key strokes. On the other hand, though the number of mouse clicks is still as similar as it before, the actions of clicking became easier and less clicks could be achieved once reporter is a default user. For instance, a nurse reports an intraday incident. Obviously, the conciseness and easiness achieved by new interface is able to enhance reporting efficiency and users' satisfaction.

There is a trade-off we have to address. To avoid catastrophic errors may lead to design a less efficient user interface, such as adding extra questions to assure the user is certain about a particular answer or action. And adding auto-complete function to pull down list can save the time and lower the memory requirements but increase the number of key strokes. Therefore, it is not realistic for system design to achieve the best on all issues, such as three factors in this paper and unmentioned ones. What we should chase might be to make a balance for an acceptable compromise.

For heuristic evaluation results, each usability violation was categorized into 4 severity level according to its averaged rating score. They are catastrophic (rating > 3.5), major (2.5 <rating < 3.5), minor (1.5 < rating < 2.5), and cosmetic (rating < 1.5). Of 19 identified violations in total, there are 9 problems at the major level and 5 at the catastrophic level. These 14 problems consist of 4 Language ones, 3 Consistency violations, 2 Memory ones and each one in other five categories (Document, Error, Control, Flexibility and Minimalist), and 3 of 4 Language ones are usability catastrophes. All violations found in the first round of heuristic evaluation would be sequenced to steer enhancement of system usability.

To sum up, the task analysis and heuristic evaluation applied in this study can facilitate developers of volunteer medical incident reporting system at the initial stage of development cycle in fulfilling the users' needs and uncovering the flaws of usability concerns. Although it is not feasible to work out all the problems, these two steps will drive usability research into a system development cycle, especially for voluntary medical incident reporting system. As a result, usability problems could be iteratively identified and fixed, and users could be much easier and more satisfied of using voluntary medical incident reporting system over the time.

Future

The usability engineering is not a one-shot task but an iterative process with usability discovery and reinforcement. Furthermore, the development of a user-centered medical incident reporting system needs to establish a relation between different levels of users which is crucial to success of medical incident reporting applications. For instance, poorly unstructured incident datasets and lack system integration of the PSN have largely impeded system's usefulness. Much electronic medical

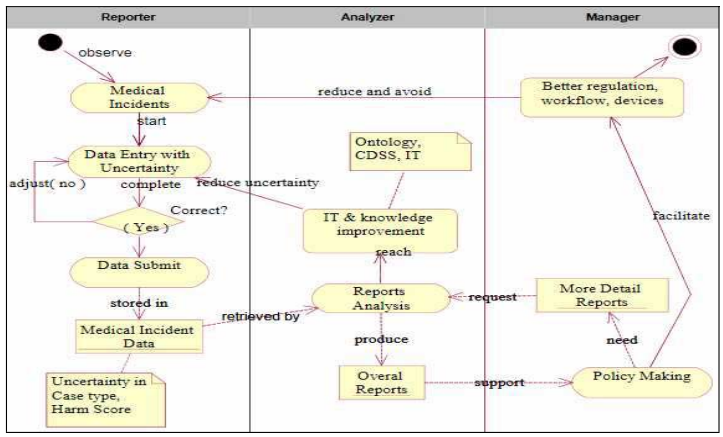

Figure 2-Iterative feedback cycle for voluntary medical incident repoting system

data have to be repeatedly entered into the PSN system and a big chunk of medical data in free text format shows inconsistency and impedes the application of data mining tools. Therefore, to advance our study we will emphasize collaborations between different systems and different types of users. The iterative development cycle shown in Figure 2 depicts collaborative feedback among three participating roles: reporters, analyzers and mangers. The reporters are in charge of data entry of observed medical incidents by reporting system. The quality of data stored in properly structured format is the key to validity of incident reports. The analysis reports will advance the applied technology and knowledge support for medical incident reporting for the purpose to diminish the uncertainty and other difficulties in reporting process. On the other hand, the analysis reports can be used to persuade managers of health unit to extend the usage of reporting system by administrative approaches, such as policy making. Ostensibly, the effective collaboration shown in Figure 2 could facilitate using and enhancement of voluntary medical incident reporting system. The more important is that the quality of care could be improved continuously with iterative enhancement of system performance and increasing use of reporting system.

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CEDRIC: A Computerized Chronic Disease Management System for Urban, Safety Net Clinics

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Abstract

To meet the challenge of improving health care quality in urban, medically underserved areas of the US that have a predominance of chronic diseases such as diabetes, we have developed a new information system called CEDRIC for managing chronic diseases. CEDRIC was developed in collaboration with clinicians at an urban safety net clinic, using a community-participatory partnered research approach, with a view to addressing the particular needs of urban clinics with a high physician turnover and large uninsured/underinsured patient population. The pilot implementation focuses on diabetes management. In this paper, we describe the system's architecture and features.

Keywords:

Information systems, Chronic disease, Diabetes mellitus, Continuity of patient care, Disease management, Clinical decision support systems, Registries

Introduction

For every 1,000 patients who receive medical care in the US, it is estimated that only one patient receives this care at an academic medical center.[1] Informatics tools specifically designed to assist those clinicians who provide the bulk of patient care in non-academic medical settings could have a tremendous impact on improving healthcare quality. About 125 million people in the US suffer from at least one chronic disease.[2] In spite of this high prevalence, there is consensus that the quality of chronic care in most primary care settings is inadequate.[3] Factors contributing to this inadequacy include deficits in care coordination, lack of information and ongoing support for self-management, poor management of clinical information, and inadequate decision support mechanisms for providers of care.[4] These are further magnified in safety net clinics by high patient-to-physician ratios, limited access to care, lack of insurance, and under-insurance. Wagner's Chronic Care Model identifies clinical information systems as a key component in addressing chronic disease management.[4-6] In particular, clinical information systems that include registries are invaluable for collecting and managing data on chronic diseases, monitoring the health status of a clinical population, and assessing the effectiveness of a clinic's quality improvement efforts.[7] Although most studies of electronic disease registries have examined their use in managed care settings, at least one study has shown that it is feasible to develop electronic disease registries for use in safety net clinics that cater to uninsured and medically underserved patients.[8]

A recent first of its kind comprehensive survey of health information technology use among California community clinics suggests that while 96% of the clinics have implemented a diabetes registry, only 31% report that all providers use the registry.[9] Another study has shown that implementation of disease registries appears to be more successful in clinical settings that already have electronic health information systems versus clinical settings that utilize paper-based systems to record and track patient health information.[10]

Nine suggested features for electronic registries are: a) short training time and easily navigable screens, b) registry systems should be web-based, c) drop-down menus and logic checks, d) HIPAA compliance and adherence to internet security standards, e) support for multiple diseases/conditions, f) incorporation of clinical practice guidelines and reminders, g) support for creation of individual care plans and disease severity rankings, h) ability to print out summary data on care quality and patient outcomes, i) linked to *but not a substitute for* an electronic medical record.[7] An evaluation of three widely used registry systems: the Chronic Disease Management System (CDMS), the Patient Electronic Care System (PECS), and DocSite showed that none possessed all of the nine suggested features.[7] Other suggested features include real-time availability of data, the ability to search for and identify patients at risk for a given clinical condition, web-based links to diabetes guidelines (for diabetes registries), and the provision of feedback to providers to aid preventive and long-term patient care.[11]

Since a goal of some existing registry systems is to spur wide adoption in primary care clinics that may not have dedicated IT staff, they sometimes utilize file-based database management solutions geared for ease of use by lay-people (e.g., Microsoft Access). Unfortunately, these solutions may not offer robust patient data security or be scalable as a clinic's population grows. In addition, some of these registry systems make assumptions about the clinical setting, (for example, assump-

tions about how patients are assigned to primary care providers), that may not correspond with reality, resulting in a need for extensive customization in settings that may not have the requisite IT staff. Recognition of these issues and a desire to address them has led to a unique community-participatory partnered research collaboration between researchers at the Center for Biomedical Informatics at Charles Drew University (CDU) and clinicians at the Family Medicine Clinic of the Hubert H. Humphrey Comprehensive Health Center (HHHCHC). HHHCHC is a Los Angeles County Department of Health Services ambulatory care clinic that has approximately 13,000 annual patient visits and caters to a patient population that is 55% Latino and 37% African American, with 70% or more of the patient population lacking public or private insurance.

The Family Medicine Clinic at HHHCHC has attempted to utilize the Chronic Disease Electronic Management System (CDEMS) in the past for depression management. Recognition of the need for extensive customization of CDEMS was one of the factors that led to the current collaboration between CDU and HHHCHC. A goal of the CDU-HHHCHC collaboration is to develop a computerized system for managing chronic diseases in primary care settings that takes into account the socio-technical barriers to successful implementation and forges academic-community partnerships with community clinics that cater to medically underserved patients. The CDU Electronic Disease Registry to Improve Chronic Care (CEDRIC) is a chronic disease management system that has resulted from this effort.

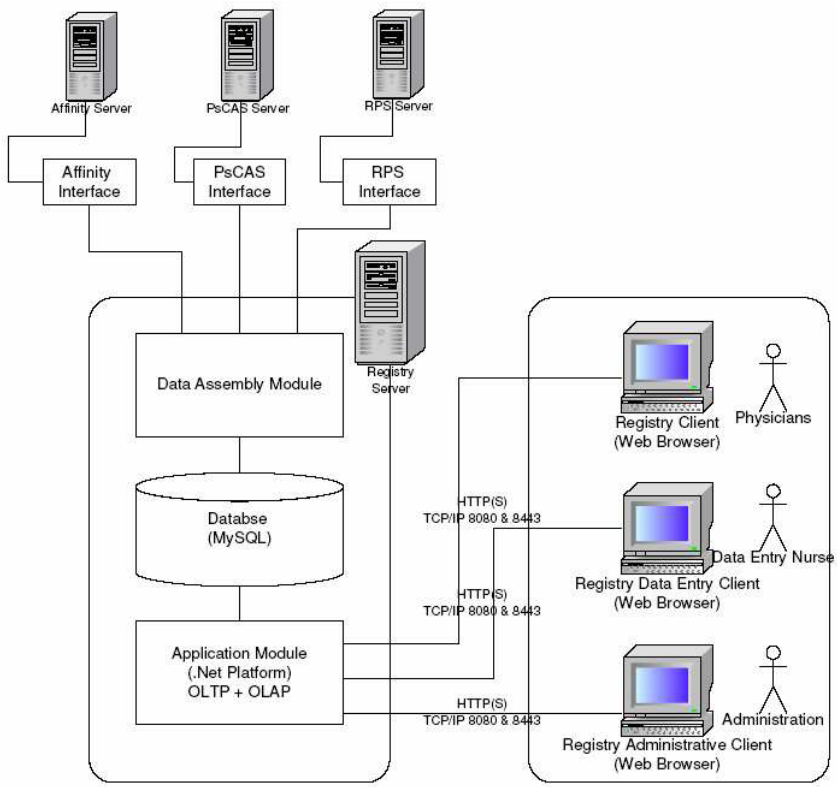

Figure 1- CEDRIC System Architecture

Materials and Methods

Through weekly meetings with clinicians at HHHCHC and researchers at CDU that have continued for over a year, key elements of a system for chronic disease management focused initially on diabetes were identified. Identified needs included: (1) robust system security, (2) access to data and system features based on a user's role as a physician, nurse or administrator, (3) system scalability and flexibility, (4) promotion of evidence-based medicine based on local and national clinical practice guidelines through the provision of automated system alerts and recommendations, (5) the ability to query and summarize pertinent information about an individual patient, (6) the provision of automated periodic reports for physicians, nurses and clinic administrators on patient lab results, care continuity, self-management, Hemoglobin A1c (HbA1c) levels, medications, and comorbid conditions, (7) a HbA1c monitoring service that enables interested clinicians to flag patients whose HbA1c levels they wish to monitor more closely, (8) the ability to track the homeless status of patients as this affects treatment options (the clinic refers homeless patients for social services prior to initiating treatment, since patients receiving insulin need access to refrigerators). While the clinic does not have a fully-integrated electronic medical record (EMR) system, it does have computerized patient scheduling, laboratory, medication, and referral systems. The need to interface with these existing systems was noted. The sociologist on the team, based on interviews with clinic providers and nursing staff, developed a workflow chart to outline the existing clinical flow of patients with diabetes in the family medicine clinic. This was done in order to understand how the CEDRIC system could be best implemented to fit into the existing clinical processes and workflow at the point of care since an understanding of workflow has been a feature of successful diabetes management systems.[12] Charting the workflow required a detailed understanding of the steps involved in a diabetic patient's visit to the clinic. We found that patient visits included the following four steps: 1) registration and financial screening at the general reception desk of the clinic, 2) initial assessment and review of vital signs by the vitalization nurse attendant, 3) visit with the clinician in the exam room, and 4) counseling and discharge by the post-visit nurse-counselor.

Results

CEDRIC has the capability to receive and process daily patient scheduling data and identify those patients with the chronic disease to be managed. The system is designed around a progress note that facilitates standardization of care for patients with particular chronic conditions. It is a database-backed web application utilizing the .Net framework, with C# and VB.Net as the programming languages and MySQL Server 5.0 as the database management system. MySQL was selected for its scalability, platform flexibility, security features, robust transactional support, data warehousing capabilities, and the fact that it is an open-source database management system. MySQL's storage-engine architecture allows the server to be configured for different applications - in our case, to support both the high-volume of transactional queries (OLTP) handled by CEDRIC via users' interactions with the progress note, and the high-speed analytical processing (OLAP) for patient care summaries/reports.

System Architecture:

CEDRIC system components include a registry server and several clients (see Figure 1). Within the server, a data assembly module is designed to collate electronic information from the clinic's health information (Affinity), referral (RPS), and medication (PsCAS) systems. It also checks for data inconsistencies and errors prior to data storage. CEDRIC's server utilizes MySQL for both transactional data processing and to support its data-warehousing environment for generating different clinical care reports. An application module that works in conjunction with a web server retrieves and processes data from the database, stores data to the database, constructs web pages containing requested information for presentation to the user, and implements logic for generating alerts and customized clinic-wide and clinician-specific core measure reports. These reports include patient summary reports, appointment reports for tracking care-continuity and on-demand registry queries. The CEDRIC system has three client categories; physician, nurse and administrator. The system display, including progress note, patient monitoring options, and care report options, is tailored to a user's login role. Users with two roles (e.g., physician and administrator) can interact with the system using either role. Figure 2 shows part of the progress note screen for a physician.

The alerts system is designed to automatically notify physicians when values corresponding to laboratory measurements are out of range, and when referrals and medication refills are overdue. The recommendation system for diabetes management is designed to deliver American Diabetes Association guideline recommendations as well as locally-tailored modifications to these guidelines on the appropriate course of action to be taken in response to alerts.

CEDRIC includes most of the suggested features outlined in the introduction. The feature not entirely implemented is linkage to an EMR system because HHHCHC does not currently have a fully-integrated EMR system. However, CEDRIC is designed to capture and utilize electronic data feeds from the different existing systems that handle patient scheduling, laboratory management, referrals, and medications. CEDRIC would be able to interface similarly with a full-fledged EMR system when the clinic chooses to adopt one.

Discussion

We have presented a summary of CEDRIC, a chronic disease management system developed through an academic center-community clinic partnership. The system implements most of the suggested features for an electronic disease registry as outlined in recent publications on the subject. A key aspect of system development was close collaboration between community clinicians and academic informaticians in identifying and addressing critical issues. We view this close collaboration as key in developing health information systems that are tailored to community health center needs, since many such centers do not employ informaticians, generally have small IT

budgets, and may not have in-house technical support to adapt existing generic IT systems to meet their unique needs. It is our view that information systems that meet the unique needs of community health clinics are more likely to be routinely used by clinicians in those settings. Support for management of chronic kidney disease, cardiovascular disease, HIV/AIDS and depression is planned.

Ongoing activities for CEDRIC include development of a data input module that supports both HL7 version 2.x and version 3.x messaging standards. The new module will accept several different data formats, including: i) HL7 v2.x compliant data, which mostly uses a textual, non-XML encoding syntax based on delimiters, and, ii) HL7 v3.x compliant data, which is based on a formal methodology (the HL7 Development Framework or HDF) and object oriented principles and is encoded using XML.

Future work will include a formal evaluation of the effect of system introduction and utilization on patient outcomes and the quality of care at the clinic. We also plan to make CEDRIC available for use to other safety net clinics.

Acknowledgements

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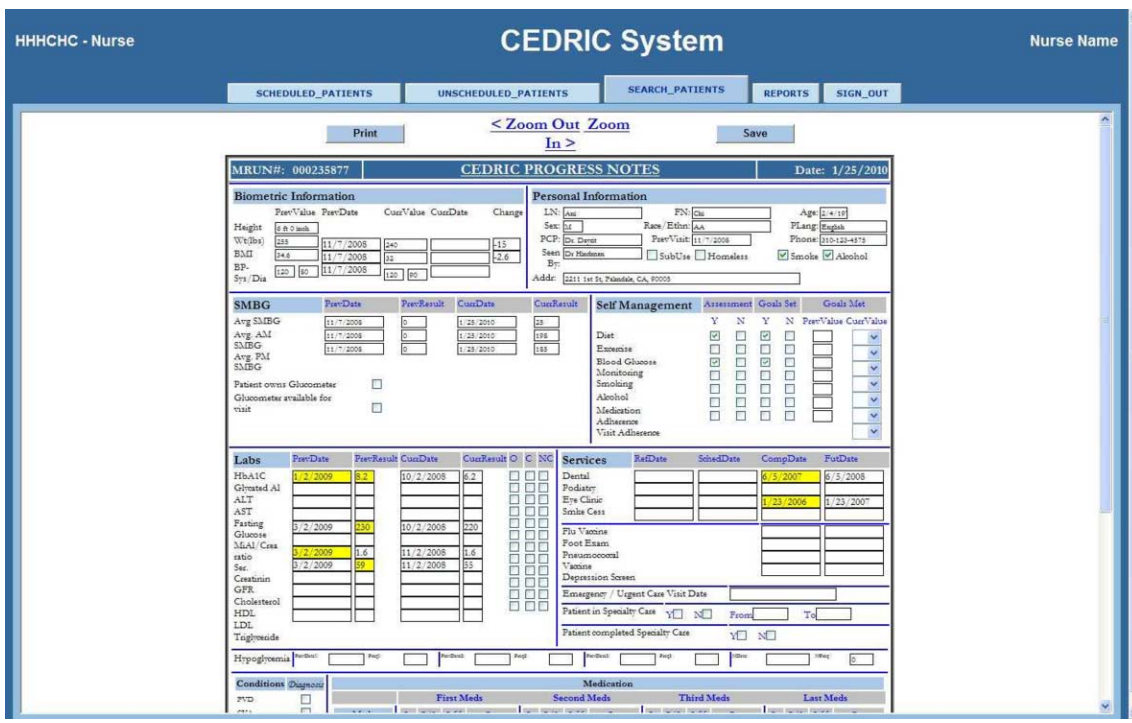

*Figure 2- Partial Screenshot of CEDRIC Progress Note**

**Screenshot does not present data from an actual patient*

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Determinants of Clinical Information System Post-Adoption Success

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Abstract

The diffusion of information technology (IT) in healthcare systems to support clinical processes makes the evaluation of physician and nurse post-adoption an important challenge for clinical information systems (CIS). This paper examines the relationships between the determinants of success of a CIS based on an expectation-confirmation paradigm in a cross-sectional survey performed at the Sherbrooke University Hospital (CHUS). 32.2% (161) of physicians and 27.1% (352) of nurses responded to the survey questionnaires. Results suggested that physician and nurse satisfaction is determined differently according to post-adoption expectations: compatibility, confirmation of expectations, usefulness, ease of use, and support. The best predictor of physician satisfaction was perceived usefulness (r=.25, p=.0003) whereas for nurses it was ease of use (r=.18, p=.0003). Confirmation of expectations was strongly associated with each post-adoption expectation and positions its importance in CIS design and redesign. This study draws attention to the differences between physician and nurse perceptions of information technology and emphasizes post-adoption evaluation to measure CIS success. Physicians and nurses post-adoption expectations were key factors to warn again potential discontinuance.

Keywords:

Clinical information system, Post-adoption behavior, Success dimension, Confirmation of expectation, Satisfaction

Introduction

Clinical Information Systems (CIS) have significant potential to improve clinical processes and patient satisfaction [1]. Analysis of the success factors is essential in assuring the initial success and survival of a system in clinical routines in order to achieve the health system objectives [2]. Many factors affect the CIS post-adoption process by health professionals; the understanding of a successful CIS implementation is critical to the improvement of health care services and future development of CIS. Furthermore, it is essential to integrate analysis of health professional expectations and satisfaction in post-adoption models, and to investigate the relationship between user characteristics, compatibility, perceived usefulness, ease of use, and user support. Several studies have shown the driving role of the compatibility [3], perceived usefulness and ease of use [4,5], and user support [2] in the evolution of the adoption process and IT diffusion in organizations. This integrative approach is supported by the combining of relevant constructs of these IS research models [4-6].

The CIS of the "Centre Hospitalier Universitaire de Sherbrooke" (CHUS) was developed relatively early, but has, from time to time, encountered resistance by professionals. The levels of use were very different from one unit to another, even though CIS aims to improve health care processes and the quality of health care systems at the CHUS. In this study, we attempt to integrate user characteristics, perceived ease of use, compatibility and support, into the expectation model in order to analyse the mechanisms through which physicians and nurses achieve their post-adoption decisions and satisfaction.

The choice of dimensions is aligned with managerial perspectives and, by their relevance and compatibility, with the action plans for the evolution of CIS at the CHUS. Each CIS success dimension was assessed in terms of the different viewpoints of physicians and nurses.

Materials and Methods

Clinical Information System and Setting

This study was conducted at CHUS, a 712-bed affiliate of the Faculty of Medicine, Sherbrooke University. The CHUS' healthcare organization is divided into 11 client programs. The electronic clinical information system (ARIANE) was installed in 1989 with a progressive implementation strategy. ARIANE is an integrated system, and supports the following clinical processes: (1) admissions, discharge and transfer (ADT), (2) electronic health records (EHR): laboratory, radiology and imaging, diagnostic test results, (3) partial computerized provider-order entry (CPOE) including laboratory and radiology tests, (4) clinical documentation (CD): patient demographic characteristics, (5) appointment and patient scheduling (APS). In clinical practice, physician notes, problem lists, medication lists, discharge summaries and nursing assessments are achieved on paper, as well as orders for medications. In general, the nurse's processes are less developed than physician's processes in the ARIANE

system. The clinician notes, medication orders and discharge summaries are digitized and made available through ARIANE. According to Jha *et al*, ARIANE is a system that evolves between "Basic EHR System without Clinician Notes" and "Basic EHR System with Clinician notes" [7].

Survey instrument

The survey was designed to measure user characteristics, CIS compatibility, CIS support, confirmation of expectations, perceived CIS usefulness, perceived CIS ease of use, and user satisfaction. A seven-point Likert-type (1=Strongly disagree, 2=Disagree, 3=Somewhat disagree, 4=Neither disagree nor agree, 5=Somewhat agree, 6=Agree, 7=Strongly agree) survey measured each dimension. All measurements were adapted from the previously validated instruments and modified based on the Clinical Information System. *User characteristics* asked users for personal information such as gender, age, whether working full or part-time, CIS training sessions and prior CIS experience. Items under *Compatibility* were adapted from Rogers and Moore [3,8,9]. *User Support* assessed the availability of CIS, help to access and understand CIS data, availability of assistance and training [2,9,10]. Items for measuring *Confirmation of Expectations* were adapted from Bhattacherjee and Van Der Meijden [2]. Four items were used to measure CIS expectations: compatibility, ease of use, usefulness and overall quality of the CIS [2,5]. *User Satisfaction* asked respondents to indicate their general satisfaction with the experience of using CIS, clinical information quality, reliability and user support quality. [2]. Scales for perceived CIS *Usefulness* and *Ease of Use* were adapted from previous studies on TAM [4,5,9].

Research model

According to the theoretical model used (Figure 1), the post-adoption user satisfaction is determined by the users' confirmation of expectations *(H3a)*, perceived usefulness *(H2a)* and ease of use *(H4a)*, compatibility *(H1a)*, support *(H5a)* and user characteristics *(H0)*. The perception of the usefulness is influenced by confirmation of expectations *(H3b)*, perceived ease of use *(H4b)*, compatibility *(H1b)* and support *(H5b)*. The confirmation of expectations *(H3c)*, compatibility *(H1c)* and support *(H5c)* directly influences perceived ease of use. In this model, the degree to which health professional expectations are confirmed is affected by both compatibility *(H3d)* and user support *(H3e)*.

Administration procedure

A cross-sectional field survey was conducted at the CHUS. We selected the CHUS to perform this study because its organization is positioned in the Post-Adoption phase for the last 5 years. The study targeted physicians and nurses working part-time or full-time at the CHUS, and used one component of CIS to support a clinical process. The survey questionnaires were anonymous and sent out to all program clients, between December 2007 and January 2008. Participants systematically received bi-monthly response reminders. In all, 1800 survey questionnaires were sent to physicians (500) and nurses (1300). 32.2% (161) of physicians and 27.1% (352) of nurses responded.

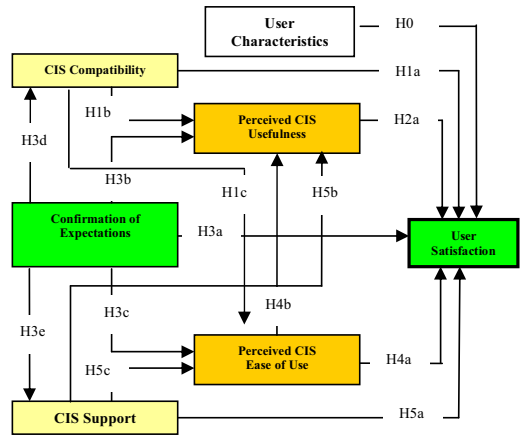

Figure 1- Theoretical Model

Data analysis methods

In the pre-test phase, the questionnaire was administered to a small target group (4 physicians, 8 nurses), in order to verify clarity of the questions. The reliability and validity of the items measuring the various elements was evaluated using Cronbach's alpha [11]. As shown in Table 1, the values were either close to or above 0.70. These results were acceptable [12]. For each dimension, we computed an aggregated variable and presented descriptive statistics, with mean and standard deviation. The mean deviation for physicians and nurses were compared by F tests. To address our research hypothesis, we performed separate multivariate regression analysis, as recommended by *Gefen* when the sample size is too small to use advanced statistical approaches such as structural equation modeling [13]. Analyses were performed using the statistical packages Statview® and Stata®.

Table 1-Validity of the instrument (Cronbach's Alpha)

Dimensions *(Items Number)*	**Physicians** (n=161)	**Nurses** (n=352)	**Total** (n=513)
Compatibility *(3)*	0.80	0.78	0.92
Confirmation of expectations *(4)*	0.96	0.93	0.95
User support *(4)*	0.80	0.78	0.74
Perceived CIS ease of use *(4)*	0.94	0.93	0.93
Perceived CIS usefulness *(4)*	0.94	0.89	0.91
User satisfaction *(4)*	0.82	0.79	0.80

Results

Users' characteristics

The sample consisted of 118 physicians, 43 residents, 324 nurses and 28 auxiliary nurses (table 2). Only 25.0% ($p<.0001$) of the respondents were male, working full time 74.5% ($p<.0001$) and having received prior CIS training 80.9%. The respondents averaged 40.1±11.4 ($p<.0001$) years of age and seniority at work at the CHUS of 14.1±10.5 years ($p<.0001$). The perception of CIS experience differed between physicians and nurses ($p=.0138$).

Compatibility

The items concerning CIS compatibility received very good scores (4.59±1.38) without any difference between health professionals (Table 2).

Table 2- Factors describing the compatibility dimension - Means (SD)

Using CIS is compatible with or (fits into)…	**Physicians** (n=161)	**Nurses** (n=352)	**Total** (n=513)
All aspects of my work	4.76(1.58)	4.66(1.45)	4.69(1.50)
My Work habits	4.55(1.56)	4.62(1.45)	4.60(1.49)
Organization of my work	4.39(1.60)	4.53 1.41)	4.49(1.47)
CIS Compatibility§	**4.57(1.51)**	**4.60(1.32)**	**4.59(1.38)**

§= Aggregated variable; Scale: 1=Strongly disagree to 7=Strongly agree

Confirmation of expectations

The post-adoption expectations such as compatibility (4.38±1.30) and perceived usefulness (4.64±1.27) did not differ, while perceived ease of use (4.60±1.21, p=.0085), quality of the CIS (4.54±1.27, p=.0199) and aggregated variable (4.54±1.18, p=.0230) scored higher on the scale for nurses (Table 3).

Table 3- Factors describing the expectations dimension - Means (SD)

The CIS…..was better than what I expected	**Physicians** (n=161)	**Nurses** (n=352)	**Total** (n=513)
Compatibility	4.25(1.55)	4.45(1.16)	4.38(1.30)
Perceived ease of use*	4.38(1.43)	4.70(1.09)	4.60(1.21)
Perceived usefulness	4.48(1.45)	4.71(1.18)	4.64(1.27)
Overall quality of the CIS*	4.34(1.50)	4.63(1.14)	4.54(1.27)
Expectations§*	**4.36(1.42)**	**4.62(1.04)**	**4.54(1.18)**

*§= Aggregated variable; * p<.05; Scale: 1=Strongly disagree to 7=Strongly agree*

User support

CIS support (4.44±1.07, p=.0002) was relatively low according to the CHUS IT objectives (Table 4). However, physician perception in appreciation of availability of assistance (p=.0028) and training (p<.0001) ranked higher than nurses.

Table 4- Factors describing the user support dimension - Means (SD)

	Physicians (n=161)	**Nurses** (n=352)	**Total** (n=513)
CIS availability when I need it	4.38(1.38)	4.41(1.41)	4.40(1.40)
Help to access and understand CIS data	4.74(1.33)	4.62(1.34)	4.66(1.34)
Availability of assistance*	4.86(1.36)	4.43(1.46)	4.56(1.44)
Training*	4.65(1.44)	3.92(1.46)	4.15(1.49)
CIS Support§*	**4.66(1.03)**	**4.34(1.07)**	**4.44(1.07)**

*§= Aggregated variable; * p<.05; Scale: 1=Strongly disagree to 7=Strongly agree*

Perceived CIS ease of use

The aggregated variable physician (5.17±1.24) perceived CIS ease of use seemed slightly higher than that of the nurses (5.09±1.18). Overall, the items of this dimension were relatively high and not significantly different among health professionals (Table 5).

Table 5- Factors describing the ease of use dimension - Means (SD)

	Physicians (n=161)	**Nurses** (n=352)	**Total** (n=513)
Simplicity	5.19(1.30)	5.23(1.18)	5.22(1.22)
Comfortable	5.19(1.30)	5.10(1.26)	5.13(1.27)
Learning	5.22(1.29)	5.08(1.33)	5.12(1.32)
Overall, perceived easy to use	4.92(1.41)	4.90(1.29)	4.90(1.32)
CIS Ease of Use§	**5.17(1.24)**	**5.09(1.18)**	**5.12(1.20)**

§= Aggregated variable; Scale: 1=Strongly disagree to 7=Strongly agree

Perceived CIS usefulness

Table 6 illustrates the CIS impact on performance, effectiveness and ability to make good decisions that were similar for physicians and nurses.

Table 6- Factors describing the usefulness dimension - Means (SD)

Using CIS…	**Physicians** (n=161)	**Nurses** (n=352)	**Total** (n=513)
Improves performance	4.78(1.76)	4.45(1.37)	4.55(1.51)
Improves effectiveness	4.72(1.86)	4.57(1.37)	4.61(1.54)
Improves ability to make good decisions	4.41(1.62)	4.16(1.44)	4.24(1.50)
Overall, CIS usefulness	5.25 (1.54)	5.18(1.28)	5.21(1.37)
CIS Usefulness§	**4.79(1.57)**	**4.59(1.20)**	**4.65(1.33)**

§= Aggregated variable; Scale: 1=Strongly disagree to 7=Strongly agree

User satisfaction

Physicians (4.79±1.28) were more satisfied with the quality of support than nurses (4.36±1.30, p=.0006). Overall, all professionals at the CHUS were satisfied with their CIS experience (4.76±1.04). For the other parameters, such as quality and reliability, both groups ranked similar (Table 7).

Table 7- Factors describing CIS user satisfaction dimension - Means (SD)

I am satisfied with…..	**Physicians** (n=161)	**Nurses** (n=352)	**Total** (n=513)
Clinical information quality	4.92(1.36)	4.91(1.13)	4.92(1.21)
Reliability	4.65(1.41)	4.67(1.22)	4.67(1.28)
User support quality*	4.79(1.28)	4.36(1.30)	4.50(1.30)
Overall experience of using CIS	4.75(1.33)	4.92(1.09)	4.87(1.17)
User satisfaction§	**4.83(1.13)**	**4.72(1.00)**	**4.76(1.04)**

*§= Aggregated variable; * p<.05; Scale: 1=Strongly disagree to 7=Strongly agree*

Model testing results

The regression results shown in Table 8 corresponded to the

model shown in Figure 2, based on the whole group of users (n=513). The model explained 68%, 53% and 59% of the variance of satisfaction for physicians, nurses and the whole group, respectively.

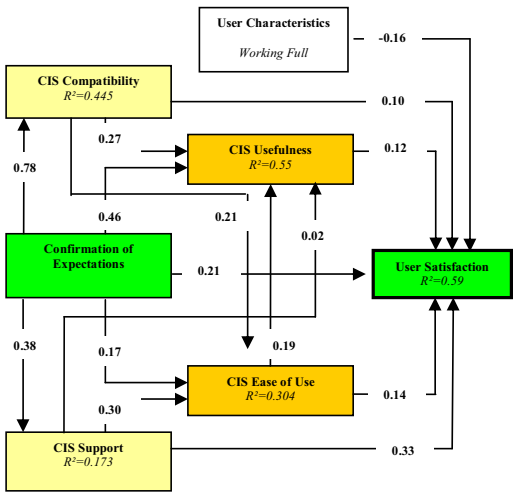

Figure 2- Model Testing Results (Total n=513)

The perceived usefulness (r=.25, p=.0003) was associated with physician satisfaction while perceived ease of use (r=.18, p=.0003) and compatibility (r=.10, p=.009) influenced nurses satisfaction. User support and confirmation of expectation were strongly correlated with physicians' and nurses' satisfaction. Compatibility, confirmation of expectation and ease of use were significant determinants of perceived usefulness. The explained percentage of variance was relatively high (≥48%). Compatibility (r=.21, p<.0001), confirmation of expectations (r=.17, p<.0001) and support (r=.30, p<.0001) explained 30.4 percent of the variance of perceived ease of use. Confirmation of expectations explained 63 percent of the variance in CIS compatibility for physicians. Furthermore, confirmation of expectations was most strongly correlated with CIS support for nurses.

Discussion

This study examined relationships between post-adoption expectations and satisfaction based on a model of confirmation of expectations. Results suggested that the confirmation of expectations was a relevant determinant of perceived usefulness, ease of use, compatibility and user support and the explained variances were relatively acceptable. The best predictor of a physician's satisfaction was perceived usefulness whereas for nurses it was perceived ease of use. Paré *et al* showed that clinician satisfaction was correlated with confirmation of expectations regarding the impacts of a PACS and perceived usefulness [14]. Thus, physicians are satisfied when the CIS provides desirable utility to their practice, and nurses when the CIS is easy to use in the nursing processes [15]. In a previous study we found that perceived CIS usefulness, perceived CIS quality and service quality had a significant effect on physician and nurse satisfaction [10]. Lee *et al*. reported that physician satisfaction was associated with ease of use, frequency of use, response times, and user characteristics [16]. Results also demonstrated

Table 8- Linear regression analysis of post-adoption model

Dimensions	H	**Physicians** (n=161)	**Nurses** (n=352)	**Total** (n=513)
		r (p)	*r (p)*	*r (p)*
*Regression 1: Stepwise multiple regressions analysis on **user's satisfaction***				
User characteristics				
Physicans	H0			.06(NS)
Male sex	H0	.09(NS)	-.04(NS)	-.00(NS)
Age	H0	.00(NS)	.00(NS)	.00(NS)
Working full time	H0	-.16(NS)	-.17 (.0494)	-.16 (.0379)
Prior CIS training	H0	.17(NS)	-.08(NS)	.010(NS)
CIS experience	H0	.00(NS)	-.03(NS)	-.020(NS)
CIS compatibility§	H1a	.09(NS)	.10(.009)	.10(.0023)
CIS usefulness§	H2a	.25(.0003)	.06(NS)	.12(.0008)
Expectations§	H3a	.16(.0349)	.21(<.0001)	.21(<.0001)
CIS ease of use§	H4a	.06 (NS)	.18 (.0003)	.14 (.0002)
CIS support§	H5a	.34 (<.0001)	.32 (<.0001)	.33 (<.0001)
Adjusted R² (p)		***.68 (<.0001)***	***.53(<.0001)***	***.59(<.0001)***
*Regression 2: Stepwise multiple regressions analysis on **CIS usefulness***				
CIS compatibility§	H1b	.35 (<.0001)	.23 (<.0001)	.27 (<.0001)
Expectations§	H3b	.56 (<.0001)	.40 (<.0001)	.46 (<.0001)
CIS ease of use§	H4b	.08(NS)	.25 (<.0001)	.19 (<.0001)
CIS support§	H5b	.04(NS)	.00(NS)	.02 (NS)
Adjusted R² (p)		***.70 (<.0001)***	***.48 (<.0001)***	***.55 (<.0001)***
*Regression 3: Stepwise multiple regressions analysis on **CIS ease of Use***				
CIS compatibility§	H1c	.28 (.0017)	.20 (.0001)	.21 (<.0001)
Expectations§	H3c	.06(NS)	.23 (.0005)	.17 (<.0001)
CIS support§	H5c	.33(.0001)	.28 (<.0001)	.30 (<.0001)
Adjusted R² (p)		***.31 (<.0001)***	***.30 (<.0001)***	***.304 (<.0001)***
*Regression 4: Stepwise simple regression analysis on **CIS compatibility***				
Expectations§	H3d	.84 (<.0001)	.74 (<.0001)	.78 (<.0001)
Adjusted R² (p)		***.63 (<.0001)***	***.34 (<.0001)***	***.445 (<.0001)***
*Regression 5: Stepwise simple regression analysis on **CIS support***				
Expectations§	H3e	.28 (<.0001)	.49 (<.0001)	.38 (<.0001)
Adjusted R² (p)		***.14 (<.0001)***	***.23 (<.0001)***	***.17 3(<.0001)***

CIS= Clinical Information System; NS p>0.05 §= Aggregated variable; H=Hypothesis

the importance of perceived ease of use in mediating the relationship of user support, compatibility and confirmation of expectations on satisfaction. For the nurse group, perceived ease of use had positive effects on perceived usefulness, according with TAM in pre-adoption [4]. As shown by Chismar *et al*, this relationship had no significant effect among the physicians, especially in post-adoption [15,17]. These findings showed that physicians and nurses at the CHUS are not experiencing the same dependence on CIS in their daily tasks. Currently, the description of the nursing processes was not electronically documented in the CIS [18]. CPOE functions are available for the laboratory and radiology orders; medication orders are input by pharmacy staff but are not yet introduced into the clinical processes. The implementation of clinician notes and medication orders associated with clinical decisions supporting (CDS) faced significant challenges for the IT practices at the CHUS in particular as well as the province of Québec as a whole. Another plausible explanation might be that nurses were considering CIS to be easy to use in their clinical processes and that they depended more on user support than physicians [10]. The compatibility influenced user satisfaction toward perceived ease of use. Chau *et al* found that compatibility was a significant determinant of perceived usefulness but not of perceived ease of use [15]. Several limitations of our study have to be emphasized. The response rate was low by physicians (<15%) and nurses (<24%). The relatively low R^2 values of CIS support and perceived ease of use compared with prior studies suggested the potential limitations and possible omission of factors important to the healthcare post-adoption context.

Future perspectives of this work could be the consolidation of the CIS post-adoption model and then evaluating its applicability in other academic hospital contexts using structural equation modelling to test and analyse post-adoption network causalities.

Conclusion

The findings of the study provide insights and implications relevant to CIS post-adoption research, communication and articulation of salient post-adoption expectations and health IT management.

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MEDAL: Measuring of Emergency Departments' Adaptive Load

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Abstract

We propose an innovative approach for measuring real-time operational load within emergency departments. Medical informatics, operations researchers, and other decision makers in the health care field have yet to come to an agreement regarding standardized matrices for measuring operational load within emergency departments. As a result, it is difficult to develop methods and approaches for reducing operational load. We propose a flexible framework based on neural networks. These networks can calculate user-tuned load value, based on a set of well-defined operational and clinical indicators. The operational load value is calculated by learning the weights of the raw operational indicators within a particular emergency department.

Keywords:

Operations research, Workload, Emergency Department, Machine learning, Neural networks (computer)

Introduction

The rising cost of healthcare services has been a subject of mounting importance and much discussion worldwide. Ample explanations have been proposed, yet regardless of their cause, rising costs impose pressures on healthcare providers to improve the management of quality, efficiency, and economics for their organizations. Significant attention has been given to the question of how to reduce this cost in the healthcare domain Hospitals are one of the major players in the provisioning of health services and within hospitals, emergency department (ED) overcrowding has been perhaps the most urgent operational problem [1, 2, 3]. Overcrowding in hospital EDs leads to excessive waiting times and repellent environments, which in turn cause: (1) poor service quality (clinical, operational); (2) unnecessary pain and anxiety for patients; (3) negative emotions (in patients and escorts) that sometimes lead to violence against staff; (4) increased risk of clinical deterioration; (5) ambulance diversion; (6) patients leaving without being seen (LWBS); (7) inflated staff workload; and more [4].

In order to reduce the occurrence of overcrowding in hospital EDs and optimize ED operations, we need to understand what the current crowding load level is. This means that it is necessary to decide how load on various resources should be defined, to whom it should be presented, and how it should be demonstrated. This task is difficult for several reasons. First, establishing which parameters contribute to the load is complex and subjective. Second, even once the parameters are established, assigning a level of contribution to each one is difficult, due to the varying conditions in each hospital, and to the perceptions of different management teams. Third, the ED is a complex environment that involves various types of entities (e.g., physicians, nurses, patients, executives); each of whom may define the load function differently. Clearly, load has to be a usage-dependent function. Fourth, the definition of load changes from time to time and needs to be updated periodically. Fifth, due to the large number of quickly-changing events and factors that are critical to saving lives, displaying a real-time snapshot of the load in the system is critical. This snapshot must be displayed in such a way that decisions based on current load can be made quickly and easily.

Our Contribution

In this paper, we present Measuring the Emergency Department Adaptive Load (MEDAL), a flexible and adaptive system that enables the calculation of user-tuned load in emergency departments, using various types of inputs and defined load functions. Tuning for the needs of the user makes the system user-specific, resulting in a load score that directly reflects the high level of input. The system is based on artificial neural networks [5] and enables the following: (1) a static mechanism for an explicit definition of load functions; and (2) a dynamic learning mechanism that enables the system to adapt to the perceptions of users with no explicit load function definition.

The dynamic learning mechanism allows the system to present different load values for the same objective situation. This is particularly useful for understanding the difference in operational load perception by physicians, nurses, patients, and the ED management.

MEDAL is a highly adaptable load measurement tool that, by scarifying rigid definition for high flexibility, allows users to analytically compare various situations, and to reach informed decisions regarding the appropriate steps to take in order to reduce the ED load.

The paper is organized as follows: the Methods section describes the main idea of our proposed solution, along with the technical details on how the system was built. In the Results

section, we describe our main results achieved from implementing load profiles. The Discussion section deals with the benefits of using our system in diverse and dynamic environments for process optimization and planning. We then conclude with a summary of the approach, the benefits of system use, and directions for future research and development.

Methods

The calculation of operational load in emergency departments and its presentation are highly important, yet difficult tasks, for improving efficiency. To that end, we developed MEDAL, a flexible framework for measuring subjective load, using iterative user feedback. MEDAL can be adapted for any user preference and view of the load in specific environments. We describe the main idea on which the design of the system was based and developed, and then elaborate on the technical implementation details.

Main Idea

MEDAL is a flexible and configurable framework for measuring ED load. By default, our framework receives an extensive set of raw indicators as input. These indicators were reported in the literature [6] as a consensus for the set of measures that are important for the calculation of ED load. Moreover, this set of indicators can easily be modified according to user needs. Also, our framework receives operational events from the existing ED infrastructure, processes them, and calculates the time-specific input indicator values. The core of our framework is a learning neural network mechanism that enables the following main features: (1) Users can modify the set of basic indicators collected from the ED infrastructure. (2) Users can configure the system with any kind of load function. (3) In cases where the load function cannot be defined explicitly, our framework provides an adaptive mechanism that learns the desired load function autonomously. This is done by learning from the user feedback on the calculated load, while viewing snapshots of ED states and the corresponding calculated load. (4) The system also offers advanced capabilities for tracking the origin of the load status and for understanding its cause at different levels of granularity. Moreover, the system can provide specific alerts regarding the high load values at various predefined internal points, even if the total load in the system is low. (5) The system enables comparison among various calculations of load, according to the perception of different roles in the ED. We further demonstrate and discuss these features in the Results section.

We now elaborate on the technical details that served as a basis for the development of the proposed system.

Implementation Details

Load Function Definition

Our framework provides a simple way to define any explicit load function, based on canonical indicators and the display of that function's behavior during different time frames. This process is described below and shown in Figure 2.

Learning Unknown Load Functions with Neural Networks

Due to the complexity of the ED environment, explicitly defining the load function is often not useful. Therefore, machine learning techniques should be harnessed to solve these issues. We chose to use the artificial neural networks [5] as our basic mechanism. These systems are flexible for composition, adaptive over time, meaningful for the user, and enable the definition of complex relationships (e.g., nonlinear) between inputs and outputs.

We first provide a theoretical background on neural networks and then explain how these were harnessed to solve the problem raised in this paper.

Neural Networks – Theoretical Background

Artificial neural networks [5] are mathematical representations of complex mathematical functions. They are composed of units named perceptrons (Figure 1a), and arranged as a multi-layered feed-forward network (Figure 1b), in which the outputs of one layer are the inputs of the next layer. This type of learning machine was inspired by the brain structure. These machines are successfully used in many applications, such as pattern classification, dimensionality reduction, and function approximation [7, 8, 9]. Because of the origins of the machines' design, the nodes in such networks are often called *neurons.* The machines' greatest advantage is their simplicity (in both representation and learning). In addition, the number of required training examples (that is relative to the network structure) is not high compared to other machine learning solutions.

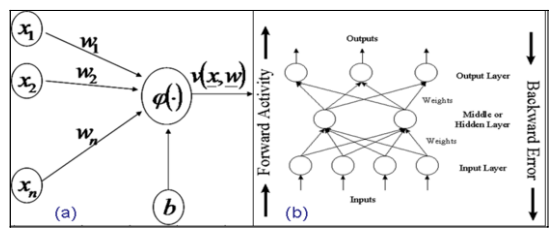

Figure 1- (a) single perceptron; (b) Multi-layer network

Each perceptron is composed of n inputs, $x_1, x_2, ..., x_n$, n weights $w_1, w_2, ..., w_n$ and an activation function $\varphi(\cdot)$. The output of the unit is $v(\underline{x}, \underline{w}) = \varphi(\underline{x}^T \underline{w})$, where $\underline{x} = (1, x_1, ..., x_n)$, $\underline{w} = (b, w_1, ..., w_n)$. Examples of activation functions are sign ($\varphi(u) = sign(u)$), linear function ($\varphi(u) = u$), and logistic function ($\varphi(u) = 1/(1 + e^{-u})$). The type of activation function affects the ability of the network to learn and is application-dependent. The units in different layers are connected in a feed-forward style to determine the network structure (see Figure 1b). The exact structure is also application-dependent, and in many cases, domain knowledge can help to determine this structure.

Given a training set of the form $(\underline{X}_i, y_i)_{i=1}^{M}$ in which $\underline{X}_i \in \Re^n$ is the input to the network and $y_i \in \Re$ is the expected output (or target function) of the network, the back propagation algorithm [5] can be used to find a set of weights that minimizes the mean square error (MSE) between the expected output and the current calculated output. There are two types of learning—offline (or batch) learning, and online learning. In offline learning, the entire training set is given in advance. In each iteration of the back propagation algorithm, all of the examples are taken into account when updating the weights. In online learning, the examples are given one after the other, and each learning iteration depends on the current example only. Online learning is typically used when the environment changes over time, and when the network is trained to fit those changes.

Harnessing Neural Networks to Calculate Load in the ED

To demonstrate the advantages of our methodology, we built a neural network that represents the collective knowledge presented in the exhaustive indicators review paper [6]. We used it as our basic network for the load calculation (see Figure 2).

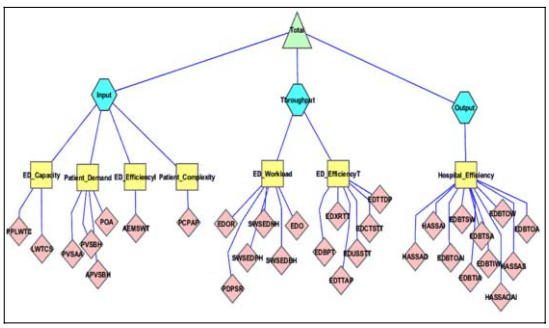

Figure 2- ED Neural Network View: The triangle is a total neuron, hexagons are the stage neurons, rectangles are the concept neurons, and diamonds are input indicator neurons

For the set of inputs, we took the set of indicators that were defined in the review paper and combined and ranked them in a hierarchical manner. The hierarchy in the network consists of four main layers: 1) ***Indicators Layer:*** This layer is the set of inputs, and consists of 31 nodes corresponding to 20 indicators that appeared in the review paper [6]. Several indicators were spliced to match their definitions. For example, indicator "*ED Throughput time*" was spliced into two nodes: one for admitted patients and one for discharged patients. Others were omitted due to the lack of appropriate input simulation data. We made minor modifications to the network, as suggested in the paper, based on additional data we could collect by using a simulator presented by Sinreich and Marmor [1]. This simulator, also used by Wasserkrug et al [10], is based on a canonical ED model, which was generated based on real-life observations within numerous hospitals. 2) ***Concepts Layer:*** The 31 indicators in the indicators layer are connected (each indicator to a single concept) to the following six concepts: patient demand, patient complexity, ED capacity, ED efficiency, ED workload, and hospital efficiency. The hospital capacity concept was omitted due to the lack of appropriate data. The *ED efficiency* concept was divided into two sub-concepts to serve the input and the throughput separately. This modification was made to keep the tree-like structure of the network. We will explain the importance of that structure later in this paper. 3) ***Operational Stages Layer:*** The seven concepts are connected (one concept to each operational stage) to the following three operational stages: input, throughput, and output. 4) ***Load Score Layer:*** This layer is the output layer and consists of a single node representing the total load function score.

As described above, we can learn the target function using either the offline or online method. Both approaches require knowledge of the true target function values on some set of input vectors. This means that we have to present each such vector to the expert user and receive the desired function value in return. However, this flow cannot be used for two main reasons. First, input vectors are often too long for human perception and embedding. Second, The desired value of the target function cannot be explicitly calculated. In the following paragraph we describe how we handle both of these challenges.

Instead of presenting the input vector itself, we present current ED status using a patient-centric dashboard (Figure 3). The patient-centric dashboard provides ED staff with information about the status of each patient in the ED. Patient status is usually presented as a row within a table-like view. This approach is commonly used in EDs around the world. By working with the patient-centric dashboard, the ED staff gains total insight regarding the operational ED load. We use this insight to enter feedback into the network, thus enabling it to learn the required load function. The user provides feedback by using the dedicated feedback buttons. For example, if the user *feels* that the represented load is far below the desired value, he pushes the larger "+" button, increasing the current load by 10% increments. A similar update process (+1%, -1%, -10%) works for other feedback buttons. Clearly, such a feedback system can be easily implemented in any existing dashboard without significant changes.

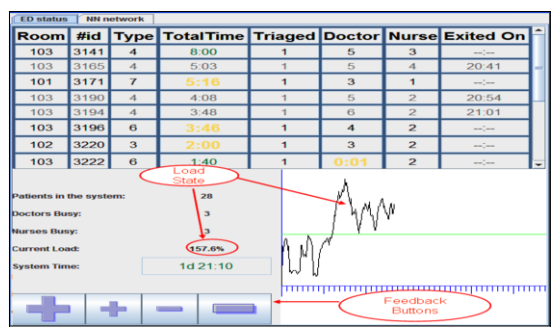

Figure 3- Dashboard snapshot. Load value (black line) is calculated as the percent of the average (green line)

Tracking Load and Bottlenecks

In our system, every neuron has an explicit operational meaning. Our neuron network design keeps the tree-like neuron hierarchy instead of the usual all-to-all connections. This allows each neuron to preserve its operational meaning during the learning process. Conserving the tree-like structure allows the user to track the current load back into the network and to gain a deeper understanding of the current load status (Figure 4). Moreover, we can get an alert from any hierarchy level in the system if a certain neuron becomes overloaded. For example, if the current system load is only 40% of the average but the CT room is overcrowded due to lack of personnel, the appropriate neuron's status will reach the high mark, and can alert the user, provided the neuron was preconfigured accordingly. As a result, the ED manager may react by temporarily adding to the CT room staff.

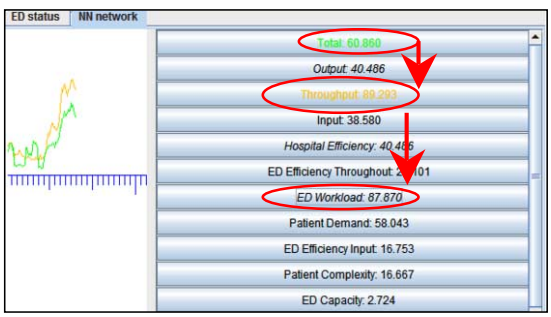

Figure 4- Tracing load: Green line indicates total load, orange line indicates throughput; the rise in the total load was clearly caused by increasing the throughput input neuron. We can trace it further and deduce that the peak in throughput was caused by elevation of the ED workload concept neuron

Comparing Different Views on ED Load

Our framework allows dynamic learning based on feedback from different user groups. We can calculate and present several different load views for the same objective situation. For example, measuring the current ED load as perceived by doctors, nurses, and patients, or even by a single individual such as the ED manager, could have interesting applications. Having an option for defining a subjective load function that best reflects the actual load experienced by a given user group could be very useful, as well. In the next section, we investigate and demonstrate the differences in load perception for three user groups: ED Doctor, ED Nurse, and ED Patient, as an example of this application.

Results

To demonstrate the system's ability to reflect subjective load, we identified three possible group types: nurse, doctor, and patient. The user profile reflects operational load as it is being experienced by a given group, or even by a specific individual within the ED. User profiles can be statically defined by fixing weights on relevant neurons, or preferably, by dynamically learning the user profile. Dynamic learning involves capturing user feedback from a specific user or user group associated with a relevant profile. To achieve this, we generated operational data using a simulator tool [1] and defined subjective target load functions for three group types. Nurse and doctor target load functions were defined as the average occupation ratio during a time period. Patient target load function was defined as the ratio of a patient's waiting time to the patient's total staying time in the ED (Figure 5).

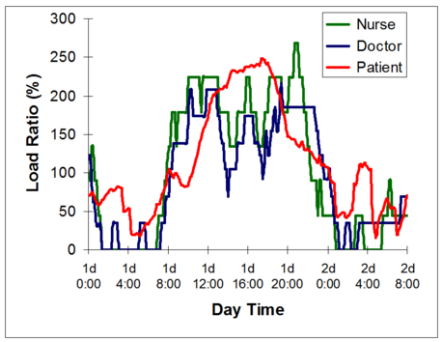

Figure 5- Simulated nurse, doctor, and patient profile behavior, where 100% is the average daily load

Figure 6 presents results from running the system multiple times and dynamically learning the three groups' profiles. Each profile is comprised of the weights of major neurons learned by the system.

Raw Indicator \ Profile	Nurse	Doctor	Patient
Patient Volume standardized for Bed Hours	42%		76%
Summary Workload standardized for ED Bed Hours	18%	45%	
ED Bed Placement Time	12%	30%	8%
ED CT service Turnaround Time	28%	25%	16%

Figure 6- User profile comprised of major raw indicator weights learned by the system

We can see that all three profiles show reasonable behavior when comparing time of day and when comparing the profiles to one another. When the system is overloaded, all users feel it. However, the load experience is different for each group. For example, doctors need to stay later than nurses at the end of the day and to close all open cases. Thus, the load on them decreases later than it does for nurses. On the other hand, triage, served by nurses, is the first station in the patient flow. Hence, the nurses' operational load starts earlier. These examples demonstrate that there are indeed different weights on the neurons, emphasizing the need for subjective load scores for the same objective ED state.

Discussion

In this paper, we introduce MEDAL, a flexible system for the estimation and measurement of load in hospital emergency departments. The development of MEDAL stemmed from the understanding that ED load is influenced by a large number of factors that are difficult for both humans and machines to consider together. Solberg et al., [6] gathered 74 experts to collect a set of 113 measures affecting the load in EDs, of which 38 were selected through a discussion and rating process. This set of measures was divided into three categories (input, throughput, and output) and seven concepts (patient demand, ED capacity, patient complexity, ED efficiency, ED workload, hospital efficiency, and hospital capacity). While Solberg provides a comprehensive set of load measures and concept categories, he does not suggest a straightforward way to use these measurements in real-life scenarios. Our experience shows that establishing a standard operational load model that fits all EDs is not practical, due to the inherent differences among them.

MEDAL is a flexible and adaptive framework for load calculation that comes with a set of initial measures (the measures that appear in the abovementioned paper) and a set of load functions. The framework can be easily enhanced with additional measures and load functions. Moreover, the system includes a mechanism to learn the load function from the user, in cases where this could not be explicitly defined. This learning mechanism is used to define user profiles, each with its own view and requirements, from the calculation of load in the ED environment. Figure 5 shows the load calculated for three possible profiles. It shows that all measures estimate the load quite similarly, meaning that when there is a burden on the hospital, all relevant entities (e.g., staff members, patients) are affected. However, this system allows users to distinguish between the load pressures felt by these entities. Measuring load is a crucial step for optimizing ED operation. This measure of load can be used in various ways. First, it can be used to optimize the staff routing inside the ED at times of high load levels. This could of course reduce the burden on hospital departments. Using the offline method, load calculation can be used to provide detailed planning for different staff members in the ED (e.g., nurses, physicians). The MEDAL approach may also be applicable to other hospital wards and even to other industries. Providing a highly adaptable measuring tool, may prove useful in many situations in which global agreement about measured indicators is out of reach. Our work on this issue is beyond the scope of the current paper.

Conclusion

In this paper, we presented MEDAL, a novel, flexible, adaptive framework for user-specific load definition and calculation. The major advantages of the presented system are its flexibility to fit specific user needs, and its ability to handle and learn from highly undefined data that represents subconscious user perceptions**.** The implementation of the method is straightforward and can be easily integrated in any current ED dashboard system. The received user-specific load score can also be used for operation optimization and for providing advice to ED personnel. Moreover, measuring operational load, while taking into account user-specificity, is an interesting research direction in and of itself.

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What effect does electronic ordering have on the organisational dynamics of a hospital pathology service?

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Abstract

The aim of this triangulated (multi-method, multi-setting, multi-staged) study was to identify the consequences of an electronic ordering system on the functioning and organisational dynamics of a hospital pathology service. The study was carried out in five pathology departments during the period August 2005 to April 2006. It included five focus groups involving 21 participants and 67 interviews with 38 participants, along with a total of 21 hours of observation. The findings revealed three key themes with implications for the functioning and organisational dynamics of the pathology service. These included: a) work process changes that affect the output of the pathology laboratories; b) temporal considerations, particularly as they related to efficiency of laboratory processes; and c) communication channels and the resulting changes in the mode of information exchange and communication. These themes emerged from a close analysis of the contextual setting of each department. Successful CPOE implementation should be premised on a solid understanding of the organisational, communication, information and temporal circumstances in which the system will operate.

Keywords:

Computer order entry, Evaluation studies, Hospital information systems, Pathology, Qualitative research

Introduction

Pathology services are made up of a complex array of organisational structures and laboratories, each with idiosyncratic work practices and specialised test procedures contributing to the prevention, detection and management of disease [1, 2]. Historically, pathology has been at the forefront of health information and communication technologies (ICT) innovation [3, 4]. This is because of the significant contribution that ICT makes to the management of the service's information-intensive work processes.

In the past, the impact of new pathology systems (eg, the introduction of a new laboratory information system) has generally been confined within the boundaries of the department, helping it to improve efficiency and effectiveness. The difference with Computerised Provider Order Entry (CPOE) is that it is not laboratory centric, but incorporates a wide spectrum of systems including imaging, clinical procedures, consultations and medications along with clinical documentation systems, which by definition increases interaction and integration across hospital departments by facilitating greater access to shared information and expanded communication channels [5]. New ICT systems such as CPOE have the potential to act as catalysts for changing interactions within the hospital, affecting the nature and definition of jobs and work processes [6]. To date these areas of impact have received limited research attention [7]. The aim of this qualitative study was to identify the key consequences of CPOE on the functioning and organisational dynamics of different departments of the pathology service through a comparison of work processes before and after implementation of the system.

Material and Methods

Research setting

This research was carried out in a pathology service employing over 300 staff located at a major metropolitan tertiary referral hospital in Sydney, Australia. The service covers a broad suburban network comprising seven major hospitals. In November 2005 the pathology service's laboratory information system was replaced by the Cerner Corporation's (Kansas City, USA) Pathnet system which automates clinical and managerial pathology data processes. This was integrated into a hospital-wide PowerChart (version 2004.01) in January 2006. Ethics approval for the study was provided by the relevant Area Health Service ethics committee.

Research design

The study was carried out across five pathology departments (Clinical Chemistry, Haematology, Central Specimen Reception, Microbiology and the Blood Bank) during the period August 2005 to April 2006. It included five focus groups involving 21 participants and 67 interviews with 38 participants. Four focus groups and 10 interview sessions were transcribed resulting in 232 A4 pages (94,198 words). All initial focus group and interview sessions were semi-structured and used a set of questions which explored participants' understanding and expectations of the new system, along with the impact they expected the system to have on their work and

relationships with professionals across the hospital. These initial expectations were then followed up as a means of exploring what happened, how it happened and why it happened following system implementation. The interviews and focus group discussions were supplemented by 22 observation sessions amounting to 21 hours.

Participants in the study were chosen on the basis of their experience and knowledge of the topic under investigation and their potential to help in the testing and scrutiny of emerging hypotheses [8]. This included 24 laboratory scientists, 18 technicians and 11 other pathology and management staff.

Analysis

Data collection and analysis were carried out concurrently and used NVivo 2.0 software to initially code transcriptions and then refine them into analytical levels related to the research aim. All quotes presented in this paper are provided verbatim as a means of conveying the contextual richness of the findings. A research log containing observation and interview recordings along with reflections on the investigation process was maintained throughout the course of the study. Closure was achieved when it became clear that sufficient data had been gathered to render the study phenomenon coherent and explicable [9]. Further data collection would have realised redundancy.

Results

Contextual make up of pathology settings

The Central Specimen Reception (CSR) can be described as the receiving dock for pathology laboratory specimens. It is also responsible for organising the collection of specimens from patients across the hospital by a team of blood collectors. Specimens are passed on to departments such as Clinical Chemistry and Haematology. Clinical Chemistry undertakes the analysis of blood and other body fluids from chemical components, while Haematology is the study of blood and its cellular elements. Both departments deal with a large proportion of urgent and life threatening tests, the bulk of which emanate from critical care units and the Emergency Department where patient treatment is often reliant on laboratory results. This means that issues like turnaround time (the time taken for a request to be processed and a result issued) are an organisational priority.

In contrast the Microbiology department deals predominantly with diseases caused by infectious agents (eg, bacteria, viruses, fungi and parasites). These agents require time to grow before an appropriate test result is available. Consequently, for Microbiology the concept of timeliness has a different contextual meaning from that of the Clinical Chemistry or Haematology department. The role of the Blood Bank is to provide compatible blood components for patients. This involves blood grouping, antibody screening and identification and pre-transfusion testing. For both departments the existence of robust communication channels with clinicians is an important aspect of their work. In the Blood Bank this meant a high reliance on the telephone and fax machine to order, confirm and send blood products. For Microbiology, their communication channels include the provision of reliable patient-centred information which can make a vital contribution to the department's test analysis, interpretation and reporting.

Changes in work practices

For CSR, the new system had minimised their previously cumbersome data entry tasks and enhanced the efficiency of work processes leading to improved levels of data accuracy and fewer incidents of test request duplication. These work process improvements were particularly evident in the changes that occurred in the department's blood collection procedures (see Table 1). In the past the collectors headed straight off to the wards where they were required to sort and verify the handwritten requests, identify any duplicates and then take blood specimens from patients which entailed a number of handwritten tasks. The new system provided a printout to the laboratory eliminating the need to sort out any duplicates. While this new procedure slightly increased the amount of time collectors spent in the laboratory to identify and organise their print outs, it resulted in the removal of a number of handwritten procedures leading to a significant decrease in the time spent on the wards. Blood collectors also reported that the new system eliminated the need to handwrite patient information and identification details through the provision of printed labels which they felt significantly reduced the possibility of making a mistake.

Table 1- Representative selection of verbatim quotes from participants

Work practices	"So even though it seems more time consuming, when they get to the ward it's a quicker process." (CSR participant)
Temporal considerations	"A lot of our work is STAT [urgent and life threatening] work, so the turnaround time is expected to be within the hour for the majority of the work. Biochemistry [Clinical Chemistry] have that issue as well". (Haematology participant) "We did try to flowchart all the processes in the lab. It was a horrendous exercise… We had to do it to try and build a new system" (Clinical Chemistry participant)
Communication channels	If it is ordered by phone or fax you know straight away, but if it is ordered electronically it will just sit in the 'end list'… (Blood Bank participant) "Do you see us … sitting reading plates and looking up the whole of the patients' clinical notes? (laughter)" (Microbiology participant)

Temporal considerations

The elimination of previous data entry requirements for the laboratories was also associated with a major decrease in the time it took the laboratory to produce a result that was available to clinicians. For the Haematology and Clinical

Chemistry departments timeliness is an essential component of their work and was one of the indicators which they identified as key to judging the impact of the new system (see Table 1).

Both departments are also subject to a complex array of organisational factors and procedures that affect the temporal flow of the laboratory process. For instance, Haematology and Clinical Chemistry are required to service several hospitals across a large metropolitan area. These hospitals have different levels of laboratory capacity. Some periphery hospital laboratories do not carry out coagulant testing while others do so only in urgent cases. The task of ensuring the temporal coordination and efficiency of laboratory work is a major task which involves a processing cycle designed to ensure that specimens are delivered to the appropriate laboratory within the correct timeframe. Failure to do so means that a courier run may be missed and the laboratory is forced to either perform extra work on site or else arrange for special (usually expensive) transportation to ensure delivery of a specimen. Participants reported that it required a major effort to identify and detail these procedures in a flowchart in order to ensure the smooth transfer, to the new electronic ordering system (see Table 1).

Communication channels

In some cases the new system involved a shift from previous synchronous communication channels (eg, telephone calls) to asynchronous channels involving standardised orders and electronic messages, which can represent major challenges for previously existing pathology processes. For the Blood Bank, the asynchronous character of electronic ordering of life-critical blood products was delayed because of department concerns that an asynchronous order may go unnoticed (see Table 1). The Blood Bank concern about asynchronous communication channels contrasted with that of the Microbiology department who were concerned that the new system's ability to improve communication across the laboratory – ward interface should not lead to the transmission of enormous volumes of irrelevant information where a lot of data is transmitted irrespective of its context or value (see Table 1).

Discussion

An organisational and communication perspective

The findings from this study reveal three key themes which have implications for the functioning and organisational dynamics of the pathology service. These include a) work process changes that affect the output of the pathology laboratories; b) temporal considerations, particularly as they related to efficiency of laboratory processes; and c) communication channels and the resulting changes in the mode of information exchange and communication. These categories emerged from a close analysis of the contextual setting of each department, their contrasting and interconnected scientific and organisational tasks and the role they play in the pathology test order process [7]. This process begins with a clinician's decision to issue an order, its collection and passage through the laboratory process and subsequent test result application as depicted in Figure 1.

Pathology services, like those in other parts of organisations, can be defined as vehicles for converting inputs into outputs. What this study shows is that the production of outputs, in this case laboratory test results, involve aspects of information processing, communication and organisation all carried out within a unique temporal framework [10].

Planning, organising and controlling the pathology work environment

The introduction of electronic ordering has important consequences for the work of pathology services and their role in the delivery of healthcare. New technologies like electronic ordering greatly enhance the speed of communication, provide the potential for higher volumes of data to be transferred, and allow the linkage and storage of information across multiple sources [11]. Prior research has shown that whilst this opens up the possibility of significant benefits including efficiency gains, [12] work innovation [13] and greater effectiveness [7], there is also the risk of the unintended consequences leading to the introduction of potentially dysfunctional work practices [6, 14].

Our results showed significant advantages of electronic

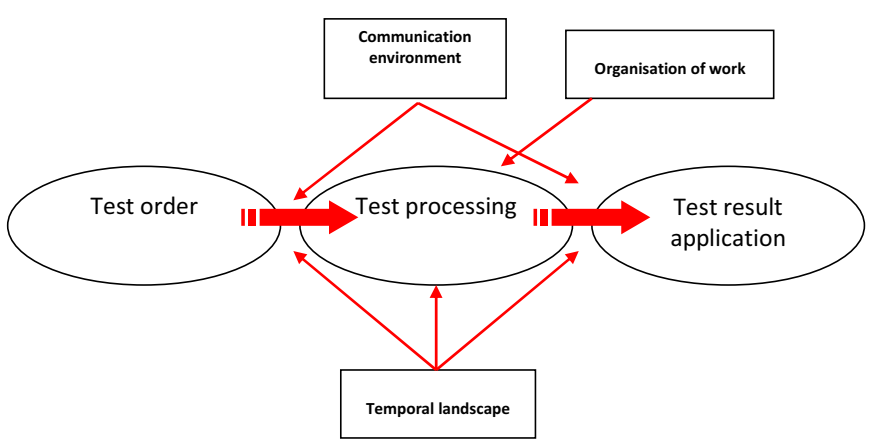

Figure 1 - The organisational, communication and temporal implications of CPOE

ordering leading to improved efficiency (elimination of data entry tasks) and safety (less handwritten errors). However, they also revealed that some features of the new system may lead to unexpected features as in the case of the Blood Bank's concern about a potential failure to be notified of an urgent blood product.

Communication environment

The idea of providing data and information to the right people at the right time and place is a key feature of most new information and communication technologies. However, a case study by Davidson and Chismar of a private, urban, acute care unit using in-depth interviews, showed that the structuring and formalisation of data in electronic ordering systems has the potential to create ambiguity and uncertainty about orders [15]. As the findings of this study highlight, the availability of masses of information to the Microbiology laboratory was not a guarantee of its appropriateness and usability. Information exchange should not neglect the social context which provides information with its meaning and importance [16]. Berg and Goorman assert that data are always produced with a particular purpose, hence their specificity and flexibility should be customised to suit that purpose [17].

The temporal landscape

Organisations are constantly searching for ways to improve their use of time. This is because of the implications that time has for how work is prioritised, allocated and coordinated [18]. Work is organised to suit timeframes that may contain different assumptions and meanings. In this study we witnessed both the concern for ensuring the efficient production of laboratory test results as measured by turnaround times, and the need to fit work into a series of time cycles that impacted on the coordination and synchronisation of work, eg, tests from remote laboratories. Time in the laboratory process can be considered either as a dependent variable (eg, turnaround time) that has been affected by data entry efficiencies introduced by electronic ordering, or alternatively as an independent variable (eg, fitting into existing laboratory procedures) whereby the electronic ordering system is modified to fit the temporal exigencies of the pathology service [19].

Limitations

This study used rich contextual data to examine key features of pathology services and the impact of electronic ordering. Even though the findings are presented in a conceptualised framework their generalisability are likely to be affected by the particular circumstances of other settings.

Conclusion

This study has shown that CPOE can impact upon many features of the pathology service. CPOE implementation should be premised on a solid understanding of the organisational, communication, information and temporal circumstances in which the system is meant to operate [17]. As this study has shown, new technology will affect the organisation of the healthcare facility, but the new technology's fit and usability will also be shaped by how users manage, plan and negotiate its uptake.

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Clinicians, security and information technology support services in practice settings- A pilot study

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Abstract

This case study of 9 information technology (IT) support staff in 3 Australian (Victoria) public hospitals juxtaposes their experiences at the user-level of eHealth security in the Natural Hospital Environment with that previously reported by 26 medical, nursing and allied healthcare clinicians. IT support responsibilities comprised the entire hospital, of which clinician eHealth security needs were only part. IT staff believed their support tasks were often fragmented while work responsibilities were hampered by resources shortages. They perceived clinicians as an ongoing security risk to private health information. By comparison clinicians believed IT staff would not adequately support the private and secure application of eHealth for patient care. Preliminary data analysis suggests the tension between these cohorts manifests as an eHealth environment where silos of clinical work are disconnected from silos of IT support work. The discipline-based silos hamper health privacy outcomes. Privacy and security policies, especially those influencing the audit process, will benefit by further research of this phenomenon.

Keywords:

Health information, Medical informatics, Information protection, Data security, Hospital information system, Privacy, eHealth, Sociotechnology**.**

Introduction

This paper analyses feedback from information technology (IT) support staff and clinicians about their perceptions of work with eHealth security implementations in the natural hospital environment (NHE). Key features of the NHE include inadequate infrastructure, pervasive computer use, shared clinical workspace, aural privacy shortcomings, highly interruptive work settings that threaten private and secure (P&S) e-health training outcomes and inadequate budgets [1].

Studies reviewing clinician work with P&S eHealth tools in the NHE began emerging from the 1980s. For the purposes of this paper, the term *eHealth* broadly refers to patient health records stored on computers in care settings. Theorists recognized the potential synergies between clinical work and IT support [2-4]. The studies are among the forerunners of multidisciplinary knowledge about the impact of IT support on clinical work with eHealth. Sociotechnical approaches advance our current understanding of eHealth implementations too [4-9]. Sociotechnical approaches "consider and optimize both the technical work processes and the social systems operating within the work environment to improve organizational performance" [7]. Post and Kagan's (2007) study of security tools trade-offs to maintain productivity furnishes an example of the sociotechnical approach in action [9].

The 2008 study by van der Linden et *al.* reviews P&S issues in the context of interoperable systems architecture emphasizing the need for a paradigm shift from centralised to localised systems to advance P&S patient care[10]. Other important works, such the efforts of Brogan et *al.* (2007), in the context of password security tools, and Williams (2008), who analysed P&S tools in the GP setting, try to understand the end-user experience of eHealth implementations [11,12]. Notably, Pagliari (2007) maintains the common pattern of working in discipline-based silos has supported the development of an IT environment that runs in parallel, rather than harmoniously, with the clinical user environment [2]. The literature suggests understanding the P&S interface between clinicians and IT support staff is a foundation of improving eHealth performance in patient care settings [5]. Hence this pilot work analyses beliefs of IT staff about work with P&S in an eHealth hospital context and contrasts this with the findings from an earlier case study of clinicians in the NHE [1].

Method

IT participants were drawn from a purposive sample of IT staff at public hospitals in Victoria (Australia). "*IT staff*" refers to hospital staff with reporting lines to executive information managers. The participants were recruited from tertiary hospitals in rural, urban and suburban locations. After human ethics clearance, managers passed on recruitment material for the study during regular meetings with groups of staff. Nine IT staff from various departments, as is illustrated in "Table 1. IT participant profile" volunteered to join the study.

Table 1- IT Participant profile

Area	Case	Sex	Title
Urban	1	M	IT Manager
	2	M	IT Manager
Subur-ban	3	M	Clinical Informatics Manager
	4	M	Computer Services Manager
	5	M	Departmental IT Officer
	6	M	Departmental IT Support Officer
Rural	7	F	Health Informatics Services Manager
	8	F	Hospital IT Support
	9	M	Hospital IT Manager

Case study data from the second group of participants, clinicians, has been added to IT data and is re-used for this work. The clinical participants comprised nine medical, eight nursing and nine allied health participants. That study asked about clinician security practices when using health systems for patient care. The participants were drawn from various departments of the same hospitals as IT participants [13]

The sampling and ethics methods for the older work reflected those used for this case study. A lack of available volunteers meant no attempt was made to select participants based on specific clinical or IT disciplines. The data collection factor in common was that all participants worked with P&S eHealth tools for patient care at the Victorian public hospitals. Presumably participants that volunteered for these studies were more interested in P&S than their counterparts.

Both case studies relied on the 'questerview' technique, which asks standardized questions during qualitative data collection [13]. Participant questions were structured, ostensibly to obtain closed answers during interviews, which were tape recorded by the researcher for later qualitative analysis. The juxtaposition of clinician feedback, published earlier, with the new data from IT support staff at the same hospitals compliments our present understanding of work with P&S in eHealth settings.

Results

The results section initially aggregates key feedback from the clinicians. A report of feedback from the IT participants follows. Taken together, the sections summarize all of the key research data underpinning this work.

Clinical evidence

Key clinician feedback is depicted in "Table 2. Summary of the clinicians' evidence" [13]. As the table shows, clinicians were required to share computers at the user-level environment. Queues for access to the computers were frustrating and delayed patient care tasks so that clinicians "sometimes did not bother" updating patient records on eHealth systems at all.

The system environment for eHealth was described as 'sluggish' by participants. Software evidently did not intercommunicate, even when on the same computer. Most applications required a unique logon combination of user-name and password for access to care information enabling clinician access to a single episode of patient care. Computerised access control lists, which tailored an individual's authorisation to eHealth systems by patient consent and work role, were characterized as cumbersome and ineffective. Finally screen-savers asking for a logon combination to continue work interrupted the diagnostic process as well as costing valuable time for patient care. Screensavers blank a monitor when no user activity has been sensed for a period of time. Feedback suggested the system environment was so slow and cumbersome; it often disrupted patient care work.

Table 2- Summary of the clinicians' evidence [14]

Implementation	Manifestation	Result
Shared computers	Queue	Frustration
Slow system	System latency	Disruptive
eHealth applications	Multiple logons	Impractical
Passwords	Fear of lockout	Avoidance
"Handover sheets"	Paper persistence	Collusion
PKI	Inflexible	Collusion
IT Support	Authority	Resignation

Passwords for logon to the eHealth system were also too numerous for participants. One medical clinician explained the range of passwords he needed to remember exceeded one's cognitive capacity. Forced password resets and alphanumeric, mixed-case combinations (e.g. M0n@5h) to enable ostensibly safe user choices exacerbated the shortcomings participants associated with the P&S tool. Further, the clinicians felt the process of obtaining a replacement password, should one be forgotten, was both tedious and frustrating. Fear of system lockout as a consequence of forgetting passwords triggered a range of clinician responses, from the illicit storage of the combination on a computer screen or notice board, to "cheat sheets" in some settings, generic ward logons and avoidance techniques, such as sharing logons. These shared logons often gave greater access to the eHealth system than the clinicians own and so were seen as pragmatic solutions for access to patient care information at all system-levels.

The table also illustrates the clinicians' beliefs that "*handover sheets*", as the clinicians called them, were an "important medical tool*"*. The sheets amalgamate patient information from a range of eHealth systems into a printed document. Sharing user credentials with colleagues allowed written updates from ward rounds to be transcribed by a staff member later in the day. Collusion over eHealth P&S tools for access to productive patient information from "the multiplicity of systems on wards" was a common participant experience.

Public Key Infrastructure (PKI) was apparently inflexible for use in patient care settings. PKI protocols incorporate digital signatures and digital certificates, which are protected by passwords or keys, to decipher encrypted data. The protocol relies on evidence of identity, generally a face-to-face check, conducted by the issuing authority [14]. Several clinicians evinced concern about the effectiveness of the security tool. For instance, PKI authenticates users for eHealth. However if the authenticated clinician leaves the computer without logging out then others might harness the PKI authorisation

for their own purposes. Given the highly interruptive NHE, this scenario often occurred in patient care settings at the hospitals. In some cases the collusion was deliberate, with clinicians often sharing their PKI user details with others during holidays or illness. In other cases, the interruptive nature of clinical work underpinned the breach. The clinicians' believed PKI was no more robust than any other security tool used in patient care settings and, in any case, would increase their dependence on IT departments.

The participants believed IT departments at the hospitals were responsible for most eHealth shortcomings. They were worried by system failure at the hospitals, although could not quantify its frequency. The expression "IT failure" was used to describe all the technical difficulties the clinicians had ever experienced or heard of in the NHE. Preparing for IT failure, one participant backed up her own system storing "paper copies of pretty much everything" on her computer. A staff survey expressing dissatisfaction with clinical IT devices were the substance of a complaint from another but "nothing …happened". Other clinicians believed IT departments "really don't meet the times [sic]". Most clinicians had "simply given up" on IT support because "the process was too much of a hassle".

Evidence from IT staff

This section reports on key data collected for this study about supporting secure clinical work with eHealth. Key themes from interviews with IT staff are summarized in "Table 3. Summary of the IT support feedback". The table illustrates IT staff feedback about personnel and technical resources shortages linked to inadequate budgets. The following comment from one participant epitomises these. He said, "No we can't afford that" in reference to a P&S tool. Another participant explained, "We're only a small team", referring to her department. Still another said, **"**We are so small …I think everywhere bogs in these days … you have to, haven't got much choice". Finally, a fourth IT participant suggested resources shortages meant IT staff were not always trained for the tasks they did. He said, **"**I haven't got teams of specialist people, they're all multi skilled … one of my colleagues did an upgrade yesterday … half past five last night we're ringing him up to find out certain things because the documentation was incomplete". Participants believed IT resources were inadequate to support their hospital communities efficiently.

As Table 3 illustrates, the IT support staff also thought maintaining a secure eHealth clinical setting was demanding. The participants knew their responses were being recorded while talking about clinicians as end-users, yet were very frank throughout questerview. One participant explained, "[eHealth P&S] is very challenging, you've got to drum it into … [users]". Yet another IT participant said "one of the things we've got to do is get security into … [users] … People don't realise that an instant could be all it takes for somebody to try and enter the computer". All IT staff had noticed clinicians using stick-it notes and cheat sheets to store username and logon combinations in patient care settings. Still another IT worker wryly commented "we will tell the business manager the password and they will give it to … [others]". A tangible frustration with the clinicians' priorities permeated the feedback. Yet participants were also resigned to managing eHealth P&S risks in clinical settings. The relationship between IT and the clinicians was sometimes contradictory.

Table 3- Summary of the IT support feedback

Experience	Manifestation	Result
Shortages	Small teams	Technically inefficient
Clinicians	Incomprehension	Resignation
Password administration	P&S tools escalate	Counterpro-ductive
CD, DVD, USB	Locked down	Flash cards
Support structure	Fragmented	Disconnection
Auditor	P&S reports	Key priority

The table also lists passwords as a key P&S concern for IT. All the participants helped to administer "one end-user one logon combination" policies at the hospitals. However complaints from clinical departments sometimes caused policy adaptations such as generic user names (i.e. "Ward 21"), where many clinicians shared a single computer account. One IT participant, summing up her colleagues feedback said, "[In] … certain wards, it's a balancing act between the [P&S implementations and clinicians' patient care work]". Evidently IT work included making pragmatic judgements about the quality of P&S tools for care in the NHE.

Notably, the IT participants, as with the clinicians, spoke about the range of logon combinations required for complete access to a single patient care record. One IT participant explained, "… you only need one username and password for both [hospital] systems. However for security you have to set up an[other] account." Evidence from the IT staff suggests P&S system requirements multiplied the number of logons need for clinician access to eHealth systems.

For the most part IT staff reported locking down Universal Serial Bus (USB) ports and portable media at the hospitals. The USB ports enable portable devices to connect to a computer without restarting it. However other staff explained this was not always the case. One participant said, "every Tom, Dick and Harry uses their USB to take [data] home". It seems even after locking down USB ports and CD or DVD drives at the hospital where he worked "Flash memories come in [sic] and people just walk in and out with the bloody stuff". Flash memories are electronic cards that store data. The feedback suggests that as security controls were implemented at the hospitals, clinicians found ways to avoid them.

Several participants commented on the structure of IT support services at the hospitals. One IT participant explained support responsibilities were fragmented. He said "what I am doing is not complete by itself, for many things I go back to [other IT staff]." He continued "… for any change, there is a Change Manager, we have to go through him personally". Another participant confirmed the feedback. Speaking about requests for IT support, he explained, "you could fix [the job] there and then but there's a procedure … part of that is the security, its

only a subsection of it [sic].” The participant was then called away to organise a major system change, ending the questerview. The reported segregation of many duties apparently ensured IT participants tended to be time-poor and disconnected from each other.

Finally, as Table 3 suggests audit priorities were paramount for the NHE. Feedback indicated IT policies were audited by external health authorities every few years to renew hospital licences. Annual internal audits of the hospitals were outsourced to contractors. The frequency of both types of audit depended upon previous findings.

Most IT participants spoke about policies emerging from audit requirements. The policies forced many of the password practices that the clinicians found cumbersome. These policies included the multitude of numbers required to authenticate eHealth access, forced password resets and alphanumeric password selection. One IT participant described the audit process. He said “… as part of a review, we have to look at everything … we have to present all our documentation to the auditors”. A participant from another hospital agreed. She said “Yes … [the auditors] … come in and interfere sometimes, well … strongly suggest that you adopt, with financial incentives or otherwise with disincentives [sic] [their preferred P&S systems]. The feedback implies that auditors generally relied on paper-based or electronic reports to inform their findings and recommendations. IT Support participants, for seemingly pragmatic reasons, considered audit requirements a higher priority than clinician P&S support tasks in the NHE.

Discussion

Three key themes emerged from this comparison of clinician feedback with that of IT staff at the hospitals. The themes concern eHealth resources, the functionality of several P&S tools and evidence of tension between both groups of participants.

Resources

Comments made by both clinician and IT participants illustrate the point made by Post and Kagan (2007), who argue organisations rarely deliver the increased IT support required to adequately underpin P&S implementations[10]. IT resource constraints, such as an inadequate number of computers and associated access queues, eHealth applications that didn’t interoperate and multiple logons for a coherent view of patient information frustrated the clinicians. As a result, some clinicians did not always update patient care records.

IT participants consistently referred to shortages of technical resources and skilled staff. These participants explained the IT teams were, by necessity, multi-skilled in a practical sense if not by certification. IT teams were time-poor due to their small size and the breadth of their responsibilities in the NHE.

The combined experiences of both cohorts are worrisome. The feedback suggests care information stored on eHealth systems may not be reliable for patient care. Auditors provided financial incentives to decide on P&S policies. The time-poor IT teams comprised a resource shared by clinicians, as well as other sections of hospital communities at the sites. The consequence of these experiences may be three-fold. Firstly, eHealth systems are likely to hold unreliable data. Secondly, unreliable data can foster adverse health affects (AHEs) for patients. Finally, the P&S tools utilized for access to eHealth were not tailored to contextual clinical needs. These findings suggest health authorities should review access to resources in the NHE to address the P&S issues emerging from questerview evidence.

Usability

The evidence indicates that clinicians did not find the eHealth system usable. “*Usability”* is a term describing the ease with which users can interact with a computer system. The clinicians believed the system was slow, clumsy and ineffective, or even worse, interrupted the diagnostic process. Applications on the same computer frequently could not communicate with each other let alone networked computers. The participants believed P&S tools for eHealth, such as logon combinations, were both onerous and numerous.

The clinicians’ widespread fear of system lockout due to forgetting one’s password resulted in the eHealth avoidance techniques, as Post & Kagan suggest [10]. The questerview evidence suggests these techniques included the illicit storage and publication of logon combinations, collusion over user credentials and the use of handover sheets, which were based on transcribed data, to provide patient care. Transcribed notes have long been associated with mistakes that cause AHEs[14]. The clinicians saw no point in PKI implementations in care settings due to their interruptive work flow. Frustrated by disruptive eHealth tools, the clinicians tended to believe IT services were at least partly responsible for their lack of control over the storage of patient care information.

Audit

IT staff feedback suggests many eHealth P&S tools made the clinicians’ concerns difficult to address. Hospital eHealth systems did not require multiple logons but P&S controls did. The P&S controls were required to pass regular system audits underpinning hospital licenses.

It seems audits, some contracted internally, generally reviewed eHealth P&S policy documentation and system processes. IT participants explained audit reviews did not extend to actual user environments. Local audits were evidently triggered by actual security incidents occurring between the hospital audits. Once effective controls to the local threat had been developed, they were incorporated into policy documents for the next audit.

The external audit process has much to commend it. The process addressed conflict of interest concerns at the hospitals. Also, system concerns were incrementally controlled as they arose and were looped back into hospital policy for future audits. Yet feedback from both groups of participants suggests a gap in the crisis management audit approach – the patient care setting. The feedback shows clinicians habitually addressed their own eHealth concerns in isolation from IT. It is reasonable to assume this habit resulted in relatively few

crises, limited IT support, and so solutions were rarely incorporated into hospital audit policies. As a consequence, unless thoroughly reviewed, audit processes may prove irrelevant to numbers of AHEs or threats to the P&S of eHealth systems.

Tension

The relationship between IT staff and clinicians was tense. The evidence indicates the clinicians believed eHealth systems were unreliable and controlled their access to patient care information. P&S trade-offs, such as shared passwords, allowed the clinicians to avoid using eHealth systems and so minimised the need for IT support. The cohorts evinced frustration with each other throughout the questerviews.

IT support staff believed achieving P&S eHealth systems in end-user environments was challenging. For instance directives to lock down removable media, such as USB ports, were corrupted by end-users carrying flash memory cards. Logon combinations were commonly stored on stick-it notes and displayed at the hospitals too. The IT staff felt they needed to "drum" P&S eHealth practices into the clinicians.

A clear contradiction between clinician and the IT work goals emerged from questerview evidence. IT tools disrupted patient care work, potentially fostering AHEs. So these were often thwarted by clinicians at the hospitals. The IT staff were both frustrated by clinicians and, by contrast, were also resigned to clinician P&S practices. Evidence suggests the participants were locked into disciplinary silos.

These findings support Pagliari's (2007) reflection about parallel clinician and IT work practices [2]. Participants did not acknowledge their differing motives and operational constraints. Thus the contribution of further research trying to understand or develop active collaboration between clinicians and IT support will advance P&S concerns. The collaborations may also reduce the number of AHEs associated with poor eHealth implementations.

Conclusion

This work compares the approach of IT support staff and with that of clinical staff to eHealth as it relates to the P&S of patient care data to show that neither cohort felt they could control P&S at the hospitals. Their evidence suggests resources shortages combined with clinician avoidance of eHealth manifested as tension between both cohorts of health workers. Further research is needed to understand the undoubted impact of resource shortages, usability and tension between IT and clinicians on effective eHealth implementations.

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Learning lessons from electronic prescribing implementations in secondary care

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Abstract

This paper reports a study undertaken in the UK to gather lessons learned from hospital sites that have implemented electronic prescribing systems. The work was commissioned by NHS Connecting for Health, the UK Department of Health agency responsible for the implementation of the National Programme for Information Technology. The aim was to capture front-line experience of the project and systems implementation, and to share it with staff who will in the future participate in other implementations. Data were drawn from detailed interviews with staff and a survey in 13 hospitals in England, as well as a review of published studies of implementations. The study output is a report and six user-facing briefing documents targeted at key stakeholder groups; nurses, pharmacist, doctors, senior executives, implementation team members and IM&T staff.

Keywords:

Electronic prescribing, Implementation, Evaluation research, Lessons learned.

Introduction

Prescribing and administering medicines is a core activity in modern medicine. Doing it intelligently and safely is one of the most significant measures of the quality of the care that patients receive. Maintaining and managing information about drugs prescribed, dispensed and used is a significant element of a patient's medical record which itself underpins good care at the point of delivery. For the managers of health care systems, from the ward or clinic up to the national level, knowing about how medicines are used is important for pinpointing areas for improvement, managing budgets and reacting to new circumstances. Electronic prescribing (eP) systems, found increasingly in both primary and secondary care settings, can support the delivery of care and the management of health care systems.

However, the level of implementation and use of electronic prescribing systems does not seem to match the potential they seem to offer and despite the substantial research evidence for their beneficial outcomes, and many official endorsements of electronic prescribing systems as a core clinical technology, it is still that case that not very many hospitals in the UK or other countries have achieved comprehensive systems in hospital-wide use. There are of course some notable exceptions and, for example, the Royal Hampshire County Hospital, Winchester in the UK became probably the first hospital in Europe to replace one eP system that had been in use for over 10 years with another. Still, the implementation of ePrescribing (eP) in acute care in the UK has been limited to a small though growing number of sites. This is in direct contrast to primary care in the UK where computer prepared prescriptions are now the norm and the electronic transmission of prescriptions from general practitioners to high street pharmacies is in use and being upgraded in England to a service with electronic repeats and full electronic signatures under the Electronic Prescription Service[1].

Existing secondary care implementations in the UK include some that have developed out of specialist clinical needs and may be localised to a single ward, (ICU, oncology, renal), some out of pharmacy systems, and some as part of a wider implementation of hospital information systems. In prospect for all hospitals are electronic prescribing modules as a part of large whole hospital electronic patient record (EPR) systems to be implemented under NPfIT, as well as more implementations of specific eP systems.

The relatively modest scale of electronic prescribing in the UK acute care setting might be explained by a number of factors. These include a perception that electronic prescribing is technically difficult and challenging, that available systems are not sufficiently well developed to deliver benefit, that other sibling systems need to be in place *before* electronic prescribing is rolled out, or that the culture change required for adoption into clinical practice is too hard to achieve. The proposed roll-out of EPR under NPfIT has suffered many delays and may have caused some 'planning blight' making it harder to secure a budget for separate eP implementations.

The work reported here was commissioned by NHS Connecting for Health, the UK Department of Health agency responsi-

ble for the implementation of the National Programme for Information Technology. The work addressed some of these impediments by synthesizing the lessons learned by staff in hospitals that had implemented electronic prescribing, and passing them on to other front line staff and managers. The aim of this study was then to help build confidence among such staff that hospital-wide electronic prescribing was achievable, and to help people to prepare for the implementation of such systems.

This study is in this respect rather different from most evaluations undertaken in health care, having as its objective a focus on the processes of implementation themselves, seeking an *emic* account, rather than a focus on outcomes of an intervention *per se*. Further, the main audience for the work was intended to be the peers of those reporting their experiences from within the hospital culture, rather than policy makers, senior managers or technical staffs.

Study background

The systems used for prescribing inpatients medications and recording administration in UK hospital are based on a model established in the 1960s. Doctors write medication orders directly onto a paper drug chart or medication Kardex, and the same document is used by nurses to find out the doses due and record administration to the patient. The drug chart is also used by pharmacists to clinically screen and supply medication, as well as by other healthcare professionals when they need to view a patient's current medication. The single document has great advantages in that everybody looks at the same version of information, but there are some known problems with this system. UK studies show that:

- prescribing errors occur in 1.5-9.2% of medication orders written for hospital inpatients [2-6]
- dispensing errors are identified in 0.02% of dispensed items [7-8]
- medication administration errors occur in 3.0-8.0% of non-intravenous doses [3, 9-11] and about 50% of all intravenous doses.[12-13] (These figures exclude errors involving wrong time of administration).

In the past decade there have been a number of significant changes in the ways in which medicines are used in secondary care [17]. For example, prescribing roles have expanded to include nurse and pharmacist prescribers, the use of patients own drugs (POD) help to manage waste and to allow patients more participation in the processes of medicines use. More attention is now focused on the consequence of adverse drug events (ADE), where the medicine use process breaks down, and patients suffer, as when allergy information is not sought or is not used or when prescribing data is unclear, incomplete or in error. Various estimates have been made as to the cost of such errors, and while the exact detail may be disputed, the overall impact of ADEs is clearly significant.

Against this background, and drawing in particular on the concern with preventing errors, there has developed a strong movement that advocates using the computers to help deliver new means of managing drugs. Influential reports from the U.K, USA and other countries have suggested that computerised medicines management should become an essential part of modern medical practice[14-17] Such systems are discussed under various names. In the United States the most common name used has been the abbreviation CPOE, though its exact definition has shifted from 'Computerised Physician Order Entry', to 'Computerised Provider Order Entry', in line with the expansion of prescribing authority. In the UK the term CPOE has not been so commonly used since UK practice in hospitals has been to separate the orders for drugs from other medical orders such as physical therapy, tests or imaging. It is more common in the UK to speak about electronic prescribing systems, abbreviated to eP, and to separate them from systems that support other types of clinical orders. NHS Connecting for Health's formal definition of ePrescribing is as follows:

> The utilisation of electronic systems to facilitate and enhance the communication of a prescription or medicine order, aiding the choice, administration and supply of a medicine through knowledge and decision support and providing a robust audit trail for the entire medicines use process [18]

Thus the phrase 'electronic prescribing' should not be taken to indicate that the only purpose is to help in prescribing activity. Prescribing is of course an important aspect of eP systems, and the use of decision support for prescribers, alerts for allergies or drug-drug interactions, or order sets, can offer significant improvements in care. But contemporary eP systems serve wider purposes in prescribing, supply, administration and recording functions, as well as audit and review. Indeed it is exactly *because* such systems can integrate these distinct activities that they are seen as useful and able to contribute to improved patient care. For example, if a drug is prescribed, and the eP system knows that it is not currently on the ward in sufficient quantity, an eP system may be able to generate a supply order in the pharmacy.

Materials and Methods

The objectives of this study were: to accumulate and summarise the varied experiences of NHS hospitals in the UK as they have implemented (or failed to implement) various versions and styles of electronic prescribing (eP), to review relevant international literature on the implementation of eP, commenting on the messages that can, and cannot, be extrapolated to the UK, and to develop a set of short and informative practitioner facing briefs that address key aspect of eP.

Data were collected by interview, through a detailed questionnaire for key personnel from eP sites, and by review of published materials. The work drew on the input from over 50 staff in 13 NHS hospital trusts, representing the implementation of 20 different systems.

The study resulted in a report but given its aims other important outputs were six user facing briefing documents (leaflets) targeted at key stakeholder groups; nurses, pharmacist, doctors, senior hospital executives, implementation team members and IM&T staff. These outputs form the basis of a toolkit including a PowerPoint presentation that can be adapted for use

in a variety of settings. The final results can be found online [19].

Results

Of course, not all people reported the same experiences, and sometimes the reported 'Lessons Learned' were contradictory. However, most often people who had experienced eP implementations told a similar story, and seemed to draw similar conclusions. Given that the focus of the study was on implementations of sophisticated IT systems we found, as expected, a number of well established themes that are associated with implementing any type of information system in a health care setting. For example, most people expressed the need for senior managers' support from the initiation of an eP project and throughout its progress, emphasised the role of champions, the importance of user involvement and the need for (and problems achieving) 'clinical engagement'.

These are undoubted necessary conditions for a successful eP project. However, there are also some subtleties that need to be added, placed within a discussion of the specifics of the implementation of eP. We explore here the critical and context-specific themes that emerged as making eP projects different or distinct, and which can help to identify specific actions and attitudes needed. Thus we reflect here an experiential, 'bottom-up', view – eP as seen by the main stakeholder groups that have to absorb the new technology and release its benefits as they develop their own new ways of working.

Getting Started

Many of our respondents had been involved from the start of their hospital's eP project. Their views, with the benefit of hindsight, were often that the 'vision' of eP needed to be established and communicated first, both in terms of the big picture (patient safety, modernisation, e-health strategy, eP's role as an innovative clinical system), but also in terms of the significant details that would shape the eP system in that particular hospital's context. Such details include identifying the benefits that eP offers to the multiple stakeholders. Is there something positive for everybody? Where are the most receptive parts of the hospital? Which specialties can be relied upon to embrace eP with enthusiasm? Which ones, once convinced, will carry the message loudest? And which ones will be most problematic?

An almost universal finding from our respondents was that eP projects must be multi-disciplinary. No one professional group can carry a successful system into widespread use. If significant professional groups are missing, excluded or unenthusiastic, then this is storing up problems ahead. As one project lead said; "Undertake lots of visits and talks, if need be grovel, go everywhere and sponsor events. Do everything to build up visibility." Many of our respondents reported a desire for more clinical participation at the outset, in particular from doctors, but they also noted the importance of support from IM&T members who really understand what is being demanded. Management backing is vital too. eP projects, inevitably raise some resistance, perhaps quite a lot from some clinical quarters. If senior managers are other than fully committed, then eP projects may be wounded or even fatally challenged. Of course, to attain the backing (and sufficient budget) from senior management requires that they are well briefed and confident both of the eP team's ability both to effect the implementation and then to deliver real benefits.

One responded advised; "If possible implement X-ray and lab test ordering before EP: this helps users realise the benefits of electronic orders". This may not be a feasible recommendation in some situations, however, the wider point is valuable –eP is best seen as part of a broader programme of implementation of innovative clinical information systems, and success in one area can reinforce success in others.

The Build up

Successful eP implementations are not just multi-disciplinary in their project team, but also reach out across the range of healthcare professionals both to communicate the benefits of eP and to bring out into the open any fears, concerns or areas in which eP may be problematic.

Planning the implementation of eP requires quite careful reconnaissance. Identifying people who can support and develop eP is important: people who can deal with information and communication technology, are happy to change the way they work, and who can enthuse and support others. Of course, not everybody falls into this category, and almost all sites studied had their stories of resistance. Nevertheless, a successful eP implementation can go ahead.

The respondents had learned from experience that eP is less easy to incorporate in some clinical specialities, and that some drugs have specific regimens that challenge the simple logic of most eP systems. For example, paediatric prescribing raises many distinctive problems; A&E work practices may require that prescribing be undertaken in different ways – e.g. using patient group directions (PGDs). And medicines such as insulin, warfarin or heparins each pose problems of how exactly they should be incorporated into eP procedures. Many eP systems struggle with these and other medicine's variable dosing, and often some paper charts must be retained. The eP system then needs to reference these paper charts and incorporate key information such as administration schedule.

In addressing such tricky problems, and thinking through the ways in which to safely accommodate them in eP, broader confidence can be built up. Certainly the early adopting eP sites had faced these problems and found acceptable solutions that work for them.

It may be surprising, but the most common 'lesson learned', and sometimes learned the hard way, was that hardware and software can be a problem! In particular, a number of the sites studied had significant problems with their wireless networks. These manifest themselves in terms of 'dead spots' where no network coverage is available, or underspecified networks that could not cope with the volume of traffic once substantial amounts of prescribing transactions were taking place. These kinds of problems are particularly troublesome and difficult as they had in more than one case meant having to withdraw an eP system when it had already been established on several

wards. Such problems also emphasised the need for a sound back-up plans so a system can fail safely, and be restarted safely too.

Building a good relationship with software and database suppliers was seen as important. In the early set-up phase of an eP project interactions with suppliers can help to solve problems, and tap into other sites with previous experience of the same software. That said, in order to take ownership of the system, and make it fit into the specific context, staff did need to work on configuring the software and making it look and feel appropriate for *their* needs. This work takes time, and some may be optional ahead of roll-out. That is, a basic system might be rolled out sooner, and extra functionality added to it as time goes by. However, in order to provide the most positive experience of eP to new users providing a rich set of features in the initial roll-out may be important.

Training people to use eP was essential. However, opinions differed somewhat as to how much training is needed and the extent to which it should be on the job or in the classroom. Classroom training was reported as being useful but only if the classroom is suitable with equipment and software that is the same as in use on wards. The counter argument some people made was that if a system is sensibly designed, and if staff have sufficient IT skills, perhaps from other clinical systems, then the training needed should be minimal – just training to deal with site-specific elements such as logons, passwords etc. But training has other roles than just imparting information. It can build up confidence, reveal concerns or pick up important bugs or problems with a system. For this reason trainers were seen an essential element of the eP team – not just teaching the system, but also feeding back changes to make it safer and easier to use. Thus the training role can extend well beyond the initial roll-out and sites with a hospital wide system in use maintained a fully staffed training team throughout the systems working life because new staff arrive, locums can appear late at night and at weekends, new upgrades of software are made, systems are improved and changed, and people may need refresher training or training for new roles.

Implementation and use

Those who had implemented eP across a hospital were almost universal in their view that, once a system has been set-up and tested in one chosen area – perhaps one or two wards with particularly supportive staff - then the full implementation should proceed quite fast. Two reasons are proposed for this. First having two systems (paper and eP) in use in the same hospital makes a lot of work when patients cross these boundaries, and second because it is as a result less safe. In any case, almost all sites studied acknowledged the need for dedicated staff to support eP going live in each location, converting medications orders from the old to the new system, providing on the job training and support, and picking up other nursing tasks as ward staff take time to learn to use eP. A number of sites had used locum pharmacists and extra nurses to bolster the staffing levels during eP implementation. One suggestion from an experienced site was by agreement to draw staff from other local hospitals during the key change-over period. In this way experienced people are available, and mutual learning can occur. This might be even more useful if local hospitals are on track to use the same or similar software in their eP plans.

Reported experience of initial use of eP was of a period of intense activity and support, with mixed reactions by clinical staff, followed perhaps after 2 or 3 months by a more positive feeling, and after 6 months by a feeling of "I would not want to work without eP". Nevertheless, support activity continues to be needed. Indeed it is needed throughout the life of an eP system since problems will keep on emerging as well as new ideas for improvements and new understandings of the possibilities. For example, in the early stages of eP use clinical staff are unlikely to think about the management potential of the data held by the eP system. But a year later, when available data is substantial and covers a period of time, reporting, trend analysis or safety audits may be attractive options. Trainers or other designated people also still need to pick up peoples' concerns and suggestions, and then do something with them. An active and positive support system that feeds back progress on fixing bugs, implementing new features or just answering question is an important part of sustaining eP, and the basis for obtaining full benefits.

eP support is an important task that demands a mix of skills, some IT related, some clinical, and some specific to pharmacy. How to set up and staff such a support operation is not straightforward, and things will not work well if technical questions go to clinical staff or vice versa. eP sites solved this problem in different ways, but perhaps the most successful was to designate a team approach with clinical and technical staff working together.

Using eP has consequences, intended and emergent. Some of these are directly related to the benefits that they offer. For example clear, legible and complete medicines orders mean that pharmacists need to spend less time making simple corrections, they may also spend less time supporting the supply of medicines. On the other hand the work involved in supporting the eP system – keeping it up to date, improving usability, implementing prescribing policies etc, will probably eat up, and may well exceed (depending on Pharmacy's role) the time savings created elsewhere. This may also lead to some consequential changes. For example if TTO (discharge) orders are sent direct to the pharmacy, then expectations will be that they are processed immediately. Meeting such enhanced expectations may not be easy. eP was reported as having consequences for staffing policy too. For example, agency nurses or locum doctors that have not been trained to use a system are less useful. A number of eP sites explained that they had become more concerned to build up a bank of part-timers who were trained, had passwords, and could use the eP system directly.

Conclusions

Our respondents involved in eP implementation in NHS hospitals shared many common insights - different sites often yielded very similar 'lessons learned'. Unsurprisingly, traditional project success factors were as relevant to eP as to any other area of IT, requiring senior management backing, good

project management and user commitment. In particular, in establishing an eP project it was seen as essential to pay attention to building the supporting network. Champions needed to be found and encouraged, and the strong backing of senior mangers obtained. Often, as reported, it is the technology and infrastructure that proved to be the weakest link. These need close attention from the earliest days. And IM&T staff must understand the scale of what is being attempted and the key safety concerns.

It was also recognised that it is important to 'sell' eP's benefits widely, but also early on to flush out potential problem areas and people with doubts. Respondents emphasized the importance of communicating clearly that eP is a major clinical system and demands that everyone involved is prepared to leran new things and change the way they work.

Overall, the key messages that were reported to us can be summarised as follows; build a multi-professional team, plan for early success and to build momentum.; maintain substantial resources to manage develop and grow the system in use.

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Implementation, monitoring and utilization of an integrated Hospital Information System – lessons from a case study

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Abstract

In most hospitals several heterogeneous Information Systems (IS) store parts of a still scattered patient record. Virtual Patient Records (VPR) are systems that aggregate known data elements about the patient from different IS in real-time. This papers aims to present the main lessons learned from the implementation and the usage during 6 years of a VPR system. Ten major lessons were divided in recommendations for software developers, information managers and institutional policy makers. Implementing and using a VPR is a difficult journey but can generate great value for the institution if most of these recommendations are taken in consideration.

Keywords:

Hospital Information Systems, Computerized Medical Records Systems, Integration of Information Systems

Introduction

Healthcare is information and knowledge driven. Good healthcare depends on taking decisions at the right time and place, according to the right patient data and applicable knowledge [1].

Patient data is more recorded now than ever before. Communication is of most relevance in today's healthcare settings, as health related activities, such as delivery of care, research and management depend on information sharing and teamwork [2]. Clinical care increasingly requires healthcare professionals to access patient record information that may be distributed across multiple sites, held in a variety of paper and electronic formats, and represented as mixtures of narrative, structured, coded and multimedia entries [3].

In hospitals, information technologies tend to combine different modules or sub-systems, resulting in the coexistence of several IS aiming at a best-of-breed approach. The integration of these IS is essential to support shared care and is a step towards full system interoperability. However, to integrate clinical ISs in a way that will improve communication and data use for healthcare delivery, research and management, many different issues must be addressed [4-6].

Many distinct technological solutions coexist to integrate patient data, using differing standards and data architectures which may difficult further interoperability [7]. Virtual Patient Records (VPR) are systems that aggregate known data elements about the patient from different IS in real-time.

This papers aims to present the main lessons learned from the implementation, monitoring and utilization during 6 years of a VPR system in a 1300 bed university hospital.

Methods

System architecture

A VPR was designed and implemented at Hospital S. João, aiming at delivering, at any point of care, an integrated view of patient data held in heterogeneous IS by retrieving clinical documents and linking federated databases. It is composed by a web-interface (VIZ), an integration system and a central repository (CRep) [8].

The web-interface was designed to include graphical components and layouts to summarise past patient data (patient chronological bars), and folders that reproduce the traditional types of patient record organisations (source, chronological and problem views). It allows ubiquitous access to heterogeneous data sources.

The integration system includes: (a) direct access to legacy databases; (b) a multi-agent based platform acting as the integration engine that ensures the communication between the various departmental information systems (DIS) and the central repository by retrieving and storing the clinical documents; (c) web-services to allow clinical data access by third party ISs; and (d) patient information viewing components to be integrated in DISs.

The central repository holds all integrated patient documents and the document version control files. It enables fast document access by implementing a hashing function to maximise the distribution of patients by directories.

Figure 1 illustrates the main features of the VPR system, namely the collection, verification, encryption, storage and presentation of the clinical documents. The final users, instead

of having to search patient reports on several different IS, use a single interface to perform that task.

System usage

Repository

The VPR has been working since 2004, regularly scanning eleven DISs and collecting an average of 3,000 new reports a day (currently it holds more than 3 million documents).

Security

To ensure confidentiality of the collected patient information the mechanisms implemented were: (a) role-based access control; (b) logging of user actions in VPR; and (c) secure communications using HTTPS protocol [9]. Sharing of logins and passwords between users has been found in 9.7% of distinct logins, which is lower than two other studied EPRs (10.5% and 22.3%) [10]. Although the role-based access control is a powerful tool, Hospital organisational issues limited its use.

To ensure the integrity of patient information the mechanisms implemented were: (a) an algorithm to detect patients' identification inconsistencies between ISs; (b) digital signing and checking for all clinical reports [11]. Patient identification errors have been detected over the years (25, 17 and 18 in 2005, 2006 and 2007 respectively).

To ensure system availability sensors were implemented to detect: (a) DISs unavailability; and (b) abnormal numbers of clinical records retrieved from each DIS. In 2005, 53 abnormal cases were detected corresponding to 44 real problems. The total VPR downtime in the last three years is approximately one hour.

Information usage

A visualization module for the VPR was made available in October 2004. The VPR has wide acceptance and growing usage among hospital health professionals (the number of users increased 29% in 2006 and 41% in 2007 up to more than 1,100 users).

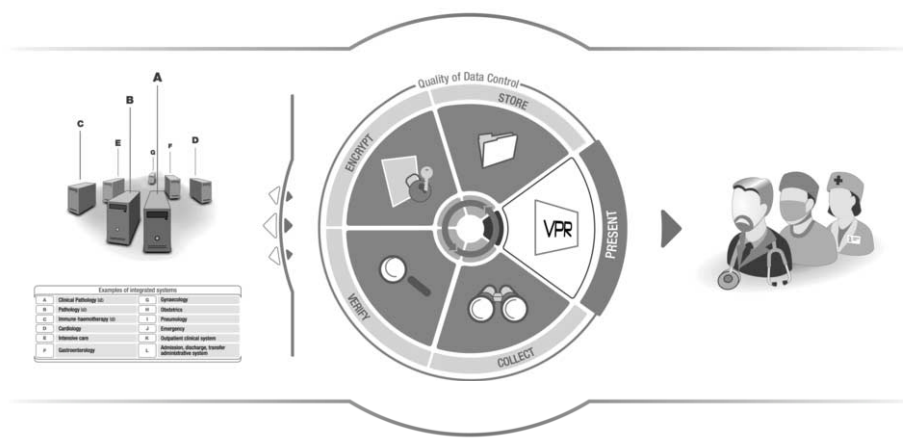
Past information of patients (data from previous hospital encounters) is still used by doctors in new encounters namely those in emergency room attendance (e.g. 52% of the reports viewed in emergency encounters were produced in previous encounters) [12]. The usage of patients' past information is correlated to the setting of healthcare (the half-life of information in documents is 1.5 days for emergency, 4.8 days for inpatient and 37.8 days for outpatient encounters) and to the content of reports (the half-life of immune-haemotherapy reports is 7 days, pneumology 26 days and anatomical pathology is 118 days). The main diagnosis of inpatient encounter is also related with half-life of information produced (e.g. the half-life of reports produced inpatient encounters with neoplasms as main diagnosis is 36 days and with injury and poisoning diagnosis is 17 hours). All these seem important factors to estimate future report relevance.

Discussion

The case study project presented in this paper resulted in the following main findings:

- Different models of integration (e.g. direct database linkage, web-services, and multi-agent systems) had to be used for effectively respond to the integration challenges. If these models are carefully adapted to each situation constrains (e.g. existing physical resources and providers know-how) then little stress is applied

Figure 1 - Architecture of the VPR system implemented



on each integration actor (hospital and several IS providers), which helps achieving proper solutions more efficiently.

- Multi-agent technologies proved to be a robust technology when operating for several years in a large Hospital. They were flexible enough to be used in a highly heterogeneous environment. Multi-agent technologies are suitable to solve complex data integration and communication problems in healthcare institutions.
- The integration of IS raised new security problems (e.g. clinical document version control), and allowed the detection of some previously hidden problems (e.g. time synchronization among servers). Our experience showed that integration could be used to make healthcare institutions take a step forward in the direction of delivering safer healthcare to patients.
- Although role-based access control tools were made available to the Hospital several years ago, the definition of groups and their roles is still practically inexistent. Also, sharing of logins and passwords among healthcare professionals was found to be significant. Defining access control in integrated healthcare environments is a much greater challenge on the organisational and cultural level than on the technical level.
- The dynamic monitoring sensors developed for the VPR that take in consideration the previous behaviour of healthcare professionals and IS, allowed a monitoring that increases both specificity and sensibility. Creating self-adjustable monitoring mechanisms allows effective management in a highly dynamic context.
- Automatically crosschecking patient data (e.g. patient identification) between different IS was an efficient way for the VPR to detect relevant data inconsistencies in all integrated IS. All information available in hospital information systems can and should be used to trigger alerts of malfunctions and inconsistencies, in order to improve patient safety, data quality and ensure a better healthcare.
- Major difficulties were found in the interpretation, data quality and maintenance in using already existing data dictionaries (e.g. patient, professionals or department identifiers). Most of these dictionaries are held mainly by IS suppliers. Healthcare institutions should have a close control on these dictionaries and re-use them in their installed IS; these dictionaries are core elements both in the interpretation of data and system interoperability.
- The usage of past patient information in the VPR case study varies significantly according to patient age, type of information, type of hospital encounter and medical cause (main diagnosis) for the encounter. As more and more patient information is stored, it is very important to efficiently select which one is more likely to be useful and promote it in a scenario where scarcity of resources (screen space, storage space, bandwidth and doctors' time) is very real.

Recommendations

Based on the previous findings, ten main recommendations when dealing with the implementation, monitoring and utilization of an integrated Hospital Information System were created. These were divided in three groups according to the role of person in the organization.

For software developers

1. to seek to comprehensibly integrate all existing IS by making use of different integration technologies;
2. to take in consideration that major differences in maturity exist among the different actors (hospital IT departments and IT suppliers);
3. to consider multi-agent systems when designing integration systems that operate in complex environments like large healthcare institutions;
4. to create user interfaces and data repositories that automatically adapt their behavior to how actually the users work with the IS;

For information managers

1. to create tools that continuously check the integrity of patient data among all IS;
2. to create self-adjustable monitoring sensors for each component of the IS;

For institutional policy makers

1. to allow health information systems to grow both within and beyond the institutional boundaries through integration aiming at semantic operability – *the whole is greater than the sum of its parts*;
2. to regard IS integration as a course to achieve a higher state of information and knowledge use;
3. to clearly define and test confidentiality policies before they are incorporated in IS;
4. to create processes that allow healthcare institutions to maintain their own dictionaries and terminologies of data used in all IS.

Conclusion

The lessons learned and the recommendations are the result of several years on practical experience in installing, maintaining and using a hospital wide integration IS. In the author's opinion, these practical recommendations are useful for most integration projects occurring inside healthcare institutions. These recommendations both can avoid some very difficult problems (e.g. maintaining multiple dictionaries on the same subject), and enable added value to the IS and healthcare institutions (e.g. improving the quality of patient data).

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Model-Driven Traceability in Healthcare Information Systems Development

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Abstract

To improve the quality of software used in healthcare information systems, traceability can play an important role. The concept of traceability establishes explicit trace links in the design, development and maintenance processes, keeping documentation complete and updated. Trace information allows validating bodies, domain experts, system designers and programmers to easily navigate along artefact dependencies and perform simple traceability analysis such as coverage and change impact. This paper presents a novel solution for traceability applied in model-driven development for services in a distributed healthcare environment. The results demonstrate the feasibility of explicitly modelling dependencies using a formal language such as UML. Based on the experience from implementing two full-scale homecare systems in the EU-IST MPOWER project, the potential improvements and challenges with a traceability solution are discussed.

Keywords:

Continuity of care, Service oriented architecture, Model-driven development, MDA, UML, Homecare

Introduction

The software developed for use in healthcare systems should not fail during execution, and ideally, it should have no errors or flaws. However, testing can only reveal errors and not guarantee flawlessness. Organisations such as the Food and Drug Administration (FDA) require a strict validation process before approving software for use with medical devices. Factors such as documentation of the software itself and the development process become important in the validation and testing of software. In [1], FDA describes some general validation principles that they consider important for the validation process. A core principle is related to traceability: "A traceability analysis should be conducted to verify that the software design implements all of the software requirements" (page 19). Furthermore, it states that "a source code traceability analysis should be conducted and documented to verify that: each element of the software design specification has been implemented in code; modules and functions implemented in code can be traced back to an element in the software design specification and to the risk analysis;"(page 21).

Traceability is a concept where the relationships between system artefacts are explicitly described to become a part of documentation, as well as direct input to software development phases and system analysis. With the advances of model-driven software development, traceability has evolved into a concept that includes all system artefacts, from initial mission documents, through requirements, design, tests, deployments, and to operational system versions. Traceability can be used for trace link navigation, coverage, orphan and change impact analysis [2], also know as the core traceability services.

Studies have shown that traceability is considered useful and may have a positive impact on development and maintenance of software [3]. During development and maintenance work, readily access to information about which features that are implemented, why (rationale) and which dependencies that exist between different features and components, is vital for correct (valid) implementation. Arisholm et al have found that "for complex tasks and past a certain learning curve, the availability of UML documentation may result in significant improvements in the functional correctness of changes as well as the quality of their design. However, there does not seem to be any saving of time." [4]

To explore how a traceability solution can be implemented within today's development paradigm, the EU-IST MPOWER project[1] has designed a traceability enabled model-driven development methodology and applied it in development of 25 healthcare specific software services. This paper presents the traceability methodology and results focusing on the core traceability services. Using Unified Modeling Language (UML) [5] as the main notation for domain modelling, requirements modelling, system design and system development, explicit traceability links were created and used for dependency navigation and analysis. Based on the experience from the development project, an extended traceability solution is discussed.

Methods and materials

Development methodology

As described in [6], the developers in the MPOWER project applied a model-driven development approach where *user*

[1] http://www.mpower-project.eu

scenarios developed by *domain stakeholders* (dementia experts, patients, patients' family and caregivers) were incorporated into a UML model for software *service* designs. A total of 137 stakeholders were involved in the requirements development phase: 62 senior citizens (22 in Netherlands, 40 in Poland); 11 Family carers of persons with dementia (5 in Austria, 6 in Norway); 49 Healthcare professionals (all in Poland); and, 15 Dementia experts (4 in Austria, 11 in Norway). The 18 scenarios (2-pages each) constitute the requirements in the domain needs, and is main input to the software service development process. In accordance with the SOA4HL7 Methodology [7], recommendations in [8] and OMG's Model Driven Architecture (MDA) [9], a complete service development process was designed as shown in Figure 1. The development is structured into the three MDA phases.

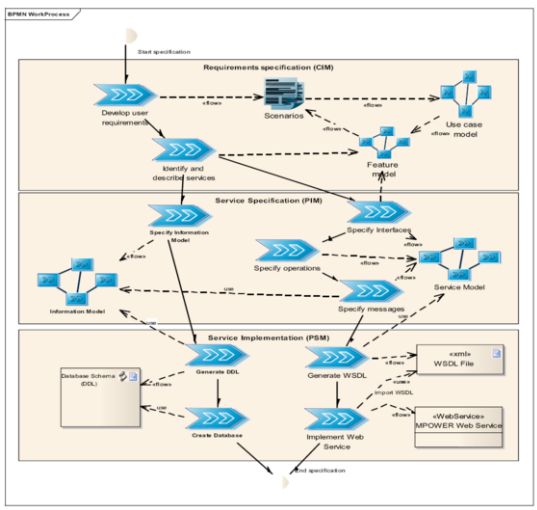

Figure 1- Development process and artifacts

Traceability model

In the development methodology, explicit and implicit trace links are established between the core development artefacts:

- Scenario ↔ Use case: implicit link by documenting the scenarios in each use case
- UseCase ↔ feature: explicit link using UML Dependency stereotyped with *<<trace>>*.
- Feature ↔ Service Model: explicit trace link between a set of features and a service. Implicit from feature to information model through the design of Service Messages (request/response)
- Service Provider ↔ WSDL file. Inserted feature traces as *<wsdl:documentation>* elements in the file.
- Documentation: direct export of navigable (HTML) models and text (RTF) from the design model.

The metamodel for explicit trace links uses the properties of a UML dependency, and includes trace link name/alias, source artefact name, target artefact name, free text field and, source and target roles.

Traceability Services

The trace information is stored within the design model and is used by the core traceability services [2, 11]:

1. *Trace navigation*: from any traced artefact (modelling element), navigate along (trace) dependencies back and forth.
2. *Coverage and orphan analysis*: query trace data for a list of traced elements and un-traced elements. Mostly used to find requirements that are not fulfilled (coverage) and elements that have no dependencies to other elements (orphans)
3. *Change impact analysis*: query trace data for information about which elements that will be directly or indirectly affected by a change in a specific element. Used to estimate cost of change requests.

A sound development methodology should support all these services.

Results

A total of 25 software services were designed using UML, realizing 168 features that were derived from 50 use cases, which involved 16 different actors and described 60 sub-activities from the 18 scenarios. 16 developers were involved in the design of the services during a 10-month period, following the methodology described in Figure 1. The complete actor and service model is reported in [6].

Trace links in the Patient Management Service

To demonstrate the traceability results, the Patient Management service is used as an example. Figure 2 shows the "Stakeholder management" use case and how it is related to actors and other use cases.

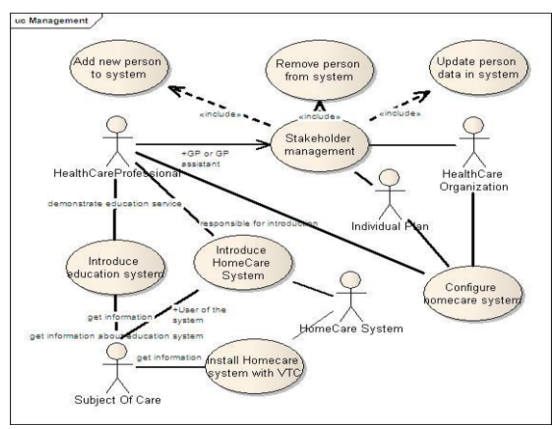

Figure 2- Use Cases for Management scenarios

The use case diagram shows an overview of the system "context", and more details can be found when looking at the properties for each use case element. The relationship from the *use case* to the *scenarios* is documented as a property of the use case element. A use case can be traced to more than one scenario description.

From the initial scenarios and use cases, a set of features are derived. A feature represents a high-level requirement for the system, and each *feature* is directly related to one or more *use cases* as shown for the Stakeholder Management use case in Figure 3. Using the use cases and features as input, the domain information model is designed and services identified following the process recommended by the OMG/HL7 Healthcare Service Specification Project in [7] and Erl in [8].

Each service design has a service rationale that traces from feature to service in a separate diagram. The features to be realized by the service provide useful information about the operations that are required on the services' interface, e.g., feature "*Get System user information for the person"* is implemented as the operations *getUserForPerson()* and *getUserForPatient()*.

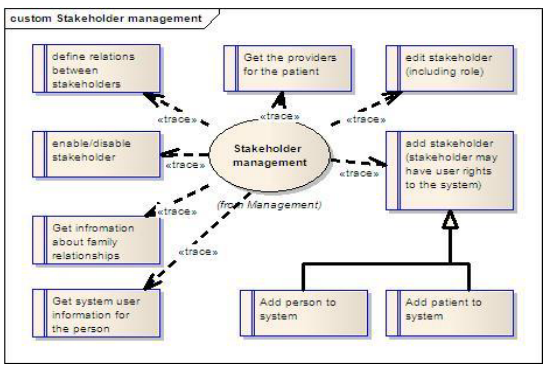

Figure 3- Features derived from the Stakeholder management use case

Traceability Services

From the models presented above, it is possible to provide the three core traceability services.

Trace Navigation

To navigate along (trace linked) elements one can use the modelling tool itself (e.g. Sparx Enterprise Architect), or an exported version of the model using any standard html browser (e.g. Opera, Firefox, Safari). Each model element is described with properties, appearance in diagrams and relationships to other model elements.

Traceability Matrix: Coverage and Orphan Analysis

To perform *coverage and orphan analysis*, most UML tools provide a relationship matrix query where the source, target, relationship type and direction can be used as query parameters. The result is a matrix showing which elements that have a relationship, indicated with a green arrow as shown in Figure 4. From the matrix it is possible to get an overview of which services that realizes which features. If a feature is not realized by any service, this indicates that not all features are *covered*, and a thorough inspection should be conducted. Similarly, if a service does not realize any of the features in the design model, it is an indication of an *orphan service*. A special situation can be identified if two services realize the same set of features.

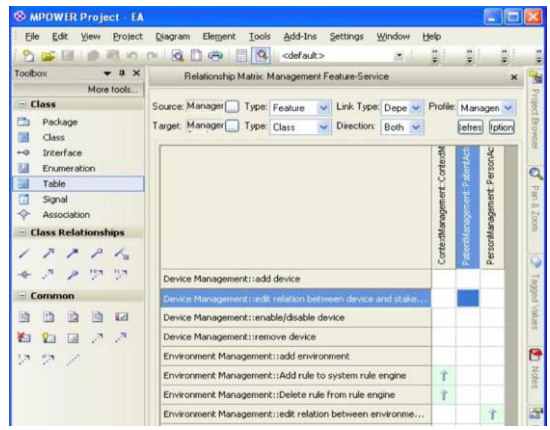

Figure 4- Coverage and orphan analysis matrix for management services and features

Change Impact Analysis

This analysis service can give product owners, administrators and project leaders a qualified estimate on the cost of making a change to the system design, based on trace links in the design model. A query to the design model can find all artefacts (services, features, actors, use cases, etc.) that have some dependency to the proposed system design change. Using the semantics in the model along with the experience from implementation, a qualified estimate on cost, risk factors and required man-hours can be made. Figure 5 shows a simple change impact visualization diagram. From the Patient Management service it is possible to visually trace the artefacts that are directly or indirectly dependent on its design. E.g., replacing the *Individual Plan* system with another system will require a reimplementation of five *features*, that each has a property value stating its difficulty.

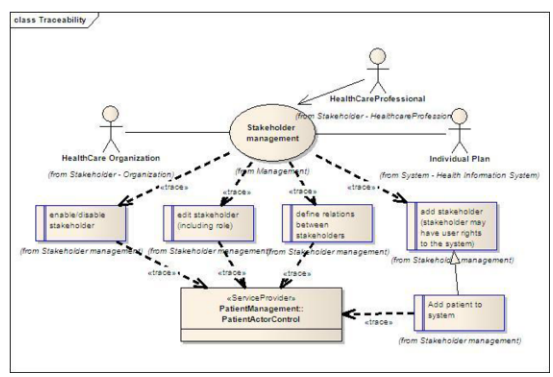

Figure 5- Example of model based view of traceability. All dependencies from between the actors, use cases, features and the final software service are shown in one diagram

Discussion

Using model-driven development and traceability solutions may improve documentation quality, and provide valuable information for many stakeholders in the design, development and maintenance phases of a system's lifecycle. However, a complete set of traceability services are not inherently incorporated in model-driven development and must be enforced by a design and development methodology. The proposed methodology offers these traceability services by using stereotyped UML dependency associations in implicit and explicit models.

Developer effort

For the developers, only minor effort is required to create the trace links. The view-based concept [13] used in MDD ensures that *model elements* are reused across *views (or diagrams)*, providing consistency and persistence of relationships. As a general principle, the more information that is incorporated in the trace data, the more advanced analysis services can be executed [2]. Nevertheless, for simple analysis services as is demonstrated herein, no additional trace information must be provided besides what is already in the model elements. Navigation in models using a html browser, reviewing relationships matrices for coverage / orphan analysis, and creating "query diagrams" for simple change impact analysis, are services that can be easily provided and used during design, development and maintenance using the proposed tools and methodology.

Benefits for healthcare information system development

To take full advantage of the trace information, the development methodology must incorporate both creation and inspection of trace information. An evaluation in the MPOWER project showed that traceability was especially useful for the developers [3].

For approval of software for medical devices, FDA strongly recommends traceability as a tool. The analysis services associated with traceability are considered powerful for improving the quality and documentation of the software. Furthermore, maintenance of legacy systems is a complex and costly process [15-17], also in the healthcare domain. Most hospitals have one or more systems that were implemented and put into production in the eighties. These systems are subject to maintenance to respond to new architectures, updates in standards, vocabularies and nomenclatures. There are many different standards and they are continuously being revised and new versions are ratified and made public many times during a system's lifetime.

Traceability services could be useful for managing maintenance processes.

Relationship to other approaches

Since 2004, the European Conference on Model Driven Architecture has organized a workshop on Traceability[2]. The conference papers reports on successful traceability projects. Also related to traceability is the increased use of business process modelling and simulation of care processes in modelling tools. IBM's Business Driven Development in Healthcare approach uses business process models and trace links to conduct advanced analysis and simulation [19].

Another model-based tool that utilizes traceability services are the three layer graph-based meta modelling tool (3LGM^2)tool from University of Leipzig, Germany [20]. The primary objective of this tool is "to describe, evaluate and plan health information systems." The 3LGM^2 tools could be used in the methodology described in the Figure 1, but in view of the fact that the 3LGM^2 metamodel is different from UML, the model elements cannot be reused in the succeeding system design and development phases.

Another model-driven healthcare software development process is the HL7 Development Framework [21]. The current version describes an approach were dependencies between artefacts are explicitly being modelled in UML. However, at the time of writing, the framework does not incorporate any traceability services.

Extending the traceability information

In terms of software management and maintenance, the meta information for trace link information play an important role, especially for the change impact analysis. Using UML as the core modelling language, one way to *extend expressiveness of trace links* is to use stereotypes and tagged values in a UML Profile. A stereotype can have tagged values such as implementation difficulty, importance level, creation date, creator and version dependencies. In addition, a profile can refine the graphical presentation of model elements and associations. Figure 6 shows an example diagram where green arrows indicate easy and red are critical/expensive implementation.

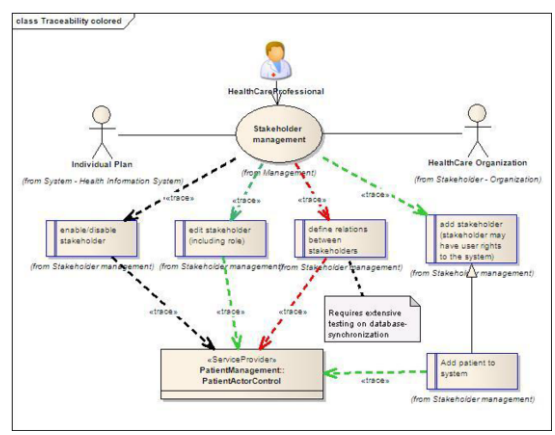

Figure 6- Example of a stereotyped change impact analysis diagram

In a larger system design, the colour coding of trace links (red for critical, black normal and green loose coupling), explicit notes and stakeholder icons (as shown in Figure 6) would make the visual analysis process more effective.

[2] http://www.ecmda-fa.org

Problems with implementation of traceability

There are some significant problems in implementing full traceability in software system development, as is discussed in [2, 22, 23]. The main problems are related to trace information sharing between tools and trace semantics. It is however possible to provide a partial traceability solution with existing tool interfaces and metamodels, and extensions could be provided from standardization organizations such as OMG, HL7 or even the FDA to further enrich the trace information database.

Concluding remarks

Traceability information can improve system development and maintenance processes. The core traceability services illustrated by Walderhaug et al [2] can be provided with a design methodology that utilizes the built-in UML dependency mechanism in a UML modeling tool. The results presented herein demonstrate that relevant and updated documentation can be made available to all stakeholders involved in a system's lifecycle.

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The Evolution of Hospital Information Systems and the Role of Electronic Patient Records: From the Italian Scenario to a Real Case

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Abstract

Health care organizations can gain great value from Information and Communication Technologies (ICT), yet, although there is growing awareness of the potential benefits associated with their use, results often fall far short of expectations. Each year, the "ICT in Health Care" Observatory – part of the Politecnico di Milano School of Management – outlines a profile of the role of ICT in the Italian health care industry, investigating current projects in terms of their impact on processes and organizations, implementation state of the art, governance models, and prospective pathways. The 2009 collaborative research process outlines the need for a change in the way health care CIOs approach technological and organizational evolutions. ICT departments lack vision, governance mechanisms, skilled resources, and top management commitment. This has led to a series of distortions in the innovation of Hospital Information Systems (HISs) and ICT departments themselves. Currently they are too concerned with day-to-day operations and delay comprehensive initiatives capable of leading to effective ICT-driven innovations. The paper points out the problems that health care organizations are tackling and how they are trying to solve them. The case of the Italian National Cancer Institute in Milan provides a valuable example of how a health care organization is developing its HIS.

Keywords:

ICT-driven innovation, Italian health care industry, Hospital information systems, ICT governance, Electronic patient record, Mobile & Wireless.

Introduction

Information and Communication Technologies (ICTs) have become necessary for Italian health care organizations – not only due to their increasing pervasiveness, but also to their ability to respond to the main innovation challenges currently facing the sector: the rationalization of health care costs [10], and the increase in the quality of health care processes [3].

The enormous volume and the intricate complexity of clinical and administrative information to be managed, make ICT essential for both running and innovating health care organizations. To understand this, it is sufficient to think of all the potential benefits that Hospital Information Systems (HISs) could achieve with a digitally-integrated management of clinical information flows, done with Electronic Patient Records (EPRs). Unfortunately, this kind of strategic role has yet to be achieved. Actually, most health care organizations:

- Continue to barely give them a second thought as a source of innovation [5], and
- Don't adequately analyze the organizational changes required to make all the benefits associated with ICT projects become a reality [1].

Thus, instead of being considered strategic resources, ICTs are often simply confused with other health technologies, and generalized as one of the drivers in the rising cost of the health care sector. Helping companies analyze and improve their information streams, EPRs, HISs and – more generally – ICTs, can be seen as a fundamental set of resources able to generate corporate benefits – with the coordination of other medical technologies and health care practitioners. In order to do this, health care organizations need more models, tools and skills on which to base the management of ICT.

Materials and Methods

This study is based on a broader and continuative research initiative promoted since 2007 by the Politecnico di Milano School of Management, i.e. the "ICT in Health Care" Observatory (IHCO), which focuses specifically on the analysis of ICT-driven innovation in the Italian health care industry[1].

Every year, the Observatory follows a stream of collaborative research [11] led by IHCO researchers, and is enriched with the involvement of practitioners in the gathering and analysis of the data pertaining to the research problem. The research stream, outlined in Figure 1, is a combination of a quantitative panel of electronic surveys, several qualitative in-depth case studies, and a series of focus groups called *Advisory Boards* (AB).

[1] The IHCO is one of the 30 Observatories specifically focused on the study of ICT and Management that the Politecnico di Milano School of Management started in 1998.

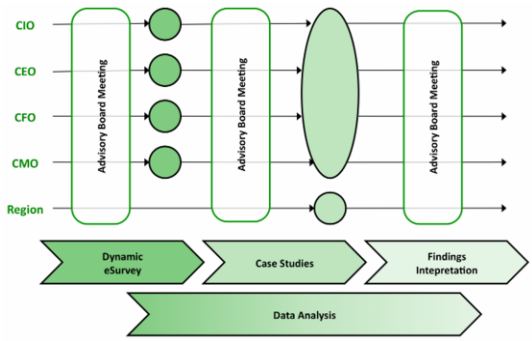

Figure 1 - The collaborative research process used by the IHCO

Every year, an electronic survey is created and delivered to a sample of more than 500 Italian health care CIOs – from representative organizations of varying types and sizes in different geographical areas. In 2009 [8], a 24% response rate was achieved thanks to: (i) a specific survey design[2], (ii) a series of comprehensibility and completeness tests from pilot respondents, and (iii) a set of improvements established with the AB. Every year, a second set of surveys is delivered to the Strategic Board – Chief Executive Officer (CEO), Chief Financial Officer (CFO) and Chief Medical Officer (CMO) – of the same health care organizations of responding CIOs, in order to cross-validate responses given.

A comparative analysis of more than 50 in-depth retrospective case studies is performed every year. The selection of target organizations is based on: (i) dimension of ICT department[3], (ii) ICT strategic importance[4], (iii) ICT projects, and (iv) AB suggestions. Data is gathered through a series of semi-structured interviews given to the CIO, CEO, CFO and CMO. The interviews are based on a common protocol constructed according to survey responses and an *a priori* analysis of the health care organization. Other information came from organizational charts, HIS architectural schemes and other materials shared with the research group (data triangulation).

The AB is a multidisciplinary focus group that advises and helps in directing the focus of the research, in interpreting data, in anticipating future research issues and confirming results. The group counts more than 50 representatives among which: (i) CIOs of the principal Italian health care organizations, (ii) National and International health technology suppliers, (iii) experienced professionals from Italian national health care associations, and (iv) other research partners. The annual AB contribution to research counts three key meetings (see Figure 1). The first one deals with informal discussion about annual research objectives and priorities in the data gathering process. In the second meeting, preliminary results are discussed, and the AB suggests potential best practices on which to perform annual case studies. In the last meeting, overall results and explanations are discussed in order to test, review and confirm them.

[2] The survey is designed with semi-closed questions (to balance usability and speed) with the possibility of expounding on each question.
[3] Measured with the rate of ICT FTE to overall organization employees.
[4] Measured in budget terms.

Results

The Strategic Value of ICT and HIS Governance

A constant piece of evidence emerging every year is the extreme heterogeneity in the ways in which Italian health care organizations give ICT a strategic value [8]. Interviews pointed out that ICT maturity is strongly related to: (i) the strong regional connotation of the Italian health care industry (including providers and vendors as well) and (ii) the historical socio-technical context in which health care organizations operate.

Thus, in order to clearly understand the real level of diffusion of ICT tools among Italian health care providers, surveys analyzed the main areas whose processes are supported by ICT. These areas are classified in: (i) primary activities of health care delivery, (ii) support activities, and (iii) network processes. The matrix in Figure 2 shows past (from 2007 to 2009) and expected (from 2010 to 2012) investment levels in these areas.

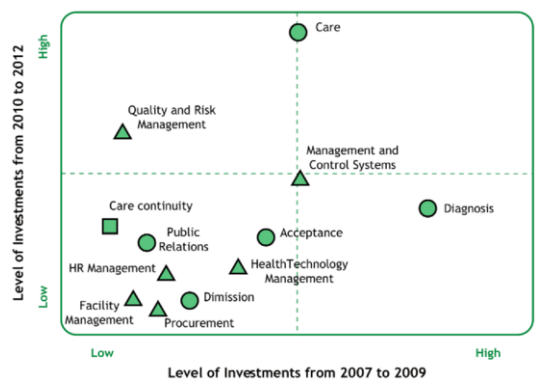

Figure 2 - Past and future ICT investment priorities areas of Italian health care CIOs (Circles = Primary activities areas; Triangles = Support activities areas; Squares = Network processes areas)

The majority of primary processes were evaluated as currently positively/highly supported (e.g. the diagnostic area), apart from core care activities (e.g. bedside, EPR, and so on). ICTs also play a relevant role in clinical support activities, but with the exception of core areas like quality assurance and risk management.

Interviews emphasized that almost all health care organizations implemented ICT solutions with the main aim of increasing resource efficiency. For example it's interesting to consider the contribution that ICT has given in the last few years to time-consuming activities like Admissions, or to costly "material-consuming" activities like those performed in radiology [4]. On the other hand, difficulty in introducing ICT in core care processes can be only partially explained by a low maturity level of market solutions: the implementation of these pervasive tools requires the agreement of all the actors participating in health care service delivery, and a high level

ing in health care service delivery, and a high level of structural integration within health department processes. ICT can play this "linking" role, as confirmed by 80% of organizations, but the level of integration of HIS remains low. Drawing on evidence from the case studies performed, approximately three out of four Italian health care organizations either aren't structurally integrated, or don't realize a level of integration able to lead to future ICT-driven innovation.

Low financial support – often pointed out as the main problem – is mainly a reflection of the low strategic commitment on the part of the strategic board, which doesn't have a clear idea about how ICT can have an impact that goes beyond mere efficiency. Reasons are multiple and range from a lack of a technological perspective on the part of CEOs, CFOs and CMOs, and the inability of CIOs to clearly propose all the advantages tied to ICT solutions, to the need for high investments to reach concrete organizational results[5].

Without a critical mass, ICT employees are forced to play help-desk or hardware manager roles. Very few learning processes are initiated to enhance their technical skills. Leadership programs are practically inexistent. Turnover rate is very low, and many difficulties are found in attracting professionals from other sectors. CIOs tend to ascribe all these criticalities to exogenous causes, rather than internal inadequacy, and to blame operational workload instead of their own incapability to face it. We found [8] that the CIO himself often has a narrow strategic view hindering an approach to innovation. This is due to: (i) a low level of managerial capabilities, (ii) difficult alignment with corporate strategies and (iii) overuse of technical language in strategic board interactions, not abstracting from ordinary operations. Hence, most of the problems can be referred to governance – not to technological matters.

The Role of Electronic Patient Records

According to Figure 2, clinical care is one of the main areas that received, receives and will receive most of ICT investments in health care. This area is highly representative of the necessity of integrated ICT-based solutions, in order to achieve affordable and effective ICT-driven innovations in health care [7]. Clinical care increasingly requires clinicians to access patient record information that: (i) may be distributed across multiple systems, and (ii) is represented as a mix of narrative, structured, coded and multimedia entries. EPR is the ICT-based solution that many health care CIOs are adopting and evolving to tackle these strategic clinical issues, and that have the highest potential to provide advanced integration capabilities to the other HIS components[6]. The importance of EPR in the evolution of HIS's integration led IHCO to include a vertical analysis on this topic in the research process [8].

A comparison between budgets allocated to EPR shows a significant increase in the number of EPR investments than will exceed 500,000 €[7]. These efforts potentially could justify the adoption of effective integrated solutions. However, surveys and case studies outlined a still fragmented situation. Literature analysis [9] allows the identification of five functional areas that characterize EPR:

- *ADT Area*: often integrated with the ADT system, this area manages patient admissions, discharges and transfers within the hospital, as well as vital statistics and administrative documentation (e.g. informed consent).
- *Diagnostic Area*: the features in this area allow exam requests and report delivery from/to wards.
- *Clinical Dossier*: this area embraces the management of all medical and nursing sheets, including initial assessment, vital signs automated monitoring, anesthesiology documents, OR reports, etc.
- *Therapy management*: this area includes support to prescription and administration of drugs, transfusions, nutrition, etc.
- *Out-patient management*: this area manages admission and medical reporting in case of out-patients, and feeds the patient's EPR with information like preliminary report or follow-up examinations.

Figure 3 shows the current and the expected percentage of diffusion of these functional areas in the research sample. Clinical Dossier (e.g. nursing sheets, vital signs monitoring) and Therapy Management are the functional areas with lower diffusion and on which CIOs recognize that they have to work in the future. Unfortunately these areas not only have a key impact on clinical activities, but also are the ones that need higher levels of integration in order to allow EPR to really become a useful clinical tool[8]. Case studies confirmed that the lack of integration with the rest of HIS and the absence of an enterprise-wide approach to solutions are the main limit of current EPR projects.

Case studies and AB meetings showed that the main hinders are, again, not related to technology, but to the extremely complex socio-technical nature of clinical processes (even more if we consider Public providers). Apart from the lack of support often occurring after implementation, the real criticalities are (i) the singling out of actual medical necessities and (ii) processes mapping – mainly because head physicians tend to act almost autonomously, without the real involvement of ICT department. External ICT supplier involvement is almost always operational or consultancy-oriented and in the few cases in which the relation is continuative, CIOs don't delegate much, and work alongside them – even in highly outsourced operations.

[5] The research reveals a generalized distance between the CIO and the top management: only 57% of surveyed CIOs are accountable to the CEO, while many ICT Units belong to Administrative or Technical Departments. Few CIOs act as true C-Levels, and often the ICT Department is not seen as a relevant actor in strategic planning activities – especially in comparison with CMO and CFO.

[6] E.g. Clinical data repository, ADT System, Diagnostic Area Systems, Order Management Application, middleware, etc.

[7] If from 2007 to 2009 the % of investments higher than 500,000 € was 6%. This percentage will increase to 24% by the end of 2012.

[8] Case studies pointed out that the investments in Clinical Dossier and Therapy Management areas will be driven by mobile hardware acquisitions. Surveys revealed that nowadays there is a clean prevalence of desktop PCs (89% of cases), while the use of fully mobile devices is still not widespread. This is a strong barrier against the implementation of really paperless health care organizations, because key clinical features must be delivered bedside with a proper device in order to support daily routine (e.g. PDAs for nurses administering drugs or transfusions, MCAs to support doctors filling daily records).

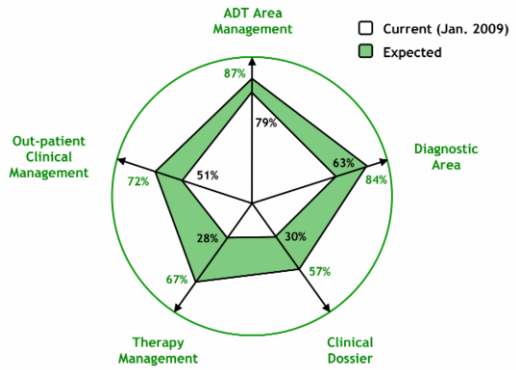

Figure 3: The January 2009 and expected diffusions of EPR functional areas

The AB meeting proposed a few guidelines to change this situation, which were also applied in the best case studies. First, to effectively sustain the change required in health care, CIOs need to work on their capabilities, as already done in other sectors [6]. In 65% of surveyed health care organizations, CIOs play a merely operative role. Obviously, this isn't sufficient: possessing more CIO capabilities doesn't necessarily constitute an ICT strategic role. The ICT department won't generate ICT-driven innovation until it has knowledge of clinical processes, relational capabilities and the ability to exploit external knowledge, working alongside Medical Offices. Thus, ICT governance models have to direct their attention to core health care businesses; to designate the ICT department as the main interface between the supply and the demand of the health care organization, and to develop strong absorptive capabilities to catch external innovation enablers[9].

A Case Study

Founded in 1925, the National Cancer Institute (NCI) in Milan (in Italian *Fondazione IRCCS Istituto Nazionale dei Tumori*) is a top-tier Scientific Research and Treatment Institution which has achieved renowned excellence in the field of preclinical and clinical oncology research and care. About 2,200 patients pass through the institute every day – with an annual average of 900,000 out-patient treatments, and more than 15,000 surgical treatments (including many liver transplants).

The NCI has consolidated expertise in: (i) exploiting ICTs to rapidly switch from experimentation to clinical practice, and (ii) developing ICT solutions able to increase processes quality in day-to-day critical areas. The interviews with the CIO and the Strategic Board outlined that the reasons behind these results are both internal and external to the ICT department[10]. The CIO has externally recognized leadership and acts as a true C-Level director. Her style of management continually strives toward the achievement of coherence within ICT and organizational strategies; and Strategic Board recognizes her key role in the definition of NCI strategies. This greater interaction with internal and external organizational actors could potentially create a loss of focus, trying to adapt to very different business needs: robust methodologies were implemented to prioritize tasks and let all ICT-driven synergies emerge.

All these targets could be met thanks to (i) a comprehensive socio-technical perspective associated with ICT-based solutions, and (ii) a homogeneous development all along the different evolutional paths of ICT-driven innovations. Taking a closer look at the five functional areas of EPR described above (see also Figure 3), we find the following:

- *ADT Area*: this is the first area that was digitalized – mainly for historical reasons. Recently NCI replaced the old central mainframe with modern systems, compliant to up-to-date requirements and international interoperability standards to feed EPR.
- *Diagnostic Area*: all core diagnostic departments are supported by state-of-the-art solutions. Only smaller labs (e.g. genetics) are supported by local applications, not integrated within the HIS.
- *Clinical Dossier*: NCI is supporting Lombardy in the test of a new clinical repository of (i) digitally signed medical reports, (ii) structured data, (iii) events (e.g. transfusions, surgery) and (iv) many others, from clinical placement to exam requests. Physicians will be able to browse through a patient's clinical history and retrieve more and more clinical information. Moreover, this clinical repository will feed patients' Regional Health Records (Italian FSE) as well as Pathology Networks.
- *Therapy management*: NCI is also leading a research program on clinical risk management in chemotherapy (funded by the Italian Ministry of Health). The program aims to develop clinical and organizational guidelines, as well as tools based on mobile & wireless technologies, in order to better integrate the therapy management system with the rest of HIS.
- *Out-patient management*: the NCI outpatient solution is fed by the Central Booking System and supports physicians for the digital signing of visit reports.

The use of mobile devices is also spreading within wards. NCI of Milan can be considered a forerunner amongst European health care organizations in its application of RFId technologies [12][11]. All the benefits associated to these last ones [2] are

[9] It is interesting to remark that the Lombardy region has recently established a set of mandatory guidelines for the development and the implementation of EHRs. Guidelines emphasize the relevance of integrated hospital-wide solutions, as well as the importance of specific functional areas like Clinical Dossier and Therapy Management. In Italy these kinds of Regional initiatives have a strong impact on the priorities that health care organizations set in order to develop their HISs. Surveys and case studies showed these changes from Region to Region.

[10] To evaluate them as homogeneously as possible, the external reasons were identified with the help of CIOs and then compared with the opinions of the CEO, CFO and CMP; the determination of internal reasons followed the inverse emergence and ratification process.

[11] Current key projects address: (i) general patient and staff identification, (ii) safety and traceability of transfusions, (iii) tissue bank

also associated with a major operational flexibility which is core, not only to clinical daily support but also to long time ICT-driven innovation.

Conclusion

The 2009 annual research done by IHCO outlines a complex scenario for ICT-driven innovations in the Italian health care industry:

- In order to be effective, research on EPR, HIS and ICT-driven innovation in health care will have to progressively involve practitioners in cyclical research processes of collecting, providing feed back, and reflecting on data;
- Geographical and historical contexts strongly affect ICT use in health care organizations;
- The major hinders to an organic and effective HIS development are related to governance, not to technology;
- The lack of effectiveness of EPR, HIS and – more generally – of ICT-driven solutions is mainly related to: (i) an organizational culture that still does not perceive ICT as a process support lever and (ii) an ICT department without the competences and poise required to play a real strategic role;
- To solve these problems health care organizations must work on the profile of CIOs and on the ICT department organization and governance mechanisms, with the objectives of bridging the gap between technological opportunities and clinicians' needs;
- In order to be effective and affordable, the development of EPR and/or HIS has to follow a clear evolution strategy managed by the ICT department in close coordination with the strategic board, medical departments and health care technology suppliers;
- The ICT-driven innovation in clinical core processes requires high levels of integration among specific ICT solutions. HISs and EPRs suggest that a lack of interoperability standards could become a barrier to integration and, thus, to ICT-driven innovation.

The analysis of the case of the Italian National Cancer Institute in Milan seems to confirm these points.

Acknowledgments

The authors would like to thank all the Italian health care organizations, health technology suppliers, national health associations and other IHCO partners for their participation in the research process. The authors also would like to acknowledge the Italian Ministry of Health for funding the project "Towards a complete competence framework and an integrated solution for patient safety in chemotherapy".

operations, (iv) chemotherapy dilution and administration (v), quality assurance in bedside radiology activities, (v) radiotherapy machines.

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Evaluation of a French Medical Multi-Terminology Indexer for the Manual Annotation of Natural Language Medical Reports of Healthcare-Associated Infections

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Abstract

Background: Surveillance of healthcare-associated infections is essential to prevention. A new collaborative project, namely ALADIN, was launched in January 2009 and aims to develop an automated detection tool based on natural language processing of medical documents. Objective: The objective of this study was to evaluate the annotation of natural language medical reports of healthcare-associated infections. Methods: A software MS Access application (NosIndex) has been developed to interface ECMT XML answer and manual annotation work. ECMT performances were evaluated by an infection control practitioner (ICP). Precision was evaluated for the 2 modules and recall only for the default module. Exclusion rate was defined as ratio between medical terms not found by ECMT and total number of terms evaluated. Results: The medical discharge summaries were randomly selected in 4 medical wards. From the 247 medical terms evaluated, ECMT proposed 428 and 3,721 codes, respectively for the default and expansion modules. The precision was higher with the default module (P_1=0.62) than with the expansion (P_2=0.47). Conclusion: Performances of ECMT as support tool for the medical annotation were satisfactory.

Keywords

Abstract and indexing, Cross-infection, Decision making, Computer-assisted, Semantic Mining

Introduction

Surveillance of Healthcare-Associated Infections (HAI) is an important activity and a real burden in the context of control and prevention. The impact on patients' health and related healthcare cost are highly significant and a major concern even for the richest countries. Furthermore, some issues were addressed concerning the workload and costs generated by this surveillance.

Alternative methods based on automation of detection procedures were experimented in different facilities. In this context, the electronic health records (EHR) represent a unique opportunity for infection control practitioners (ICP) to automate manual processes. Few experiences of applying data and text mining techniques for monitoring adverse events are reported in literature [1-2]. Data mining offers methods that can recognize patterns in these large data sets and make them actionable: e.g. the Data Mining Surveillance System uses data from the clinical laboratory and hospital information systems to create association rules linking patients, sample types, locations, organisms, and antibiotic susceptibilities [1]. The Geneva team was testing a classifier to distinguish between HAI and non-HAI [3].

The objective of the overall ALADIN Project [5] is to develop an automated HAI detection tool based on screening French natural language documents and reports of the EHR, especially from discharge summaries. This project began in January 2009 and will last 3 years. For the evaluation of the tool, the gold standard used will be manual annotations of these medical documents by using a French medical multi-terminology indexing tool (French acronym: ECMT). The annotation will firstly provide the correspondence between terms used in current medical language and not directly available in the standardized terminologies and secondly it will provide standardised data for building algorithms of detection. The objective of this study was to evaluate the French ECMT tool, in terms of recall and precision for the annotation of natural language medical reports of healthcare-associated infections.

Material and Methods

Development of the HAI detection tool

The first step of the HAI detection tool was the development of a clinical questionnaire by the CNRS-UMR 5558 team (on a MS Access computer application named NosIndex). The purpose of this questionnaire is to enable ICPs from 4 French University hospitals (Lille, Lyon, Nice, Rouen) to manually collect all relevant medical terms (symptoms or diagnosis, medical intervention, medication, microorganisms, medical

imaging…) from 2,000 medical reports. The ICPs will also enter their conclusions regarding the outcome: suspicion of HAI or not. The manual annotation of each medical report will be conducted independently by two different ICPs. In case of annotation discordance, the two ICPs will meet for a consensus procedure. The final decision regarding the outcome "suspicion of HAI or not" will serve as gold standard for the evaluation of the detection tool performances. From the 2,000 medical reports selected for this study, 400 HAI reports and 400 reports without HAI will be randomly selected for the evaluation of the detection tool. The gold standard used for this evaluation in terms of sensitivity and specificity will be the manual medical annotation.

Building a French Health Multi-Terminology automatic indexer (ECMT)

All relevant medical terms selected by the ICPs and entered in the questionnaire will be coded by using the tools developed by the CISMeF team, which include several health terminologies.

In 2005, the CISMeF team decided a strategic shift: from a mono-terminology approach based on the MeSH thesaurus to a multi-terminology approach based on the main health terminologies available in French. Some of them are integrated in the UMLS metathesaurus; some are not because they are French terminologies (e.g. CCAM, DRC, Orphanet). These terminologies have their respective objectives and may explain why the health sector is so rich in terminologies: the MeSH is devoted to documentation, SNOMED to describe patient records, ICD10 to epidemiology, CCAM to procedures, ATC to drugs, ICPC2 and DRC to general (or family) medicine, ICF to disability. To adapt the CISMeF information system to the new paradigm "Multi-Terminology approach", the CISMeF team had restructured the CISMeF database models to integrate as generically as possible the various health terminologies. These terminologies are also integrated into a Health Multi-Terminology Server (HTMS) [6], which is based on the ITM platform of the Mondeca private company (URL: http://www.mondeca.com/**)**.

The new ECMT tool presented here is largely inspired by the CISMeF algorithm for information retrieval for the Doc'CISMeF search engine [9] and F-MTI [7], which is a multi-terminology automatic indexer, developed in collaboration with the Vidal Company. As most of indexing tools, it is language-dependant and works for the French language.

The EMCT tool has two query modules: one default module based on bag of words algorithm [7] and one expanded module based on textual indexing, using Oracle text indexing®. The information retrieval allows retrieving all the terminologies descriptors that contain the words of the query, with a minimal score, which depends on the number of query words. By construction, the expanded module will provide more results than the default module.

The ECMT tool has four main steps for the default module:

- Step 1: Query normalization

The unimportant words are removed from the initial query, and then the phonetic spelling and the stems of the remained significant terms are extracted and alphabetically sorted out.

- Step 2: Identification of the descriptors

For each terminology, 0 to (n-1) words from the set of the significant terms are removed in order to identify the descriptors.

Query Example: lead intoxication in France (intoxication du plomb en France)
step1: {intoxication, intoxi, 1toksikasion, France, franc, fr4s, plomb, plomb, plan}
step2: example for the thesaurus MeSH
-remove 0 word: identify the descriptor composed of {intoxication, france, plomb}
-remove 1 word: identify descriptors composed of {intoxication, france}, {intoxication, plomb}, {france, plomb}.
=> Identification of the descriptor "intoxication plomb"
-remove 2 words: identify descriptors composed of {france}

- Step 3: Determination of affiliated descriptors (MeSH qualifiers) for each identified descriptor.
- Step 4: Supplement the query indexation by the MeSH indexation rules and pharmacological action rules (MeSH is the main thesaurus for indexing in CISMeF). For example, if the query is indexed by the supplementary concept "racecadotril", it will be indexed also by the descriptor "antidiarrheals" describing the pharmacological action.

The ECMT tool can be queried by a human but much more interestingly by any software application using a dynamic URL as long as this software application is connected to the Internet. In both cases, the tool is provides an XML answer which can be displayed for the human or integrated in the software application, eventually after a filtering process among the 9 available terminologies.

The ECMT algorithm is now available freely for the research community. It will become a commercial product thanks to the collaboration with the Vidal Company in the coming months. The URL for human (POST method) is: http://doccismef.chu-rouen.fr/Interpreteur.html. The URL for computer (GET method) is: http://doccismef.chu-rouen.fr/servlets/Interpreteur?Mot=enfant+asthmatique[2].

Development of a software application (NosIndex) for the manual annotation of medical reports

In the context of this project, a MS Access application (NosIndex) was developed by the CNRS-UMR 5558 team in order to collect the manual annotation of the medical reports. Figure 1 summarizes the process and exchanges between NosIndex and ECMT. When an ICP enters an original term

[1] The query in French means: asthmatic child

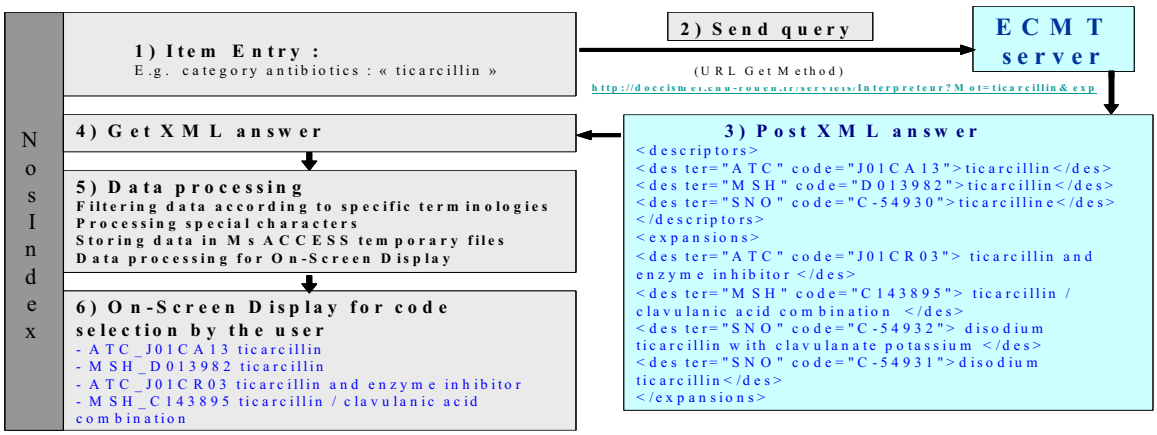

Figure 1 - Process and exchanges between NosIndex and ECMT

from the medical report into NosIndex by using a standardized clinical questionnaire, the application exports the request to the ECMT tool and imports the XML file containing all the corresponding codes. The process lasts 2 to 3 seconds before the ICP can visualize all the proposed codes. Then, the ICP can select the most appropriate one. If it does not find any satisfying code, the term will not be coded by the ICP and the term will be in a second step analyzed by semantic experts for decision. The structured questionnaire was developed on the application in order to classify all the medical terms relevant for implementing the detection algorithms of HAI.

The following categories (symptoms/diagnoses, bacteriological exams, type of microorganism, biological exams, radiological exams, antibiotics, and type of surgical intervention) were selected by HAI experts and have been coded specifically in order to limit the noise generated by the use of the 9 terminologies. (a) Symptoms/diagnosis: ICD10, SNOMED 3.5, MeSH; (b) Bacteriological exams: SNOMED3.5, MeSH; (c) Type of microorganisms: SNOMED 3.5; (d) Biological exams: SNOMED3.5, MeSH; (e) Radiological exams: SNOMED 3.5, MeSH, CCAM; (f) Antibiotics: ATC, MeSH; (g) Type of surgical intervention: CCAM, MeSH. The NosIndex application filters the results provided by ECMT, depending on the category of the medical terms. These filters were chosen manually by the expertise of the ALADIN project members.

Evaluation methods of the ECMT tool

Data sources

Medical discharge summaries from patients with hospital acquired infection managed in intensive care units (n=42), orthopaedic surgery (n=12) and digestive surgery (n=8) of the Lyon University Hospital were randomly selected. An ICP evaluated the terms proposed by the ECMT when a medical term was entered in NosIndex. From these medical reports, the first 50 terms (not redundant) for symptoms/diagnosis and the first 30 terms for other categories were manually selected by an ICP. He entered the terms in NosIndex and evaluated each term proposed by the ECMT. The level of satisfaction of the term proposed was evaluated by using the following score: (a) 0 if no match; (b) 0.5 if approximate match (too precise or on the contrary too little accuracy); (c) 1 if perfect match.

Evaluation of the ECMT default module

We defined Recall R_1 as the number of relevant terms found by the ECMT default module divided by the total number of relevant terms provided by the two ECMT modules.

We defined precision P_1 as the number of relevant terms found by the ECMT default module divided by the total number of terms provided by the ECMT default module. F_1-measure was calculated as follows:

$$F_1 = \frac{2P_1R_1}{P_1 + R_1} \quad (1)$$

An average precision and average recall were calculated by category of medical terms. It is then possible to calculate an average precision by category, as the average of precision values for each term of this category (e.g. the average precision = $(P_1 + P_2 + P_i \ldots + P_n)/n$, with P_i = precision for the term i and n = total number of terms evaluated for this category). It is also possible to calculate an average recall by category.
Then, an overall mean average precision and mean average recall were calculated, as followed:

- Mean average precision = average of the average precision for each category;
- Mean average recall = average of the average recall for each category.

The exclusion rate is defined as the ratio between the number of terms not found by the ECMT default module and the total number of terms evaluated. This exclusion rate was calculated by category and overall.

Evaluation of the expansion performances

We defined the precision P_2 as the number of relevant terms found by the ECMT expansion module divided by the total number of terms provided by the ECMT default module. Recall

and F-measures were not calculated because no gold standard is available for determining the denominator. For example, the number of relevant terms existing in the multi-terminology indexing tool. An average precision was calculated by category. The same terminologies as for the ECMT default module were selected by category. The exclusion rate is defined as the ratio between the number of terms not found by the ECMT expansion module and the total number of terms evaluated. This exclusion rate was calculated by category and overall.

Results

The results of the ECMT tool are summarized in Table 1. For the evaluation of the 237 medical terms of medical reports related to HAI, the number of terms proposed by the ECMT default module was 9 times less than the number proposed by the ECMT expanded module (428 vs. 3,721). Then, the overall precision P_1 (ECMT default module) was higher than the overall precision P_2 (ECMT expanded module) (0.62 vs. 0.47).

The overall F-measure was 0.59 with a minimum of 0.46 for the category "bacteriological exams" and a maximum of 0.71 for the category "antibiotics". The overall recall R1 was 0.58 but important variations were observed between categories (min: 0.45; max: 0.70). The only use of the default module could be satisfactory (R_1= 0.70) but for other categories and particularly for the type of surgical intervention (R_1 = 0.45), the expansion module improved consistently the number of relevant terms proposed for annotation.

The overall exclusion rate for the default module was 0.15. The expansion lowered significantly the exclusion rate of 0.15 to 0.11. By category, the expansion lowered significantly the exclusion rate for "radiological exams" (from 0.13 to 0.06) and for "type of surgical intervention" (from 0.22 to 0.09). Exclusion rate was rather small for four categories with both modules. The exclusion rate remained important for two categories: 0.26 for bacteriological exams and 0.23 for antibiotics.

Table 1- Summarized results of the ECMT evaluation

	Number of terms evaluated	**Number of terms (ECMT default module)**	**Number of terms (ECMT expansion)**	**Evaluation "default module"**			**Evaluation "expansion"**	**Exclusion rate**	
	N	N	N	P1[3]	R1[4]	F-measure	P2[5]	Default module[6]	ECMT expansion[7]
Symptoms/ diagnosis	50	141	1424	0.60	0.62	0.61	0.42	0,06	0.04
bacteriological exams	31	63	122	0.41	0.51	0.46	0.38	0,32	0.26
type of microorganisms	31	38	147	0.77	0.63	0.69	0.64	0,10	0.06
biological exams	30	43	639	0.77	0.60	0.67	0.43	0,07	0.03
radiological exams	32	55	989	0.53	0.53	0.53	0.38	0,13	0.06
Antibiotics	31	23	38	0.74	0.7	0.72	0.71	0,23	0.23
Type of surgical intervention	32	65	362	0.54	0.45	0.50	0.40	0,22	0.09
Overall	237	428	3721	0.62	0.58	0.59	0.47	0,15	0.11

[3] e divided by the total number of terms provided by the ECMT default module
[4] R1 = number of relevant terms found by the ECMT default module divided by the total number of relevant terms provided by the two ECMT modules
[5] P2 = number of relevant terms found by the ECMT expansion divided by the number of terms provided by the ECMT expansion
[6] Exclusion rate (default module) = = ratio between the number of terms not found by the ECMT default module and the total number of terms evaluated.
[7] Exclusion rate (expansion) = ratio between the number of terms not found by the ECMT expansion module and the total number of terms evaluated.

Discussion

The main objective of this study was to evaluate the ECMT tool, in terms of F-measure, recall, precision and exclusion for the annotation of natural language medical reports of healthcare-associated infections in French. If the overall F-measure could be considered as satisfying (0.59), some efforts need to be made to improve the F-measure for certain categories (bacteriological exams, radiological exams and type of surgical interventions).

An important result of this study is the relative good overall precision P_2 (ECMT expanded module) compared to the overall precision P_1 (ECMT default module) (0.47 vs. 0.62), although the ECMT expanded module provides 9 times more terms than the ECMT default module (3721 vs. 428). Furthermore, the overall exclusion rate of the ECMT expanded module is rather small (0.11).

We need to improve the results for two categories: bacteriological exams and antibiotics. For the category "bacteriological exams", we plan to add a partial translation of LOINC.

For antibiotics, we have already translated in French 8,200 out more than 180,000 MeSH Supplementary Concepts [8]. We plan to go further. We have also planned to increase our cooperation with the Vidal company, leader of French drug database market.

This evaluation of the ECMT tool was done in a specific context, namely healthcare-associated infections, with the purpose to help the professionals who are not experts in standardized terminologies annotate medical reports. A software application can be easily developed as an interface for annotation of various medical topics (e.g. epidemiological studies, clinical research, adverse event surveillance…). By filtering relevant terminologies and by selecting default or expansion module depending on the medical category of terms, the investigators can find a satisfactory balance between inevitable noise and lack of precision.

Conclusion

The aim of this study was to evaluate the performance of the ECMT as a support tool for the manual medical annotation. This study showed that the performance of the tool was good enough for helping ICPs to annotate medical reports with the different standardized terminologies. In parallel and in the context of the ALADIN project, the ECMT tool will also be used for the development of an automated HAI detection tool.

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A Lab-EMR Interoperability Profile as an eHealth Architecture Component for Resource-Constrained Settings

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Abstract

Implementation of computerized systems in resource-constrained settings have been gaining traction as a means of improving the delivery of health care, the use and reuse of information, and providing a standards-based capacity for assessing the process and impact of health care. In a resource-constrained environment, systems are often implemented as stand-alone entities focused on specific care activities (for example, delivering antiretroviral therapy). As such, in many countries, taking a generalized approach to linking electronic medical record systems with laboratory information systems (EMR-LIS) is an important area in which to achieve interoperability. In this paper we describe a scenario of use and information interaction interoperability profile based on our experience implementing EMR-LIS integration in two resource-constrained settings. Of significance, the profile emphasizes queued matching in order to avoid mutual dependence while achieving interoperability between systems.

Keywords:

Clinical laboratory information systems, Developing countries, Computerized medical record systems, Public health informatics, Systems integration

Introduction

In resource-constrained settings, both government and donor agencies are emphasizing implementation of computerized systems to improve the use and reuse of information, to improve the delivery of health care, and to assess the process and impact of that care. While operational efficiency, as well as internal and external goals in the distribution and reuse of data are motivations for using such systems, their implementation is a challenge. Identified barriers to implementation have included funding limitations, variety in health care data, the differing ways used to represent those data, and the variety of locations in which it is collected and stored.[1] In a resource-limited environment, how does one support the exchange of data required for effective use and reuse?

This paper proposes the use of interoperability profiles as one component of an eHealth architecture framework that integrates laboratory information systems (LIS) and electronic medical records (EMR) in resource-constrained environments. The goal of this interoperability profile is to enable point-to-point healthcare information exchanges between these two primary and heterogeneous health information systems.

Following background information regarding health architectures and the accepted protocols for creating and elaborating the components and steps of an information interaction profile, we describe a scenario of use and interoperability profile that enables LIS-EMR integration appropriate to the constraints of resource-constrained settings.

Background

There are a number of eHealth architecture initiatives currently funded through organizations such as the Rockefeller Foundation, the World Health Organization's Health Metrics Network (HMN), the International Development Research Center (IDRC), and the Centers for Disease Control and Prevention (CDC). These initiatives provide information to support three essential eHealth architecture goals:

- A framework into which stakeholders can easily place themselves and their systems;
- A way to identify dependent and interacting components and systems within a broad framework; and
- A description of common semantic, syntactic and interaction standards or guidelines that support interoperability.[2]

The goal of interoperability--i.e., the exchange of information between two or more systems or components and the use of the information that has been exchanged--has been identified as key in connecting systems to create more integrated views of health data in support of both individual and population care. This point was emphasized in the 2008 "Making the eHealth Connection" background paper in which Bailey, et al described different types of standards required to support interoperability including: identification standards; semantic

and syntactic standards; and standards of content, such as core data sets.[3] Other important types of standards are transport protocols; security standards; and operational standards (back-up/data reliability, training, service level agreements, etc.).

In a resource-constrained environment, systems are often implemented as stand-alone products focused on specific care activities (for example, delivering antiretroviral therapy). As such, in many countries, taking a generalized approach to linking EMRs with LISs is an important area in which to achieve interoperability. As important as data standards are, we propose that it is equally important to specify "interaction standards", or standards that describe the specific information flows between the dependent and interacting components and systems whose identification comprises the second goal of eHealth architecture. These standards are written around the business rules that govern the flow of information, and describe the constraints upon, and usage of, semantic, syntactic, and other standards to support specific transactions.

Here we propose a method that provides concrete implementation guidance with a scenario of use contextualized in a resource-constrained setting. This methodology is based on our work in the Integrating the Health Enterprise (IHE) Showcase [4] as well as in Haiti and Côte d'Ivoire where we have implemented two open-source projects—the iSante EMR [5] and OpenELIS system [6] in over 55 sites—experience which has provided an excellent testbed in which to explore generalized, standards-based interoperability between these two representative systems. In addition, our goal is to use this reference implementation for Lab-EMR interoperability to support more general interoperability between other systems, such as the Bika LIS[1] and OpenMRS EMR[2].

Methods

The IHE Initiative[3] aims to improve interoperability of healthcare information systems by promoting the adoption and use of existing healthcare information technology (IT) standards. IHE provides a framework through which existing healthcare standards are applied in a structured and consistent way to address specific needs in healthcare operations, care and treatment, research, and public health. The Technical Framework presented by the organization is something similar to an integration guide describing interactions between systems. The IHEs Integration Profiles use this framework and expand it by identifying actors and transactions to address information needs that occur with specific use cases. While the IHE profiles support interoperability between a wide variety of sophisticated commercial systems, resource-constrained settings present different challenges and require an approach that addresses these challenges as presented below.

Fewer Clinical Systems and Number of Tests

In resource-constrained countries there are typically only a handful of different clinical information systems implemented and they tend to focus on specific populations, such as people living with AIDS. This presents both a benefit and a risk: the benefit is that there are fewer partners with whom one must interact to achieve develop consensus on interoperability, the risk is that partners face a constant temptation to build ad hoc linkages between the systems with which they work, rather than addressing interoperability in a more general way. We have found that we have to work conscientiously to engage other partners, and have set as a goal that our initial interoperability profile fits within the work processes and system architecture of at least two different EMRs communicating with at least two LISs.

Clinical laboratories in many resource-constrained countries have a narrower range of tests available than that which might be found in a US or European laboratory. For example, a third-party index intended to facilitate the interpretation of lab results commonly available through clinical laboratories in the USA lists over 1000 separate studies[4] yet our experience in Haiti suggests that a typical clinical lab in those settings may have a catalog of approximately 120 studies. This difference may be significant and affect the priorities when implementing interoperable systems.

Challenges in Implementing IHE Profiles

While IHE profiles are built on the real-world standards in use in health information systems which tend to be complex and use HL7 2.x messages; but the complexity of HL7, as well as the financial cost of joining the organization and accessing the standards, have limited utilization by developers working with limited resources. Since IHE profiles make use of the richness of HL7 and other standards, they inherit that complexity which presents an additional barrier to profile use in some settings.

In the laboratory domain, Logical Observation Identifiers Names and Codes (LOINC)[5] provides a semantic standard with a set of universal codes and names to identify laboratory and other clinical observations. LOINC is an open standard, however, the size and richness of LOINC may be daunting to some. Our observation has been that systems like Bluebird[6] tend to develop their own tailored specifications for exchanging data, often in XML, and often using locally developed code sets. Our experience has been similar; two large HIV observational cohort projects in which we are involved similarly use local code sets agreed upon by the participating institutions.

As mentioned in the Introduction, it is common to see stand-alone systems implemented in resource-constrained settings so linking EMRs with LISs is an important area in which to achieve interoperability—especially since the need for such linkages for reporting purposes is strong.

[1] www.bikalabs.com/
[2] openmrs.org/wiki/
[3] ihe.net/
[4] www.labtestsonline.org/map/aindex.html
[5] loinc.org
[6] www.bluebird.co.za

Documents or Messages

IHE offers both document- and message-based protocols. In the clinical domain, the former are based on variants of the HL7 Clinical Document Architecture (CDA), and include ways of exchanging medical summaries, lab results, immunization summaries, and other structured documents. Given ad hoc profiles often seem to be developed using short objects, structured using XML, we were initially tempted to use an IHE profile as the basis of our EMR-LIS interface. We explored XDS-Lab which we had used in other IHE demonstrations of public health capabilities [4] however, after consultation with other collaborators working on EMRs for resource-constrained settings, we elected to use a message model, using HL7 2.x as the syntactic standard.

At first glance, message- and document-based systems appear to be substantially different, with messages tailored to convey a stream of events that must be assembled to reconstruct the current "state" of a patient and documents able to capture a rich "snapshot" of patients. However, this is more a function of the level of information traditionally included in the syntax standards commonly used for each of these modes, rather than innate characteristics. In essence, if one takes a message, and prints it out, it becomes a document, regardless of its content, with all of the attributes of that type of artifact. And if one takes a document and carries it across the room or from the clinic to the lab next door, it becomes a message.

Developing a Resource-Constrained Appropriate Profile

To develop the resource-constrained EMR-LIS profile, we first identified the important components (see Figure 1 for acronyms and definitions) and the order in which they are utilized. The "traditional" order is as follows:

1. Patient Identification: Based on the PIX and PDQ IHE profiles.
2. Order Transmission: Based on the LSWF IHE profile.
3. Results Transmission: Based on the LSWF IHE profile.

PIX - Patient Identifier Cross Referencing - cross-references patient identifiers between organizations

PDQ - Patient Demographics Query - allows for query of a central server for demographic and visit information on a patient

LSWF - Laboratory Scheduled Workflow - establishes the continuity and integrity of clinical laboratory testing and observation data throughout the healthcare enterprise.

XD*-LAB – Sharing Laboratory Reports - a clinical laboratory report as an electronic document,

XDS - Cross Enterprise Document Sharing – allows for registry and location of documents between organizations

Figure 1- IHE Profiles of interest [7]

However, in resource-constrained settings, the first two steps are often paper-based—therefore the value of a profile is concentrated in what is traditionally the final step, Results Transmission. Because labs have needs beyond the receipt of orders and delivery of results, including quality assurance, reporting of laboratory performance indicators, and communication of inventory for supply-chain management, we believe that laboratory needs are best addressed through implementation of a laboratory information system, interoperable with an EMR, rather than the extension of the EMR to include a "laboratory module". In addition, we wanted to develop a reference implementation for Lab-EMR interoperability and to use that implementation to support more general interoperability between systems.

To accommodate the reality of the environmental constraints, we addressed these components in the following order, reverse from the order in which they occur in a typical workflow:

1. Results Transmission Only
2. Order Transmission and Results Transmission
3. Identification of Patients in EMR, Order Transmission and Results Transmission

The information interactions required to support the three use cases were assigned to specific parts of the Laboratory Testing Workflow (LTW) as described in the IHE Laboratory Technical Framework, Vol. 1: Profiles.[7] Next, the specific "actors" in those use cases were assigned to either the EMR or LIS, a constraint that further simplified the IHE profiles. Finally, the message specifications were reviewed to determine if additional simplifications could be made.

Results

The context within which we composed the profile assumed the following scenario of use that we found to be common in our work in countries like Haiti and Côte d'Ivoire.

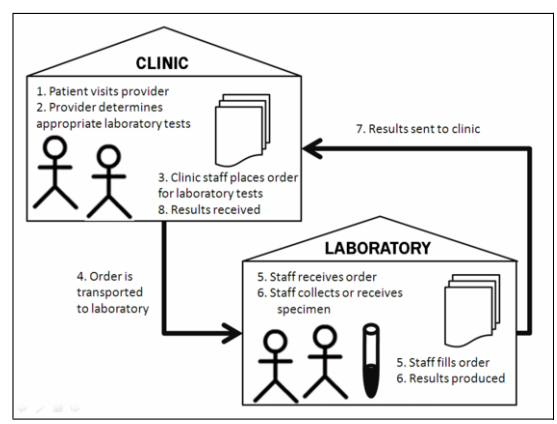

Figure 2- Lab-EMR integration scenario of use

In the clinic, a patient visits a provider, appropriate laboratory tests are identified and orders for the lab tests are placed. The order is transported to the laboratory. In the laboratory, staff receive an order, specimens are collected or received, tests are performed/orders are filled and results are produced and reported/sent to the clinic. Back in the clinic the results are received. Of note is that in the settings we are addressing, one, several, or none of these steps may involve electronic systems and when systems exists, connections may exist with similar inconsistency.

Figure 2 depicts this resource-constrained scenario of use. As stated, we are focusing first on the Results Transmission step (Step 7 in Figure 2), as the glue between an EMR and LIS. In this way, we are not only addressing the principal gap of interdependency between these two systems but we are also creating a business case for further development and funding to design and implement an LIS-EMR integrated system.

Use Case Actors and Workflow

IHE profiles define actors in terms of their roles, but in this profile, we can further assign the roles played by the use case actors to the two systems in use, with the EMR as the "Order Placer" and the LIS as the "Order Filler". The EMR also acts as the "Order Result Tracker".[7] We were able to tailor the representative workflow described in the IHE profile using both fewer potential actors as well as more limited information interactions, in order to support a more constrained set of workflows. This allowed us to limit the message types required for implementation.

The criteria used throughout this process ensured that the interactions described were part of the IHE document structure, could be referenced specifically to sections of those documents, and included only those elements of the profile which were needed to support interoperability using HL7 2.x messages between the two types of facility level systems, LIS and EMRs.

Final Profile and Scenario of Use

In the context of the LTW Profile, our resource-constrained scenario of use includes an order that is created by the laboratory and specimens which are assumed to be collected by the lab or ward, i.e.:

- Filler creates Order Filler Number
- Results transmitted post validation to the Order Result Tracker

We extended the case above to include transmission of orders, with demographics, from the EMR to the LIS. However, this does not include the ability for the LIS to query the EMR for demographics and resolve LIS patients to new or changed patients in the EMR. Therefore, we added the Patient Identification in the EMR component which both addresses this need and simplifies the cycle described. For this step, orders are placed with specimens identified by a third party and transmitted electronically. The result is that the LIS will gain the ability to query an EMR for patient demographic information, with the EMR playing the role of a Master Patient Index (MPI) component.

This profile encompasses demographics, orders and results, which are generalizable components of other information interactions. Related and potential extensions of this profile as tailored to a resource-constrained environment includes pharmacy, which is a very close match, as well as patient lookups for remote patient list management, remote sample entry, linkages to demographic surveillance systems, and other applications.

Discussion

The resource-constrained profile we present is limited in its focus primarily on transmission of results and in its assumptions. Although we believe that there is value in approaching this problem of integration stepwise, we also acknowledge the significance to all parts of the process, the issue of patient identifiers and patient matching. Patient identification presents challenges in any setting, for example there is no way for the lab to know for certain that the patient has been identified accurately. In this case, the EMR will need to be enhanced to both match on more than one identifier and to put questionable results in a queue for manual matching. Where connectivity between the LIS and EMR is intermittent, this scenario may occur fairly frequently.

We anticipate that developing an appropriate matching scheme in this case will likely need to be based on an exact match of the Patient Medical Record Number transmitted with the paper order or patient, in combination with some secondary identifiers as a double check (for example, last name, ordering facility/physician, age/Date of Birth, visit date, lab entry in the EMR). Some of the challenges of this case include: 1) There is no guarantee that a visit will have been entered in the EMR by the time the result comes back from the LIS; 2) Some (or many) patients may not be able to provide a date of birth; and 3) The ordering physician may not be part of the workflow for a particular site. For these reasons and others, it may be necessary to leave the choice of secondary identifiers for automated assignment of results in this profile to be determined on the institutional level. However, we believe that this queued matching is important in resource-constrained settings as even interoperable systems should avoid mutual dependence.

Alternatively, a purely manual system, with a strategy for catch-up when an interface is restored, must be developed. Direct entry of imperfect match results into the EMR would be a suitable strategy, and may be a reasonable alternative for manual matching and entry of results, as above.

Although insights into this interoperability profile have the benefit of being informed by our work in many resource-constrained countries, there is no way of knowing without a formal evaluation how generalizable a profile such as the one presented here would be to a wider set of EMR and LIS implementations. Future work includes such an evaluation, as well as a demonstration of this profile, in order to gather input from a wide audience of developers working in similar settings.

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eVisit: A Pilot Study of a New Kind of Healthcare Delivery

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Abstract

Patient online eVisits are gaining momentum due to increasing consumer demand for improved access to clinical services, availability of new technologies to deploy such services and development of reimbursement initiatives by major payers. The eVisit service provides patients with an online consultation through a series of structured, secure message exchanges with a physician, providing an alternative for onsite office visits and non-reimbursed phone-based care. In this study, we evaluate a pilot deployment of eVisits in a primary care clinic providing online consultation service for 7 simple health conditions at its three locations. We examine usage data over 3 months and survey and interview results for trends in adoption, demographic and temporal patterns of usage, clinician and patient expectations and experiences, and challenges to sustainability of the service. Based on our analysis, we conclude that the eVisit pilot was a success. Patients valued the new service being offered as demonstrated by a rapid increase in usage. The quality of service was good with fast turnaround times and few exchanges to resolve a request. These positive outcomes combined with a reimbursement model are promising indications of sustainability but several challenges remain.

Keywords:

Patient portal, Online consult, Adoption trends, Usage analysis.

Introduction

With secure internet transactions providing standard offerings in many industries and progressing to over 50% of online users in industries like financial services, the healthcare delivery sector is seeking to leverage deployment of the electronic medical record (EMR) to provide improved customer service and market differentiators to consumers by supporting appropriate levels of care in a secure, online environment [1, 2]. Patient health portals are becoming a critical part of a healthcare organization's service delivery strategy [3]. While the EMR facilitates access to patient health information for providers and caregivers to make informed decisions at the point of care, health portals empower patients to access their clinical information and interact with their healthcare team. It allows patients to take a more active role in their own health by providing secure and convenient electronic access to their own health information [4].

Patient portals provide value to the healthcare organization by streamlining workflow, empowering the patient, and creating new communication pathways [5]. Through patient portals, users have the ability to self-service and research their own health information and health issues. By providing them with access, they can review and validate portions of their medical record. Interactions with the office also become more user-friendly and efficient. Requests for prescription refills, appointments, medical advice such as appropriate medication use, and other related information can be received electronically, automatically routed to the correct resource, and managed in a timely fashion that integrates into workflow with minimal disruption to the patient or staff [6]. Properly leveraged, patient portals can also be a valuable tool for an organization to inform patients of services and resources. Health reminders can be automatically and safely sent to patients reminding them of upcoming appointments, the need to schedule for an appointment like an annual physical or flu shot, or inform them of a new service available from the organization [7].

Perhaps one of the most valuable capabilities of patient portals is the ability to provide services to treat patients for non-urgent health conditions [6, 7]. This offering provides patients with the ability to complete and submit basic information for designated non-urgent episodic illnesses and receive an online evaluation from their physician, providing convenient, timely, and comprehensive access to care. Furthermore, this approach can evolve into a service that assists patients in managing chronic health conditions. By providing the tools to enter data such as blood glucose levels, weight, and blood pressure, and resources needed to monitor and control their health conditions over time, patients have an improved ability to actively participate in their health care and achieve more favorable health outcomes. Despite these perceived benefits, adoption rates have been uneven across patient groups [8].

In this study, we examine adoption and use by analyzing data from a pilot eVisit project implemented by a major academic medical center to provide online consultation service to patients in the ambulatory care setting. The eVisit service provides patients with online consultation through a series of secure message exchanges with a physician, providing an alternative for onsite office visits and non-reimbursed phone-based care. These are distinct from email consultations because they use a structured template-driven questionnaire to capture relevant

information about the patient's acute condition. We study eVisits in a primary care clinic, covering 7 simple health conditions at its three locations. We examine actual usage data over 3 months as well as survey and interview results for trends in adoption, demographic and temporal patterns of usage, clinician and patient expectations and experiences, and challenges to sustainability of the service.

Study Setting

The e-Visit service was piloted in one primary care outpatient practice associated with a major medical center as part of its strategic plan to computerize all ambulatory services with the ambulatory electronic medical record (EMR) for clinicians and an extensive patient portal for patients. Only patients of the health system can access the portal which has been in use for four years and currently has over 8,000 patients. The portal is integrated with the ambulatory electronic health record, which allows the health care team to interact with patients through their current applications and workflow. The application utilizes the underlying technical infrastructure and solutions offered by Epic Corporation (EpicCare EMR http://www.epicsystems.com/software-clinical.php and MyChart Patient Portal http://www.epicsystems.com/software-ehealth.php). There are several options that offer a variety of services to patients.

The clinical component of the portal provides patients with the abilities to view lab results and diagnostic studies, solicit medical advice from their healthcare team (such as questions regarding a specific medication), request prescription refills, receive health maintenance reminders, request or schedule medical appointments, and more. The business component of the portal offers automated scheduling, registration and billing services that are standardized across the enterprise and integrated with the EMR. This integration allows the health system to offer patients self-service solutions for appointment scheduling, pre-registration to update select information like address and payer information and correspondence with the business office.

On August 19, 2008, the medical center released an additional function for the clinical component, called eVisits. The eVisits service provides patients with an online consultation through a series of secure message exchanges with a physician. The primary objective of this new online service is to provide an alternative for onsite office visits and reimbursable phone-based care. This eVisit system currently provides service for 7 conditions: cough, red-eye, vaginitis, diarrhea, sore throat, urinary tract infection, and back pain as well as a generic category of "other." A standardized template creates structured documentation of the consultation, is easy to use and integrated with practice workflow. It also captures information that is stored in the EMR.

This new offering was tested in Fall 2008 at a single community primary care practice encompassing three office locations. The physicians and staff at the offices encouraged patients to sign up for the patient portal and use eVisits for the treatment of specified episodic illnesses. Thus use of the service was purely voluntary. As of December 5, 2008, 126 patients had used the service and 11 physicians were participating. During the pilot phase, the eVisit service was offered at no cost to the patient.

The key stakeholders in this project are the physicians, the patients, and the insurers. The patients need to be convinced that the eVisit system can provide them with good quality of service while offering the additional convenience of accessing a physician's medical advice online. The physicians need incentives to participate in the system, primarily through reimbursement for their services, as well as providing better care. Insurers need a clear understanding of how this service is going to be implemented, and the policy and guidelines, so that it can be covered under current health plans. The success of eVisits is dependent on the buy-in from the stakeholders mentioned above.

The eVisit Process

The process is initiated by a patient who logs into the patient portal to submit an eVisit for a non-urgent health condition. The patient is introduced to information regarding eVisits, including overview, warnings, and frequently asked questions, linked to "Submit an eVisit" option as well as a video demo of an eVisit for patient education. The patient must accept the terms and conditions of eVisit comprising emergency disclaimers and privacy policy before accessing the main forms to list symptoms associated with any of the 7 conditions covered by the eVisit service (Figure 1). An 'Other' category is available to allow specification of conditions that are not included in the 7 well defined areas (Figure 2). The patient may select pharmacy for any prescriptions needed for the visit or add their own, and review health issues, medications, and allergies.

Figure 1- Screen Shot of eVisit Request Form

In the case of the 7 specific conditions, a questionnaire with branching specific to a chosen condition and related symptom is completed and free text added for symptoms not on the list. Once the eVisit is submitted, the message goes to a support staff pool, a successful message submission acknowledgement is received and the patient is notified of subsequent steps. These include forwarding the eVisit to a physician who is on call to provide a timely response during regular business hours. The physician reviews the eVisit, makes diagnosis, and replies to

the patient about how to proceed. Once the patient receives the information, and it is deemed to have addressed the health condition, a satisfaction survey is completed. If the patient has additional concerns, a few request-response exchanges take place before the physician closes the encounter and notifies the support staff. This completes the eVisit.

Figure 2- eVisit Questionnaire for 'Other' Category

Data Collection

Data for analyzing usage and trends came from several sources. These included portal activation data for eligible members of the medical center as well as the clinic participating in the pilot study, de-identified patient demographics and eVisit transaction data, patient and physician satisfaction surveys, clinician interviews, phone encounter records, and payer information. Transaction data related to eVisits submitted between August 20, 2008 and December 5, 2008 included a unique message identifier, associated eVisit, patient and physician identifiers, date, time and subject of the message (one of the 8 conditions), and whether the message was from/to the patient. Patient demographics included age, gender, ethnicity, marital and employment status. Total patient population of the study clinic and the subset who had activated portal access were also available. Overall, 152 eVisits were submitted by 126 unique patients, with 18 patients submitting requests more than once,16 patient and 11 physician satisfaction surveys were completed, and 417 total messages were exchanged between patients and physicians.

Analysis of Usage

The data described above was analyzed to examine the following patterns of usage and trends. The demographic characteristics of residents in the 3 locations of the primary care practice were quite similar. During the eVisit pilot period, the number of new portal patients increased from August to October and decreased from October to November. However, new eVisit patients kept growing from August to November. In August, only 4% of the new portal patients used eVisits. From September to November, the percentage increased to 14%, 18%, and 25%, respectively, indicating that patients were adopting the eVisits service.

Who is using it?

The clinic has a population of more than 23,000 patients, of which about 1,600 have activated portal accounts, 375 submitted medical advice requests, 152 submitted eVisits and about 1,300 received phone-based care during the pilot study period. Across all these groups, age was normally distributed. A cross-sectional study of the demographic profiles of patients drawn from these populations indicates that more than 50% of eVisit patients are between ages 36 and 55. Analyzing gender distribution among these different groups shows that in all five groups, the female population is substantially more than the male population, with women using eVisits, in particular, three times more than men.

When are they using it?

75% of the messages sent by patients initiating an eVisit were during the hours of 9am and 6pm. At the same time, 94% of physicians responded between 6am and 3pm, so physicians tended to start early in the day to catch up on messages that may have been sent the previous day by patients. Messages were evenly distributed across weekdays with very little activity on weekends. Most of the eVisit messages were responded to within the same day, however, messages sent between 3pm and 6pm were likely to be responded to on the following day. On average, patients waited about 6 hours to receive a response at any given time. During physician office hours (9am-3pm), the waiting period reduced to an average of about 3 hours, indicating a reasonably responsive turnaround time by the health system. In particular, a significant majority, 65% of all patients, received a response from a physician within the hour.

How are they using it?

A request-response pair of message exchanges between a patient and physician in an eVisit is termed a 'volley'. Volleys are an important measure of the workload associated with online consultations. As the number of messages exchanged with patients to resolve a specific health issue increases, physicians may perceive an office visit to be more fruitful. Volleys help in examining these trade-offs. Our analysis indicates that eVisits require, on average, 1.22 volleys to achieve closure on a request. Out of the 152 eVisits logged in this study, 82% were completed by physicians within 2 responses, indicating that most eVisits are fairly straightforward, and do not require patients and physicians to go back and forth several times.

Frequency of eVisits usage had some interesting aspects as well. Out of 126 unique patients, 14% submitted an eVisit request more than once. Among the conditions for which the eVisits were submitted, over 50% of patients submitted requests for the "Other" category and 25% for Sinus/Cold symptoms. Within the "Other" category, there were no significant patterns in patient conditions; however, skin related disorders, such as breast rash and skin lesions, did appear a few times more than others.

Patient Satisfaction

Patient satisfaction with the eVisit service was analyzed using surveys that were submitted by 28 patients after using an eVisit.

In general, patients were highly receptive to the service. Patients found the service to be easy to use and were satisfied with the quality of care received. 95% of patients said they valued online access to the physicians and intended to continue using eVisits again, as well as recommend it to others. The typical concerns patients voiced when informed about eVisits were around privacy and confidentiality and co-pay. Senior citizens found the concept confusing while the younger and computer savvy patients were excited about the new service.

Clinician Perceptions

11 physicians participating in the eVisits pilot deployment completed surveys after using eVisit at least once. There were 4 female physicians between the ages of 36 to 54 and 7 male physicians between the ages of 41 to 57 in the sample. Physicians were concerned about the ease of use of the interface, finding it somewhat non-intuitive and inflexible to address a diagnosis at any point during the consultation. eVisit was clearly not a preferred mode to treat patients with acute conditions. However, interviews with the physicians highlighted the value of eHealth as an important component of modern medicine with the potential to improve healthcare, increase income for organizations and be convenient for patients. Reimbursement was an important incentive for adoption and use of eVisits. Physicians considered younger and more tech-savvy patients to be the target audience for this service. Due to concerns about patients underreporting their conditions or requesting inappropriate advice online, 50% felt that face to face was a better way to diagnose. Interviews were also conducted with 3 office staff and 3 nurses involved with the service at the 3 locations of the primary care practice. Office staff alerted and educated patients about the eVisit service. They perceived that the number of phone calls had reduced since the eVisit pilot began, but this has yet to be determined quantitatively.

Analysis of Phone Encounters

One of the objectives of the eVisit pilot deployment was to estimate the potential for shifting non-reimbursable phone-based care to reimbursable online consultations. Phone encounter records over a period of 2 years were analyzed to examine the significance of this potential. From June 2006 to June 2008, there were 40,489 phone calls from patients to the three office locations of the practice. As shown in Table 1, about 10% of the calls were related to the 7 eVisit conditions. The majority of the phone calls were related to other conditions such as checking test results or requesting medication refills (portal functionality is also available to meet these requirements). Furthermore, about 18% of all calls were by portal users who were eligible to access the eVisit service. Phone encounters by these users during the eVisit pilot period, shown in Table 2, indicated the same distribution of phone calls, with about 10% of the phone calls being potential eVisits.

Table 1- Analysis of All Phone Encounters June 2006 - June 2008

	# of Phone Calls/month	**Percentage**
eVisit potential (7 conditions)	172	10%
Other Conditions	1400	83%
Inappropriate	116	7%
Total	1688	100%

Table 2- Analysis of Phone Encounters with Portal Users August 2008 – November 2008

	# of Phone Calls/month	Percentage
eVisit potential (7 conditions)	25	10%
Other Conditions	212	85%
Inappropriate	13	5%
Total	250	100%

Discussion and Conclusions

The success criteria for the pilot deployment were identified to be (1) positive perceptions regarding eVisit service including both workflow and technology experience on the part of eVisit patient and provider users; (2) increasing frequency of use in practices which marketed eVisit services; (3) documented opportunities related to translating phone encounters into reimbursable services; and, (4) accurate and thorough data and operational documentation for reimbursement analysis. On the first and second measures, while patients expressed satisfaction and value through increased use of the service over the pilot phase that was well beyond expectations, providers had some concerns about functionality and value of the service. Based on our analysis of phone-based encounters, there is some evidence that the potential exists for getting value from converting these users to eVisits. However, the total returns are clearly tied to reimbursement policies that would be eventually adopted. On the fourth measure, the implementation of the eVisit process for specific health conditions with branching logic that automatically captures date and time stamped critical documentation and treatment details and associated participant

information ensures the capability of the service to capture all the necessary data for reimbursement analysis. Thus, based on these measures, our preliminary analysis indicates that the pilot was a reasonable success.

Three distinct areas posed challenges associated with expansion of the service: 1) reimbursement model, 2) patient adoption strategies, and 3) provider adoption strategies. The medical center has implemented a reimbursement model from April 1, 2009, which is being evaluated currently. Patient education and outreach efforts combined with improved usability and innovative marketing campaigns, optimizing the triage process for providers by filtering out the inappropriate eVisit requests, demonstrating workload benefits from secure messaging, and analyzing the clinical computing workload and workflows through better interface design are additional characteristics that need to be studied.

In summary, patients appeared to see value in the new service being offered and this was demonstrated by the rapid increase in usage. The quality of service was good, with fast turnaround time and low number of messages exchanged before resolving an issue. eVisits may also prove to be of considerable valuable in post operative management and chronic care management settings, another focus of our ongoing evaluation. By further developing the portal strategy, the medical center can provide greater service to patients and improved value and competitive advantage for the organization.

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Chapter 4.

Documentation and Workflow

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Patients' Needs Assessment Documentation in Multidisciplinary Electronic Health Records

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Abstract

The purpose of this study is to describe and discuss physicians' and nurses' documentation of the patient's needs assessment in electronic health records (EHR) in the neurological care setting. Both physicians and nurses collect, record and interpret data during patient care episodes. Assessment of patient's need for care and treatment is an important part of the care process. Planning, implementation and outcome assessment of the care process are based on needs assessment data. The data of this study consist of 48 neurological medical narratives and nursing care plans. The data were analyzed using descriptive statistics and content analysis. Physician's medical narratives include referrals to physiotherapy and consultations in other care specialities in which they have recorded the reason for the care, anamnesis and status praesens data. Nurses have documented patient's needs assessment in nursing care plans using Finnish Classification of Nursing Diagnoses (FiCND) and additional narrative text. Physicians' and nurses' patient needs assessment documentation complement each other. Nursing documentation includes more detailed information about patients' needs for care due the use of FiCND in documentation. The use of standardised documentation improves quality of the documentation and retrieval of data from EHR.

Keywords:

Medical records systems, Computerized, Medical informatics, Nursing informatics, Documentation

Introduction

Patient's needs assessment documentation is an important part of electronic health record (EHR) data. Documentation of the planning, implementation and evaluation of patient care is based on needs assessment documentation. Among the various health care professionals who record in EHR are physicians and nurses. The EHR include all information documented by different health care professionals during patient care episodes in health care organizations. [1,2] EHR refers here to an information repository where patient data is stored in digital form. It contains retrospective, concurrent, and prospective information and its primary purpose is to support continuing, efficient and quality integrated health care. [3]. The primary function of EHR is to support health care professionals' decision-making while providing the patient with care. The goal is patient-centered recording and use of data of EHR for co-operative care both within one health care organization among different health care professionals and between health care organizations. [1,4] According to earlier studies EHR has been noted to support collaboration and communication between health care professionals. [5-7] The aim of this study is to describe and discuss physicians' and nurses' documentation of patients' needs assessment in EHRs.

Background

Patient's needs assessment documentation in EHR

EHR includes both physicians' documentation of the assessment of patients' complaints and nurses' documentation of patients' needs assessment. Physicians' notes may include subjective symptoms expressed by the patient, physician's objective observations based on physical examination and patient's medical, family and social history. [1,8] Nurses also collect and record patient health data by discussing with and examining the patient and utilize this information while assessing the patient's needs for nursing care [1,9]. (Table 1)

In information systems physicians document patients' assessment data in problem lists e.g. [10-14] templates or forms e.g. [15-17] or data is recorded in medical narratives e.g [8,18]. Earlier research on physicians' documentation of patients' assessment of complaints has mainly focused on information quality e.g. completeness or accuracy of documentation. Earlier studies reveal that use of information systems improves the completeness of documentation. [2] Galanter et al. argue that physician documentation of the problem list is incomplete. The quality of problem lists has improved with the integration of clinical decision support into the process of medication. The system proposes that the physician should add a diagnosis to the problem list based on the prescription. [14]

Nurses' documentation of patient's needs assessment is in nursing care plans. Earlier studies have shown a lack of notes on needs assessments including nursing diagnosis e.g. [19-20]. However, the inclusion of nursing diagnoses has been shown to improve the quality of patients' needs assessment

documentation, and the quality of nursing interventions and the outcomes of nursing interventions. Although deficiencies were found in the documentation of signs and symptoms. [21]

Bakken et al. (1995) has compared physicians', nurses' and patients' problem list between each other. Each patient has problem that occurred on more than one problem list. Problems which occurred only on nurses' problem lists were knowledge deficit and potential for injury. Nurses' problem lists provided additional significant information related to patient status that had the potential to affect patient outcomes. [13]

The unified content of EHR

In a national EHR development project in Finland the content of EHR was developed and unified. The core data elements and headings were defined [22]. The core data elements of EHR include patient identification information, the provider's identification information, care episode, risk factors, health patterns, vital signs, health problems and diagnosis, nursing minimum data set, surgical procedures, tests and examinations, information about medication, preventive measures, medical statements, functional status, technical aids, living will, tissue donor will, discharge summary, follow-up care plan and consent information. The documentation of the core data requires the use of vocabularies, nomenclatures and classifications. [23] Classification of Diseases and Related Health Problems (ICD 10) which is based on the WHO International Statistical Classification of Diseases and Related Health Problems is used in the documentation of medical diagnoses in specialized care. Surgical procedures are recorded using the NOMESCO Classification of Surgical Procedures. The Nursing Minimum Data Set includes information on the nursing diagnosis, interventions, outcomes, intensity and discharge summary. Nursing diagnoses and aims for care are documented according to the Finnish Classification of Nursing Diagnoses (FiCND). The Finnish Nursing Classification is based heavily on Clinical Care Classification e.g. [24].

The headings are almost the same as the core data elements supplemented with items such as reason for care, anamnesis or status praesens under which physicians record mainly narrative text.

The unified content of EHR also fulfills legislative demands. According to the Finnish legislation, each health care organization must create a cumulative patient record, which must include necessary and sufficiency information on patient care: reason for care, history, status, findings, tests, problems, diagnosis, health risk, conclusions, planning, delivering and assessment of patient care, progress notes and discharge summary for each care episode. [25]

Both physicians and nurses document patients' needs assessment information as free text in their own words and using, headings and classifications (Table 1).

Table 1 – Needs assessment documentation by physicians and nurses

	Free text	Use of headings	Use of classifications
Physician	Descriptions of subjective complaints as expressed by the patient and the findings of physicians, medical, social and family history	Reason for care Anamnesis Status praesens	Initial diagnoses (ICD 10)
Nurse	Descriptions of patients' signs and symptoms	Nursing diagnoses	Nursing diagnoses (FiCND)

Materials and Methods

The site for this research was a central hospital in Finland using an EHR system since 2000 and a nursing care plan component since 2004 in neurological care. An electronic health record comprises several data components (Figure 1). Data collection in this study was from anonymous medical narratives, nursing care plans and administrative data components in neurological care. The director of the Hospital District approved the study.

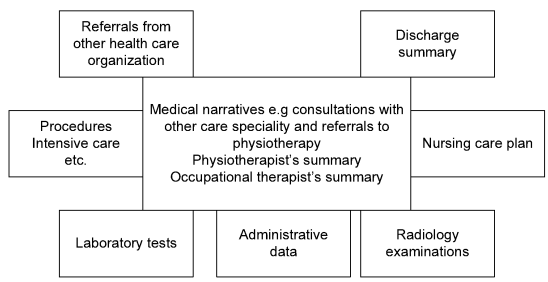

Figure 1- Data components of EHR

The Finnish Classification of Nursing Interventions (FiCNI 1.1), FiCND 1.0, ICD 10 and Classification of Surgical Procedures were implemented in an EHR system. The nurses did the documentation according to the national nursing documentation model based on the WHO nursing documentation model and use of Finnish Nursing Classifications [26]. Physicians may make entries themselves in the EHR system or dictate their documentation to be transcribed by audiotypists.

The data consist of 48 inpatient patient nursing care plans and physicians' medical narratives including consultations with other care specialities and referrals to physiotherapy. The duration of care episodes was from 6 to 127 days (mean 45). The nurses updated 11 patient's nursing care plans during care

episodes once or more frequently. The nurses recorded in almost all nursing care plans admission notes such as reason for care (n=44) and from where patient was admitted to the ward (n=43). Most of the patients (n=37) arrived from other wards or from the emergency department (n=3) of the hospital. Furthermore, one patient arrived from a university hospital. Some patients (n=2) had appointments for treatment. Physicians' documentation included consultations with different specialities (n=37) and referrals to physiotherapy (n= 46). The physicians documented 1-8 consultations with other care speciality or referrals to physiotherapy per patient. Mainly (n=38) physicians' documentation included only referrals to physiotherapy.

The frequencies of the nursing diagnoses were calculated. Physicians' medical narratives were first analyzed using deductive content analysis and categorized according national core data elements and headings. Secondly, frequencies of headings and data elements were calculated. The data were analyzed using statistical software SPSS® 14.0 (Statistical Package for the Social Sciences; SPSS Inc., Chicago, IL, USA).

Results

Nurse's needs assessment documentation

The nurses assessed each patient's need for care and recorded nursing diagnoses mainly using FiCND and complementary narrative text. Only in two patient's nursing care plan were nursing diagnoses documented using only narrative text. The nurses documented 2-17 nursing diagnoses per patient in the nursing care plans (mean 9).

Nursing diagnoses were documented mainly using FiCDN major categories or subcategories. All Care Components of FiCND except "Health services" were used in the documentation of nursing diagnoses. Nursing diagnoses were documented more frequently using "Self care", "Activity" and "Elimination" Care Components of FiCND. In table 2 is shown frequencies of different Care Components and major and subcategories of frequently used "Self care" and "Activity" Care Components. (Table 2) Inability to carry out activities of daily living were deficits in self care e.g impaired ability to perform ablutions alone, impaired ability to dress and tidy oneself, impaired ability to eat unaided or impaired ability to urinate or defecate unaided. The deficits of activity were changes in patient's physical or functional actions which were related his illness. The patients' elimination needs of nursing care include urinary and bowel incontinence.

Table 2 – Nursing diagnoses for 48 patients (N=407)

Care Component	Major/sub category	n	N	%
Self care			128	31
	As Care Component level	5		
	Self Care Deficit	11		
	Bathing/Hygiene Deficit	33		
	Dressing/Grooming Deficit	30		
	Feeding Deficit	5		
	Transferring Deficit	21		
	Toileting Deficit	17		
	Technical aids need	4		
	As free text	2		
Activity			58	14
	As Care Component level	3		
	Activity Alteration	1		
	Activity Intolerance	3		
	Diversional Activity Deficit	1		
	Physical Mobility Impairment	41		
	Sleep Deprivation	2		
	Sleep Pattern Disturbance	5		
	As free text	2		
Elimination			42	10
Physical regulation			34	8
Psychological regulation			25	6
Role relationship			22	5
Skin integrity			18	5
Coping			16	4
Sensory			15	4
Summary of care			14	4
Nutrition			10	3
Health behavior			7	2
Fluid volume			5	1
Respiration			5	1
Medication			4	1
Safety			4	1
Health services			0	0
Total			407	100

Physician's documentation

Physicians' medical narratives (n=83) included referrals to physiotherapists and consultations with other medical specialty e.g. surgery. These notes also included patient assessment documentation. Medical narratives were stored mainly as free

text. Only diagnoses (n=6) and surgical procedures (n=3) were documented using classifications in consultations with other medical specialties. ICD 10 was used in diagnosis and the NOMESCO Classification of Surgical Procedures in surgical procedures documentation. Notes were structured using headings in six patients' documentation. Physicians recorded reason for care, anamnesis and status praesens in referrals to physiotherapy or to other care specialties. (Table 3)

Table 3 – Documentation in physicians' medical narratives for 48 patients (n =83)

Headings	Data Element	n	%
Reason for care		27	32
Anamnes		46	55
	Laboratory test	2	
	Radiology	11	
	Medication	8	
	Functional status	23	
	Surgical procedures	15	
	Health patterns	3	
	Technical aids	6	
	Vital signs	8	
Status praesens		46	55
	Laboratory	3	
	Radiology	11	
	Medication	1	
	Functional status	29	
	Technical aids	2	
	Risk factors	1	
	Vital signs	9	

The reason for care was documented in 27 physicians' notes. Both anamnesis and status praesens information were documented in 46 physicians' notes. Anamnesis and status praesens information included information from laboratory or radiology tests, likewise on medication, functional status, technical aids and vital signs. Furthermore, anamnesis included information on surgical procedures, health patterns and status praesens documentation described risk factors. (Table 3) Physician documentation of patient's functional status described patient's problems in physical or functional actions related to medical diagnosis.

Both in physicians' and in nurses' notes more frequently described patients' inabilities to carry out activities of daily living and deficits in activity.

Discussion

The aim of the study was to describe and discuss physicians' and nurses' patient's needs assessment documentation in EHRs. The results indicate that both physicians and nurses had documented needs for patient care and treatment in their own documentation. Nurses mainly described patients' needs for care using the nursing diagnosis classification (FiCND). Nursing diagnoses represent patient problems requiring clinical care by nurses. The most used Care Components of FiCND were Self Care and Activity, which describe the functional health pattern of clinical care in nursing practice. It is obvious that these health patterns emerge in neurological patient nursing documentation. Nurses' documentation also included admission notes such as reason for care and arrival information. In Finland this is obligatory information for national statistics and perhaps therefore nurses also recorded these items. Thus the information on reason for care in nursing care plans include information which partially overlaps what is documented in physicians' medical narratives e.g. in anamnesis documentation and the information is related in medical diagnosis.

Physicians' medical narratives include referrals to physiotherapy and consultations with other treatment specialities. These notes include information on the reason for care, patients' subjective complaints and physicians' objective findings. Data retrieval of patients' problems could be easier if physicians' documentation of patients' problems were separately e.g. in a problem list rather than in medical narratives. Furthermore, the use of the structured and coded core data elements of the EHRs also facilitates e.g problem linked with free text. The use of classifications or structuring notes with headings in documentation could improve the completeness of patient records and data retrieval from patient records. [8,12]

Both nurses' and physicians' documentation described patient's problems in physical and functional actions. Bakken et al. (1995) has also noted that the same problems occurred in nurses' and physicians' documentation and these problems are related to medical diagnoses. Thus nurses' documentation used the FiCND and this documentation provided detailed descriptions information on patients' problems.

The use of the other health care professionals' documentation is necessary in patient care during care episodes. This study shows that nurses and physicians must also know where they can find other health care professionals' notes. It is remarkable that physicians' only notes recorded during care episodes are about consultations with other care specialities and referrals to physiotherapy. This may be due the use of paper notes in parallel: physicians utilize these paper notes while recording the discharge summary at the end of the care episode.

Conclusion

Both physicians and nurses record needs assessment data regarding patient care and treatment. Nurses' documentation is more detailed than physicians' documentation. Physicians' notes are narrative text, and due to this it is difficult to locate information. The use of standardised documentation would improve the quality of the documentation and retrieval of data from EHR.

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Impact of a Critical Care Clinical Information System on Interruption Rates During Intensive Care Nurse and Physician Documentation Tasks

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Abstract

Computerized documentation methods in Intensive Care Units (ICUs) may assist Health Care Providers (HCP) with their documentation workload, but evaluating impacts remains problematic. A Critical Care clinical Information System (CCIS) is an electronic charting tool designed for ICUs that may fit seamlessly into HCP work. Observers followed ICU nurses and physicians in two ICUs in Edmonton, Canada, in which a CCIS had recently been introduced. Observers recorded amounts of time HCPs spent on documentation related tasks, interruptions encountered by HCPs, and contextual information in field notes. Interruption rates varied depending on the charting medium used, with physicians being interrupted less frequently when performing documentation tasks using the CCIS, than when performing documentation tasks using other methods. In contrast, nurses were interrupted more frequently when charting using the CCIS than when using other methods. Interruption rates coupled with qualitative observations suggest that physicians utilize strategies to avoid interruptions if interfaces for entering textual notes are not well adapted to interruption-rich environments such as ICUs. Potential improvements are discussed such that systems like the CCIS may better integrate into ICU work.

Keywords:

Intensive care, Clinical information systems, Interruption, Time and motion study

Introduction

Health Care Providers (HCPs) working in Intensive Care Units (ICUs) attend to highly acute and complex patients. Effective care requires continuous monitoring by specialized and costly HCPs. Coordinated care among different HCPs and over time is called continuity of care and is a central determinant of patient outcome [1-3]. Continuity of care depends on the communication of patient condition changes and care plans to pertinent care team members, frequently using patient charts. Information contained within patient charts is vital for decision making, and ideally should be current, complete, and correct.

One approach aimed at assisting HCPs working in ICUs with their documentation workload uses computerized clinical information systems. A Critical Care clinical Information System (CCIS) is designed to replace paper charts and interface with ICU bedside equipment and laboratory systems to automate some documentation tasks for HCPs [4]. It is believed that a CCIS may aid communication among HCPs but little evidence currently exists.

This paper reports part of a larger project evaluating whether a CCIS in two ICUs in Edmonton, Canada is beneficial for patient care [5]. Trained observers followed physicians and nurses to record the amount of time spent on documentation related tasks and numbers of interruptions HCPs encountered while going about their work. Needs for timely communication in environments such as ICUs and emergency departments result in HCPs interrupting and being interrupted more frequently than in other hospital environments [6,7]. Rates of adverse medical events in ICUs are more frequent than in other hospital wards [8]. Interventions aimed at reducing error, along with more methodologically sound research investigating relationships between medical error and work interruptions, are needed [9,10].

To formulate effective plans to manage and reduce the consequences of interruptions recent work has investigated reasons HCPs initiate interruptions in high acuity health care settings [11]. Interruption recipients may block or delay interruptions [12] suggesting that recipients can take an active role in prioritizing interruptive communication patterns above or below their current or 'primary' task [13]. HCPs are likely to prioritize patient care tasks above documentation tasks [14]. We suggest that interruption rates during documentation tasks may provide a measure of the extent to which this prioritization occurs.

We report interruption rates during documentation tasks for nurses and physicians in two ICUs before and three months after the introduction of a CCIS. The findings are discussed with reference to frequent types of documentation completed by nurses and physicians. The results demonstrate needs for more interruption tolerant data entry mechanisms in ICUs and emergency departments.

Methods

Setting & Participants

The University of Alberta Human Research Ethics Board approved this study prior to data collection. The study was conducted at the Pediatric ICU (PICU) at the Stollery Children's Hospital and the General Systems ICU (GSICU) at the University Hospital, both in Edmonton, Alberta, Canada. Both are located within busy academic tertiary referral hospitals. The PICU has 17 beds. GSICU has 30 beds with 24 operational due to staff shortages. Laboratory results are accessed with computers at nursing stations and throughout the unit. The ratio of patients to nurses is 1:1 in PICU. In GSICU, the patient to nurse ratio is 1:1 70% of the time and 2:1 30% of the time depending on patient acuity.

Staff members were informed of our study with presentations given by the research team, and with posters distributed around the units. Research team members approached nurses and physicians to obtain their consent to be observed. Of 215 nurses in permanent staff positions, 97 agreed to participate. Of 36 physicians, 34 agreed to participate. Chief residents and sub-specialty fellows were included in the group of observed physicians.

Observations

Observers were trained for at least 12 hours prior to conducting observations. In training sessions, trainees were paired with experienced observers to observe and score a single participant. Inter-rater reliability scores were then calculated from the reported amounts of time spent on the task categories. Observers conducted their own observations after obtaining inter-rater reliability scores above 85%. Observations were conducted for a maximum of 90 minutes without advance notice to participants. Equal numbers of nurse observations were conducted during mid-day (07:00-19:00), mid-night (19:00-07:00), morning shift change (06:30-08:00), and evening shift change (18:30-20:00). Physician observations were conducted during morning rounds (08:00-12:00), sign-out rounds (16:00-17:00), and at night rounds (20:00-00:00). Observers kept field notes recording how busy units appeared, whether students were present, and contextual information to help with interpreting observational data. Observations were suspended if participants left the unit.

Baseline observations were conducted between September and November 2008 in PICU, and between January and February 2009 in GSICU. The CCIS was introduced to the GSICU and PICU in March, 2009. Once connected, patient vital signs were automatically recorded in charts. Lab results, ventilators and dialysis machines did not interface with the system at the time of observation. Medication orders were handled with paper records. Post-CCIS observations were conducted between May and June 2009 in both units. Before the system was introduced, 57 hours of physician observations and 60 hours of nurse observations were conducted. After the introduction, 50 hours of physician observation and 56 hours of nurse observations were completed.

PDA Data Collection Tool and Work Definitions

The WOMBAT software runs on Hewlett-Packard iPAQ hx2490 or 110s [15]. Time stamped data was extracted into Excel spreadsheets via a laptop computer. Westbrook and colleagues provided detailed task definitions which we refined to include tasks specific to the observed units [16]. Observers carried the paper work definitions to assist in recording the tasks observed into PDA categories. Documentation tasks were scored when participants wrote or typed in information into permanent records, CCIS, other computer applications, or other paper. The complete definitions are described elsewhere [16]. Observers recorded the medium using the WOMBAT software. Interruptions were also recorded using the WOMBAT software if any external factor (e. g., an alarm, another care provider, a patient) appeared to cause the participant to cease their task and perform a secondary task [15].

Statistics

Interruption rates and proportions of time spent on documentation tasks were calculated for observations. Interruption rates when completing documentation tasks using the CCIS and other Non-CCIS methods (permanent records, paper, or other computer applications) were compared using t-tests assuming unequal variances. The significance level was set at 0.05.

Results

Amount of time spent on documentation tasks

During our observations, physicians spent 15.2% of their time (mean, +/- 5.3%; 95% Confidence Interval) and nurses 26.4% (+/- 3.1%) performing documentation tasks before the CCIS introduction (Figure 1A). After the CCIS implementation, both physicians and nurses used CCIS and non-CCIS methods of completing documentation tasks. The percentage of time spent on documentation tasks while using the CCIS was 1.6% (+/- 1.9%) for physicians and 14.8% (+/- 3.2%) for ICU nurses. The time spent on documentation tasks after the CCIS introduction using Non-CCIS methods was 7.3% (+/- 2.8%) for physicians and 5.7% (+/- 1.8%) for nurses.

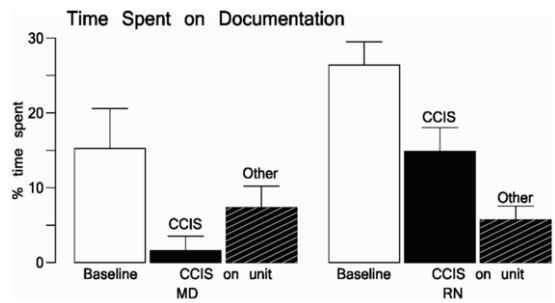

Figure 1- Mean percentages of time spent on documentation tasks before the CCIS and after by ICU physicians and nurses using the CCIS or Non-CCIS media (+/- 95% Confidence Intervals).

Interruptions during documentation tasks

Before the CCIS introduction, the rate of interruption during documentation tasks was 2.2 (+/- 1.4) interruptions per hour for physicians and 4.5 hr^{-1} (+/- 1.9) for nurses (Figure 1B). When physicians performed documentation tasks using the CCIS the interruption rate was 0.35 hr^{-1}(+/- 0.45). Physicians were interrupted significantly more often when documenting with Non-CCIS methods, at a rate of 4.0 hr^{-1}(+/- 3.4). After the CCIS introduction, nurses were interrupted at a rate of 8.8 hr^{-1} (+/- 3.5), which is significantly more often than when performing documentation tasks using Non CCIS methods (1.4 hr^{-1}; +/- 1.2).

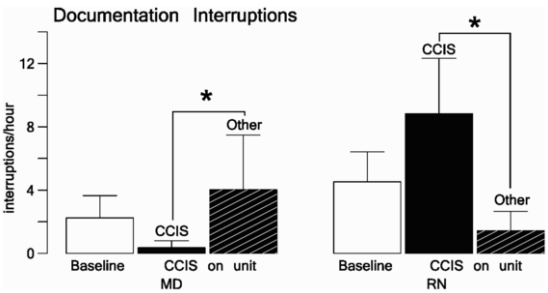

Figure 2- Mean interruption rates during documentation tasks observed before and after the CCIS introduction for ICU physicians and nurses. Interruption rates for documentation tasks were determined based on the media used, the CCIS itself or Non-CCIS media (=p<0.05)*

Discussion

The results identify role specific changes in interruption rates during documentation tasks depending on the media HCPs use after a CCIS introduction. In the two ICUs studied, physicians spent more time documenting care using Non-CCIS methods than they did using the CCIS after the CCIS introduction. When physicians performed documentation tasks using the CCIS, these tasks frequently consisted of long notes. If physicians were interrupted while writing notes, the session could time out due to inactivity. When the physician returned, they would spend additional time amending their note. As 'copy' and 'paste' functionalities were unavailable using this system, physicians would often need to rewrite the note completely.

Strategies used were documented by observers with field notes. For example, an observer noticed a senior physician approach a trainee to initiate a conversation. The senior physician first confirmed that the trainee was not busy writing a note in the CCIS before they continued their conversation. In another incident a physician accepted a newly admitted patient following a surgery. Once the immediate task of receiving the verbal information from the surgeons and providing orders to the care team was complete, the physician moved to an unused terminal at some distance from the patient to enter a note into the CCIS. In other instances, observers noted some nurses remarking that physicians using the CCIS could be less responsive to requests than when completing other tasks. Based on these observations, ICU physicians may attempt to reduce the likelihood of being interrupted when they use the CCIS. Strategies may include deferring communications to later times, or performing documentation tasks in locations more distant than using paper charts. The observational data are consistent with this as ICU physicians performing documentation tasks using the CCIS were interrupted less frequently than when using Non-CCIS documentation methods.

A contrasting situation exists for nurses completing documentation tasks using the CCIS. The observational data show that nurses were interrupted more frequently when performing documentation tasks using the CCIS than when using Non-CCIS methods. The increased rate of interruption during CCIS documentation tasks likely has causes and effects that are not yet identified. The workload associated with nursing care requires that nurses spend large proportions of their time at the bedside or at nursing stations near patients. Nurses may not have the same degree of flexibility to employ strategies that physicians use in deferring interruptions. Alternatively, nurses completing documentation tasks with the CCIS may be able to resume with less disruption compared with physicians. Nurses are discouraged from entering text notes into the CCIS. The increased rate of interruption could be accounted for if nurses have less incentive to delay or block interruptions.

Significance

These findings may have implications for patient care provided in ICUs. One implication involves physician availability. HCPs value the convenience of being able to perform documentation tasks and review chart information remotely rather than at the bedside [17]. For some classes of information, such as lab results, physicians may more easily obtain current information at an unoccupied computer than at the bedside. Physicians accessing chart information remotely may be able to make better decisions about when they need to come to the bedside.

Care providers working at the bedside will typically prioritize patient care above documentation tasks [14]. Data entered into the chart about procedures performed and assessments of patient status may not be completely updated, depending on workload. If physicians choosing to work remotely so as to avoid interruptions during documentation tasks tend to spend less time on the unit, there is the potential for subtle reductions in physician availability to come about as an unintended consequence of introducing clinical information systems such as the CCIS. We posit that the inability of the CCIS to pause and later resume note entry represents a potential area of improvement for a system designed for the critical care environment.

Potential Solutions

One solution might involve physicians adopting documentation methods much like other HCP roles, where text entry is discouraged. Difficulties with this approach surround the complexities of medical documentation. Most physicians are trained to write text notes that are human readable rather than completing their documentation tasks using other data entry

mechanisms including drop-down boxes. As a result, physicians may resist this option.

A second potential solution involves enabling copy-paste functionality. Recent work has investigated some of the unintended consequences that can result when physicians use copy and paste functions [18]. Some of these consequences include the potential for notes from previous days to be brought forward inappropriately and thus fail to track changes in a patient's progress over time. Investigations into physicians' attitudes toward and usage of copy and paste functions from other hospitals where these functions are enabled in documentation tools have shown that physicians report that they value these functions to keep up with burgeoning workloads [19]. The percentage of time physicians in our study spend using the CCIS is highly suggestive that senior physicians tend not to use this system to complete their documentation tasks, but may delegate CCIS documentation tasks to more junior physicians, and resort to more flexible methods. These methods include using paper and other software including word processors where copy and paste functions are available. Although not including these copy and paste functions may avoid the potential unintended consequences described above, it may also severely limit the utility of the CCIS to physicians. Appropriate physician training regarding potential issues around the use of copy and paste functions could be included in medical school curricula, residency training, and continuing medical education, such that systems like the CCIS provide better utility to physicians.

Third, the system could save a partially entered note as a 'draft' when locking out a user. Other care providers could view the note with cues or notifications marking it as incomplete. Physicians returning to the computer could then complete their note. In a very busy environment many 'drafts' may be left on different charts. This solution should be no worse than is the case under paper charts if the CCIS facilitates the completion of documentation tasks.

Strengths and Limitations

The current study benefits from a clear, previously defined, definition of interruption [15], thus enabling comparisons to be made between our study and other units considering introducing a CCIS. We report interruptions occurring during one primary task, documentation, to investigate how well the CCIS fits in with the workload experiences of ICU physicians and nurses.

No studies, to our knowledge, have validated the WOMBAT method in ICUs, and this represents a potential minor weakness of this study. The results may not generalize to other wards, depending on the clinical information systems in place, particularly if those systems better tolerate interruptions to text entry. This study may have benefitted from collecting data from more junior physicians as they were more frequent users of the CCIS. We did not follow junior physicians as their varying familiarity with ICU work would present an obvious confounding variable. Future investigations of electronic documentation methods would clearly benefit from their inclusion in our study.

Conclusion

Currently, adoption rates of hospital based EMRs languish [20]. Challenges encountered by HCPs in ensuring informational continuity around their patients in the ICU environment may be either mitigated or aggravated by the tools they are provided. Clinical information systems designed for ICU environments may not take into account the interruption-rich environment. As HCPs become more familiar with the system, these effects may be lessened. Meanwhile, we posit that the lack of interruption tolerant data-entry mechanisms represents a deficiency that may impact documentation quality, communication between HCPs, and thus patient care.

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Author Contributions

MAB performed the data analysis and wrote the manuscript. MAB and KJA coordinated the data collection. NTS is the senior author on the CCIS research study. She designed the study and provided editorial advice. DCM provided statistical advice. MAB, NTS, KJA, DCM and RTNG provided input into the project design. All authors approved the final version of the manuscript.

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Conceptualization of an Electronic System for Documentation of Nursing Diagnosis, Outcomes, and Intervention

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Abstract

Electronic nursing documentation constitutes technical, scientific, legal, and ethical documents. The objective of this study was to develop an electronic nursing documentation system. The system was developed in four phases (conceptualization, detailing, prototype building, implementation), and the knowledge base was based on domains and classes according to the NANDA-I, NIC, and NOC unified framework. The result is an electronic system (PROCEnf - USP - Nursing Process Electronic Documentation System of the University of São Paulo) which allows documenting nursing process generating reports of nursing process, besides supporting decisions on nursing diagnosis, expected outcomes, and interventions. Integration of different fields of knowledge, as well as the institutional feature of valuing continuous theoretical and practical improvement of nursing process were factors of success of this technological project.

Keywords:

Nursing informatics, Computerized medical records systems, Nursing diagnosis.

Introduction

The clinical nursing documentation has been oriented by the Nursing Process (NP). In Brazil, the NP was introduced in the 1970's by Wanda de Aguiar Horta to make nursing (which was conceived as the science that deals with human care treating the basic needs of the human being [1]) operational.

After using the NP in teaching and health services, it became known and recognized by the title of *Systematization of Nursing Assistance* (SAE). In this text, the expressions 'NP' and 'SNA' will be used with the same meaning, and describe a tool that provides a systematic guide to assist nurses develop a "a style of thinking that leads to appropriate clinical judgments" [2].

The NP orients a style of thinking in a continuum of questioning-answering-questioning in dynamic contexts for making appropriate decisions about what the patients' care needs are (diagnoses), what the expected outcomes are(outcomes), and what are the best nursing actions to meet the expected outcomes (interventions) [3].

Nursing documentation, in addition to providing technical, scientific, legal and ethical documents, and providing health institutions with important records for billing purposes, subsidizes the audit of nursing actions, and above all, allows estimating quality of care provided to the client [4].

However, one can observe that current nursing documentation often presents problems in terms of accuracy and relevance, and is rarely used to evaluate the care given.

The combination of three elements has been the focus to improve nursing documentation: definition of core data which should be included in each care meeting [5-6], internationally acknowledged as *Nursing Minimum Data Set* (NMDS), use of standardized language systems (or classification systems) [7-8], and networking [9].

Classification systems like *NANDA-International (NANDA- I* [10]*)*, *Nursing Interventions Classification (NIC)* [11] and *Nursing Outcomes Classification(NOC)* [12] are tools to improve reliability, validity and usability of nursing documentation.

In an attempt to integrate the classifications, NANDA-I, NIC, and NOC Alliance proposed a framework called NNN (NANDA, NIC NOC), which establishes a set of four domains and twenty eight classes to organize in a single framework the contents of NANDA-I [10], NIC [11], and NOC [12].

Using NNN framework in an electronic nursing system improves documentation, encourages nurses to adopt the NP, and improves diagnostic accuracy and patients' outcomes [13-14].

Computerized systems must overcome the mere transfer of documentation from paper to computer, and the "*check lists"* of diagnoses and nurses' orders emphasizing decision making

and nursing clinical judgment in patient care, expanding and supporting nurses' clinical decision

Decision Support Systems (DSS), which use databases (facts and/or rules), designed to assist a health professional in the process of clinical decision making have a great potential to help nurses cope with the required amount of data and information [15].

The Nursing Department (ND) of the University Hospital of the University of São Paulo (HU-USP), since its establishment, has implemented the NP in clinical practice. Aware of the advances in information technologies for health systems and the importance of ensuring that nursing was prepared for it, the ND included the computerization of clinical nursing documentation in its goals. Thus, since 2000 computerization of clinical nursing documentation was the main concern leading to the implementation of nursing classifications [16]. In 2003, by gathering researchers from the School of Nursing of the University of Sao Paulo, and nurses from the HU-USP, the project received a grant from the National Council for Scientific and Technological Development (CNPq), which enabled the leverage of the project to build a DSS for the nursing process and its documentation.

This paper reports the development of the system and its features.

Objective

To develop an electronic system for nursing documentation supporting adult clinical and medical patients' assessment documentation, and decision on nursing diagnoses, expected outcomes and interventions.

Method

This was a methodological research on technology production in the modality of case study. The system development method used 4 cyclical phases of technological product development: Conceptualization, Detailing, Prototyping and System implementation, adopting a project management model based on the *Project Management Institute* (PMI) [17].

The project presents a data model that enables electronic documentation of NP data of medical and surgical adult patients admitted in the HU-USP.

To develop the project, a multidisciplinary work group was established. The scope of the project was limited to NP documentation, in a way that it could be integrated into the hospital system of clinical documentation, .

The Steering Group of the system development was constituted by the Director of the ND, the Director of the Clinical Nursing Division of the HU; a nurse from the Nursing Continuing Education Service of the HU; two faculties of the School of Nursing of USP, and two staff nurses from Clinical and Surgical wards of HU-USP. In detailing phase for modeling data and system development, HU-USP contracted a company that had previously developed other systems for the Institution. Validation of use cases and system approval was done by Steering Group meetings with the technicians of the contractor company and a representative of the IT Department of the HU-USP.

Considering other areas within the ND will eventually incorporate the system, Directors and representatives of the Maternal-Child Nursing and External Patients Nursing Divisions were contacted, aiming at helping to organize materials the for databases.

It is noteworthy that nursing diagnosis classification was effectively in use in all the HU-USP wards since 2005 and that nurses developed tools to manually document nursing diagnoses, nurses orders and progress notes [18], which guided the construction of the electronic system.

The research project was approved by the Ethics and Research Committee of the Institution.

Results

PROCEnf-USP (Nursing Process Electronic Documentation System of the University of São Paulo) was developed in four planned phases.

The conceptualization phase emphasized the scope of the system, and established basic requirements. To do so, clinical and managerial Minimum Nursing Data was identified, and questionnaires were prepared to guide assessment data documentation needed for nursing diagnoses for clinical and surgical patients [17].

The framework for clinical assessment documentation was organized according to a database based on nursing diagnosis definitions and their components, following the hierarchy of domains, and classes proposed by the unified framework of NANDA-I, NIC and NOC [19], which could be a documentation guide able to generate a list of nursing diagnosis hypotheses in accordance with assessment data documented in the system.

Then, the automatic method used in the patient's nursing assessment record was to develop a "branched questionnaire" in which the nurse would go through several questions which could be customized for each patient [15].

The *PROCEnf-USP* guides the nurse to respond to a set of questionnaires with tabulated responses that lead to a set of likely diagnoses supporting the generation of diagnostic hypotheses. The evaluation, analysis, and choice of the defining characteristics, related factors and risk factors applicable in the structured database of likely diagnoses, allow the nurse to decide the set of diagnosis that best fits the patient's responses at admission, according to the nurse clinical reasoning, which corresponds to the phase of hypotheses testing, and final decision in the diagnostic process.

The branched questionnaire was developed by the Steering Group with questions based in the definitions, defining characteristics and related factors/risks of each diagnosis. For each class of unified framework of NANDA-I, NIC and NOC[19], questions were created on related subjects, whose answers include at least one cue for every diagnosis in the same class. In addition to the questionnaires for the 28 classes of the NNN structure, 4 other questionnaires which are required to admit any patient (social and demographic data, events which led to service, vital signs and conditions when arriving to be serviced) were created. The NMDS and the previously established institutional protocols guided the

definition of the additional content to the NNN structure. Once documented, the data of these 4 additional questionnaires which are relevant to any NNN class, are automatically copied to the class(es) in which they belong.

The linkages between answers and diagnoses were defined by consensus in the Nursing Group, based on the NANDA-I classification [10], the theoretical framework of reference areas, as well as on the clinical experience of nurses. In order to guarantee the linkages between answers and diagnoses in the logical system, every diagnosis had to have at least one answer they could be linked to. A rule was adopted that it was necessary that all diagnoses could be hypothesized at least once through the answers to questions included. Thus, after the nurse documents data collected (in total or in part), the system itself presents automatically the diagnostic hypotheses (calculated diagnoses). Then, the calculated diagnoses (hypotheses generated by the system) are confirmed or refused by the nurse, ensuring that final decision on the determination of the diagnosis is made by the user.

When relevant, questions with the same statement and same possible answers were repeated in more than one questionnaire (class), as recursive questions. These recursive questions, once documented in a class, are automatically documented in the other class(es) in which they are present. This avoids the duplication of work without violating the structure defined for the organization of questionnaires.

In order to support the choice of nursing outcomes and interventions, possible linkages between diagnoses and expected outcomes and between outcomes and interventions pertinent to the context of HU-USP were introduced in the system. Therefore, the components of the Nursing Classifications Advanced Node (NACEnf)[1] of the ND mapped 66 nursing diagnoses which are the most frequent in the Institution; for each one of these diagnoses, expected outcomes in the scope of HU-USP were chosen; for each outcome, interventions and activities pertinent to practices of the HU-USP were also chosen. Nursing diagnoses, outcomes and interventions were linked, therefore integrating NANDA-I [10], NOC [11] and NIC [12] classifications. Nursing diagnoses and expected outcomes were included in linkages according to their titles, and interventions were linked according to the activities recommended by the NIC. Linkages were based on available literature and reflections on clinical nursing practice in the Institution.

In the Detailing phase, software that would be used to develop the system was selected, as well as Use Cases, system interfaces and conceptual, logical and physical data modeling were described, adopting paradigms of ease of use and good quality user interface system. System specification documents followed current HU-USP standards, which use a sub-set of *Unified Modeling Language* - UML.

Information system project requires the use of databases characterized as structures of data storage and organization, arranged in a predetermined order according to system design, aiming at reorganizing data and producing certain information [20]. A database is usually maintained and accessed through software known as Database Management System (DBMS), which provides an interface (characterized as managing module) so clients can add, change or retrieve data.

In this project, the chosen database was Oracle®, because it is the tool used by HU-USP. This database provides an interface for customers to add, change, or retrieve data using a specific programming language: PL/SQL (*Procedural Language/ Structured Query Language*).

The data storage model used was relational, structured in the tables that allow for data relationship.

Platform.NET, a Microsoft® *framework* developed for internet, was used to establish the system web interface. F*ramework* is understood as a group of methods, standards and classes which define and offer resources for the development of systems.

The system has two environments: professional and academic. The professional environment will be used for documenting data of actual patients. The academic environment will enable the simulation of situations for teaching purposes with the same characteristics of actual clinical documentation, in which nurses, students and teachers register fictitious patients and simulate making diagnoses, selecting outcomes and interventions. The creation of fictitious patients prevents real patients from being included for education outside the field. This procedure is necessary to educate students and nurses and to keep the non-violation of ethical elements recommended.

When preparing the prototype, a preliminary version of the system was developed (functional prototype) aiming to verifying functions and business rules, and to observe system operation, facilitating the visualization of system constraints and system validation. During this phase, meetings were held to validate functions and business rules in the system.

During implementation phase, the system entered into a testing environment. Several versions were tested, and the system was finally approved by the Steering Group to enter into the production environment. In this phase, the system was installed on the HU-USP server, and *login* and access passwords were distributed to users.

PROCEnf – USP

The system allows the user, whether a nurse or a student, to make clinical decisions, supporting judgments to establish nursing diagnosis, expected outcomes and nursing interventions.

The user can choose between two paths, depending on their needs, being allowed to enter assessment data and view nursing diagnosis hypotheses generated by the system or to directly choose nursing diagnoses. Stages to be covered by the user follow clinical reasoning from documenting interview and physical examination data to documenting nurse orders.

To document data and care planning, the user shall follow *PROCEnf - USP* steps, detailed below:

1. Assessment**:** to begin documenting the assessment, it is necessary to choose an actual patient (in the professional environment) or a fictitious patient (in the academic environment).

[1]Nursing Classifications Advanced Node (NACEnf): Research support group created by the Nursing Department of the HU-USP aiming at deepening the application of standardized nursing language systems in the clinical practice of nurses.

2. Answer Questionnaire: the user shall answer the required Questionnaires and have the option of responding to the remaining Questionnaires (which are structured according to NNN classes) which it deems appropriate. Answers to Questionnaires generate Nursing Diagnoses hypotheses.
3. Calculate diagnosis: the system will show all diagnostic hypotheses on the screen, so the user can view Defining Characteristics, Related Factors, or Risk Factors that were identified through the answers documented in questionnaires.
4. Indicate diagnosis: the user can include Nursing Diagnoses in addition to the system hypotheses. On this screen, one has the option to look up Nursing Diagnoses definitions and add Defining Characteristics, Related Factors, or Risk Factors.
5. Select diagnosis: the user is responsible for choosing the most accurate diagnosis for the care of the patient.
6. Outcomes: after the decision on nursing diagnosis(es), the system will indicate the possible outcomes for each diagnosis, and the user will select one(s) that best represents the goals to for patient's care plan. The system allows adding other outcomes besides those automatically suggested.
7. Interventions: after the choice of Nursing Outcomes, the system will indicate the possible Interventions related to the Outcomes selected. The system allows the inclusion of other Interventions.
8. Activities**:** the system presents a set of nursing activities for each Intervention decided by the user. It allows the user to include other Activities that are linked or not to the Intervention selected. It is possible to add complementary information to an activity, such as "frequency" and "local application". The location of the patient's body related to the activity can be pointed out by the user by means of an iconographic system corresponding to the regions of the body.
9. Summary: the system displays a summary of the "Assessment" made by the user with the following data: evaluator's name, approver's name (certified nurses), questionnaires, diagnoses linked to their outcomes, interventions, and activities.
10. Reports: the user can request the following reports: "Assessment" (Nursing Diagnoses, Outcomes, and Interventions) "Daily Activities" (Nursing Diagnoses and Nurse Orders) and "Questionnaires".

Conclusion

The *PROCEnf-USP* will be registered as software by the USP Innovation Agency, and is ready to be implemented, evaluated, refined, and expanded.

Reasons because this technological production project was successful include institutional features (academic hospital, pro-active management of the ND; tradition in using nursing process; ND position in the organizational structure, for example), financial support, and positive attitudes toward collaborative work between clinical and research personnel from varied disciplines.

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Medication Counseling: Analysis of Electronic Documentation Using the Clinical Care Classification System

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Abstract

Medication counseling is a central aspect of medication safety. Counseling refers to the process of informing, advising and administering medication to help patients manage their medication regimen. This pilot study examined 379 descriptions of medication counseling carried out in surgical care and documented in an electronic patient record system by using the Clinical Care Classification System. The objective was to identify counseling methods and to evaluate the need for additional counseling descriptor codes in the record. Eleven counseling methods were identified and the data were classified according to counseling methods with and without documentation of the nature of the interaction with patients. There were no descriptions of the nature of counseling conducted in 127 of the documented entries. These results can be used when developing the documentation of medication care in electronic patient records.

Keywords:

Medication administration, Patient safety, Counseling, Terminology

Introduction

The purpose of medication counseling is to support medication care by educating patients about their health status and medications needed to support it. This education during hospitalization results in the improvement of their knowledge regarding medications [1], increases their participation in care and enhances medication adherence [2].

Studies detailing the methods used in medication counseling are numerous. However, there is variability of study results based on methods used and outcomes measured in daily practice [1,3]. Standardized classifications can provide needed structure to organize the documentation and analysis of nursing care in a more systematic manner [4]. Structured descriptions of interventions used in an electronic patient record can be analyzed and evidence about safety, quality and use of resources evaluated [5, 6].

Most electronic systems that use structured data entry also allow supplemental information to be entered into the system in a narrative text format. Analyzing both the use of the structured codes and narrative text allows for the determination of potential additional structured codes that could further enhance the extraction and analysis of data [7]. In a study of narrative documentation in an otherwise structured clinical information system, Moss et al. found that almost 75% of the documented entries did not have a structured code in the system, increasing the time and effort needed to analysis these entries [7]. However, it has been shown that structured nursing terminologies, such as the Clinical Care Classification System, can be successfully used to classify nursing documentation in a structured format [8].

The purpose of this paper is to describe the evaluation of structured (using a nursing classification) and unstructured (supplemented free text) documentation of medication counseling in surgical care to determine methods used in counseling and how the narrative documentation in the record might inform additional coding for structured electronic documentation in the future.

Background

Finnish Classification of Nursing Interventions

The Finnish Classification of Nursing Interventions (FiCNI) has been implemented in electronic health record systems in Finland and is used in nursing care planning and documentation. Primarily, nurses use this portion of the electronic record, however all health professions can also access and document interventions carried out on patients. FiCNI is effectively a cultural revision of the Clinical Care Classification System (formerly the Home Health Care Classification) [9]. This standardized terminology consists of 19 care components, 164 main categories and 266 subcategories and is used to define planned and performed nursing actions. The *Medication component (G)* is divided into three main categories: *G.1 Medication Administration, G.2. Medication Side Effects and G.3 Medication Counseling*. In electronic health record systems documentation using intervention codes in these categories can be supplemented with free text narrative information. [9,10] According to a study focusing on the analysis of FiCNI use in nursing documentation in surgical and internal care the Medication component was one of the three most frequently used tools in documenting care provided [11]. In an other study assessing how the Medication component and its categories were used in daily documentation (N=4,594), 70 % of nursing actions

were found to be focused on medication administration and the single subcategory medication administration 'per os' was used most often [12].

Medication Counseling

Medication counseling is a central part of medication safety. Counseling refers to the process of informing, advising and administering medication to help patients in their medication regimen. [13] The objective of counseling is to promote its rational use to insure the best therapeutic action of the medication [1, 3]. Several studies show that lack of information causes patient non-adherence towards medication care regimen [1-3]. Kerzman and her associates (2005) found out that counseling was an important factor affecting correct knowledge about medication therapy at discharge. They also emphasize the importance of assessing a patient's cognitive abilities and highlight the provision of written material after counseling to reinforce the counseling success. [1]

In a previous study, five areas of teaching interventions related to medication management were found to be documented in the patient records in general medical ward: information, motivating conversations, explanations, instructions and setting expectations. According to the results documentation of patient teaching was inadequate. Although 80 % of patient records contained details of pedagogical relevance, they were not documented in a structured way and the use of terms and expressions were fragmented. [3]

The timing of counseling is extremely relevant for insuring correct knowledge regarding medication therapy. Counseling during hospitalization appears to help the patient better comprehend the information given and to ask for additional information. [1] Counseling is also needed when a medication care regimen changes. For instance new dosing and timing may cause adverse events in medication therapy if the new instructions are not given to and understood by patients. [1, 13-14]

Overall electronic information systems have been shown to reduce the number of medication errors associated with order entry [15-16]. Perhaps using standardized electronic documentation codes for medication counselling will help prompt caregivers to provide more complete and effective medication counselling to reduce errors and enhance therapeutic efficacy.

Purpose and aims

The purpose of this paper is to describe the evaluation of structured and unstructured documentation of medication counseling in surgical care to determine methods used in counseling and how they might be coded for structured electronic documentation.

Research questions in this study included:

- What are the methods used in medication counseling?
- How often is medication counseling provided to patients?
- Who provides medication counseling to patients?

Methods

De-identified patient data were extracted from the electronic patient records of a central hospital in Finland during 2004-2005. Before this analysis the FiCNI classification had been in use for two years in the electronic patient record system. The analysis was restricted to 11,543 patient records from a surgical ward in the year 2004. The Medication component as a code was used at least once in 3,902 (33.8%) of these records. For this pilot study the use of category *Medication counseling* of the FiCNI Medication component in the surgical ward documentation was analyzed. The code of medication counseling was used to describe nursing interventions in 379 records. These records included documentation entries of medication counselling in 269 patients, some of which had multiple admissions to the hospital that year.

Each record consisted of the following items: de-identified patient number, date and time of documentation entries, title of the personnel documenting, the heading and medication counseling category (G 3) with supplementing narrative text for each documentation entry. The data were extracted using SQL queries then converted to MS Access to process the raw data for research purposes. The data were analysed using MS Excel and further with SPSS 14.0 for Windows for descriptive statistics. Qualitative content analysis was used to analyse the content of narrative documentation. For the purpose of this study structured data was coded to the following variables: de-identified patient id (created for the study), counseling time by shift (morning/evening/night) and personal type (registered nurse/primary nurse/other).

Coding and analysis of the narrative documentation was performed independently by two researchers familiar with nursing practice and documentation. The disagreements (n=26) in coding were resolved by referring to the original free text descriptions. The content analysis of the unstructured narrative supplemental documentation revealed two main categories (Medication counseling with interaction and medication counseling without interaction) and further 11 sub categories that described the content of medication counseling (Table 1). The major category 'medication counseling with interaction' refers to documentation of medication counseling that involves interaction with the patient. For example, if the patient and nurse conducted a discussion of the proper method for self-administration of the medication, this documentation was categorized as 'medication counseling with interaction. On the other hand, if a nurse was only delivering information regarding a medication to the patient without any verification of the patient's understanding of this information, this documentation was categorized as 'medication counseling without interaction'. All documentation entries were entered into the information system by the healthcare providing the counseling shortly after the intervention was performed.

Results

Documentation Patterns

The data (N=379) evaluated consisted of descriptions of medication counseling entered in an electronic record in both structured and narrative formats. Medication counseling was

mostly provided by registered nurses (N=366). Only 13 other staff documented medication counseling in the record: primary nurses (n=10) and ward sisters (n=3). Counseling was documented only once for the vast majority of the patients (N=269), 74 patients had two documentation entries, of medication counseling 20 had three, 9 had four, 4 had five and 3 had six entries. Only one patient had seven narrative descriptions of counseling. Thus the average frequency for counseling documentation per patient was 1.4 per hospital admission. Counseling occurred mainly during the morning shift i.e. between 7 am and 3 pm (n= 283). Nearly 25% of the counseling (n=89) was provided in the evening before 9 pm, and 2% (n=7) during night shifts.

Unstructured Narrative Text Entries

In the category 'Medication counseling with interaction' the interactions with patients documented in the narrative text were mostly related to giving verbal instructions. Those counseling descriptions containing interaction could be differentiated into the categories: discussion (n=19), refresher/repetition (n=13) and side effects (n=9). Patient participation such as practicing was also used when educating patients to give injections for themselves. Those descriptions also contained assessment of the teaching success (e.g. *"injection succeeded").* When patients were given instructions verbally or given printed teaching material there usually were also narrative documentation regarding the patient's interaction with the nurse (n=30). For instance there were narrative documentation entries regarding changes in timing or dose or nutrition.

In the category Medication counseling without interaction the most often used method for counseling was giving verbal instructions when administering medication to patients (n=95) as shown in Table 1.

When administering medication verbal instructions contained descriptions regarding the dose, timing, route and the purpose of the medication. However, the descriptions of medication counseling did not contain any descriptions of the feedback from patients. Nurses documented using a variety of teaching materials with counseling leaflets being the most common. Many of these descriptions (n=47) did not have any information about patients reactions or comments.

Table 1- The contents of unstructured text and their frequencies complementing the use of FiCNI code Medication counseling (n=379)

Medication Counseling with Interaction	
Verbal instructions and written material	30
Practice and assessment	26
Verbal instructions - discussion	19
Verbal instructions - refresher	13
Verbal instructions - side effects	9
Demonstration and assessment (discussion)	1
Total	**98**
Medication Counseling Without Interaction	
Verbal instructions - medication administration	95
Written instructions: manuals, leaflets, other written material, video	47
Diary	6
Practice	5
Demonstration	1
Total	**154**
No narrative content	**127**

Discussion

Medication Counseling

The creation of categories to describe free text narrative entries analyzed in this pilot study were intended be very discrete to be able to differentiate the narrative descriptions of counseling methods. The categorization may have resulted in some overlapping between the categories *written instructions* and *verbal instructions with written material* due to some short narrative free text descriptions. The distribution of medication counseling with and without interaction as a result of the content analysis was a little surprising. However, based on the results it was obvious that a lot of teaching material is given to patients without any description of patient's learning outcomes in the records. The frequencies of documentation entries in the two categories counseling with interaction and counseling without interaction were eminent. They revealed that a lot of counseling is performed without any documentation of feedback from patients. We were unable to determine from the data whether the counseling occurred near discharge, an important time for counseling based on previous studies [1].

The most often used counseling method was discussion with patients i.e. giving verbal instructions when administering medication. However, medication administration should be interactive when possible and narrative entries related to counseling did not include any documentation of perceptions from patients. Friberg et al. (2006) in their study emphasizes the importance of the interaction between the patient and the nurse when delivering teaching material [3]. A variety of teaching materials such as manuals, leaflets and videos were also used when counseling patients. In this study the nurses had not documented any use of computerized or web-based material when counseling patients.

In this study, we found that the medication component was used for documentation of medication counseling in only 10% of the patient records in this surgical ward. It is not clear if this documentation is an accurate record of the frequency that medication counseling is actually occurring in this ward or if more counseling is occurring than is being documented. Counseling is a very demanding activity in hospitals due to the number of medications used in therapeutic treatment [13,15] and the amount of time needed to educate patients in their medication regimen [17]. Surprisingly, almost one third of the medication counseling documented did not have any narrative description. This may be due to an understanding among certain healthcare professionals as to standard and accepted content of medication counseling. Whether or not true the data does not support this argument. A better understanding of the reason for the lack of documentation would allow us to design either an educational intervention to encourage accurate documentation or an intervention to ensure that all patients are receiving medication counseling Previous studies suggest that medication education should be assessed to assure that patients receive appropriate medication education [3, 13]. Perhaps the addition of structured codes representing the content of counseling sessions would decrease the time necessary to document these actions and increase the rate in which nurses document counseling activities.

Additional FiCI Categories

According to previous studies nurses have a tendency to use the subcategories of the nursing classification in various ways. [12, 18] In this study nurses had also made narrative notes about medication care in *Activity* and *Health Behavior* components documentation section of the electronic record. Nurses also gave information to patients concerning side effects of medication therapy using the medication counseling code. In the FiCNi classification the medication component has a structured code for side effects. Thus, these descriptions should be additional information to documentation using the side effect code.

The data for this pilot study were collected only from one surgical ward. Thus, the results only reflect the situation in one hospital ward. However, the data provided a good opportunity to analyze counseling methods used by nurses. The use of a nursing classification in this electronic medical record is also available for physicians. These data only represent nursing staff using the platform for documenting medication counseling. Pharmacists being an important group regarding knowledge in medication therapy did not participate in this hospital in the medication administration process. Increasing the use of this portion of the record for documentation of medication counseling by other healthcare professionals would increase our ability to monitor this interventions and its impact of patient care.

More data is needed to make accurate recommendations for potential additions to FiCNI codes for medication counseling. However, it seems that those counseling methods containing interaction with patients: verbal instructions with discussion, refresher, and use of written material could be potential additional codes in the future. The most natural and beneficial time for counseling might be when administering medication to patients. Increasing the use of and documentation of medication counseling with patient interaction could increase medication safety and patient satisfaction. For example, patients need practice and nursing feedback to adequately learn to give themselves injections. This could happen after a nurse's demonstration during the medication administration process. The option for patients to keep a diary and get feedback from the healthcare provider is another potential addition to structured codes that might be added to the category of medication counseling in the future.

Conclusion

The narrative free text analyzed in this study suggested the need for additional structured codes be added to the FiCNi component for medication counseling. The structured coded subcategories would help nurses document more precisely the content of nursing activities in medication care. More research is needed to test the validity of the subcategories prior to implementing them as a part of medication component and medication counseling category of the FiCNI.

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HL7 CDA Implementation Guide for Structured Anatomic Pathology Reports Methodology and Tools

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Abstract

Anatomic pathology reports (APR) provide diagnostic and prognostic information crucial to patient care, clinical research and epidemiology. Currently, it is difficult to collect and exchange APR data between different healthcare organizations at an international level. Objective: IHE and HL7 anatomic pathology joint efforts aim at providing a methodology and tools to define an international HL7 "Clinical Document Architecture" (CDA) implementation guide for APRs and especially in the domain of cancer. Methods: A four-step methodology is employed, consisting of comparing existing clinical model of APRs originating from different countries; deriving consensus-based clinical models (Delphi technique); providing the corresponding HL7 CDA implementation guide ("CDA templates") and validating these templates. Results: International experts defined HL7 CDA implementation guides for breast and colon cancer APRs within an IHE content profile. CDA templates include required data elements, as well as optional ones, that can be further specified as required in national extensions. Conclusion: This study demonstrates that it is possible to define an international HL7 CDA implementation guide for cancer APRs. Further efforts are needed to provide CDA templates for approximately 60 other cancer APRs dedicated to different organs, diagnoses, and procedures as well as for APRs of non neoplastic pathologies. The methodology is not confined to APRs and could be applied to clinical documents of any type.

Keywords:

Anatomic pathology reports, Synoptic reports, Cancer checklists, Structured reports, Structured data entry, Delphi method, IHE, HL7, CDA.

Introduction

Anatomic pathology reports (APR) document the pathologic findings in specimens removed from patients for diagnostic or therapeutic reasons. This information can be used for patient care, clinical research and epidemiology. Currently, APRs for cancer patients have generated the greatest need for the collection and exchange of data contained in APRs, and many organizations have created templates in an effort to standardize APR reporting. The heterogeneity of such templates and lack of standards for structuring the relevant data elements in reports, hamper the exchange of this information among different information systems and healthcare organizations. Standardizing and computerizing APRs is necessary to improve the quality of reporting and the exchange of APR information[1].

As part of joint IHE and HL7 anatomic pathology activities, our objective is to provide a methodology and tools that facilitate the development of international clinical models for APR, including cancer APRs, as well as the production of the corresponding HL7 CDA implementation guides (CDA templates).

Several studies provide recommendations that delineate the required, preferred, and optional elements which should be included in any APR, regardless of report types (e.g reporting guidelines in[2].

Several international initiatives intend to define standard clinical models for specific types of APRs. For example, in the cancer domain, in the United States, the CAP (College of American Pathologists) has published 67 cancer checklists and background information[3]. In France, the SFP (French society of pathology) has published 23 minimum data sets for 21 cancer locations[4]. Together, the recommendations for generic and specific APR reporting have become clinical guidelines, the use of which may be required by accrediting bodies. The majority of encoded elements of these clinical models are associated with encoded value sets. The most frequently used coding systems in anatomic pathology domain are SNOMED Clinical Terms®, ICD-O-3 and ADICAP in France [5].

Since these standardization efforts are conducted at a national level there are some discrepancies between clinical models across countries and even some heterogeneity between clinical models within the same national initiative. There is a need to propose a methodology and tools to achieve better consistency of clinical models at an international level. There are several methods to achieve consensus-based agreement among experts. One such method is based on Delphi technique: a sys-

tematic, interactive forecasting method that relies on a panel of independent experts[6].

In addition to standardizing the cancer APR contents, it is necessary to computerize them. Several studies have focused on defining an appropriate IT standard comprising the structured and encoded clinical documents (e.g. CAP eCC). HL7 CDA is one of the most reliable standards that can support these needs[7]. CDA allows the clinical data to be both human and machine-readable and provides a framework for incremental growth in the granularity of structured, codes-bound clinical information. However, there are currently very few national initiatives of CDA implementation guides for the APR, one example being developed at the National IT Institute for Healthcare in the Netherlands, another one by HL7 Germany[8].

Materials and Methods

We followed a 4-steps methodology to define an HL7 CDA implementation guide for APR:

Step 1: Defining clinical models for APR (structuring and standardizing APRs medical content)

Clinical models for APR should address all Anatomic Pathology reporting domains such as surgical pathology, cytology, autopsy and even research (e.g. molecular biology or tissue micro arrays (TMA)). In order to ensure consistency among clinical models, we first defined a set of constraints that apply across all APRs regardless of domain. We then further identified the set of constraints that apply across all **cancer** APRs.

Generic clinical model for APR

Based on analysis the available recommendations that outline elements which should be included in an APR regardless of report types [2], we identified the sections of the generic clinical model for APR.

Generic clinical model for cancer APR

Based on the recommendations[2], specific to cancer APR, we defined sub-sections specific to the generic clinical model for cancer APR [2]. Then, based on comparison of the existing organ/diagnosis/procedure specific cancer checklists as defined by the CAP and by the SFP, we identified the elements that were most frequently present in the various organ/procedure specific checklists.

Organ/diagnosis/procedure specific clinical models for cancer APR

Based on the generic clinical model for cancer APR, we created organ/diagnosis/procedure specific clinical models. We merged the CAP and SFP checklists keeping a single occurrence of each common data element, and flagged the other elements with the name of the source template.

Step 2: Validating clinical models for APRs

Consensus sessions were organized by IHE and HL7 Anatomic Pathology workgroups and European COST action IC0604 in order to validate the clinical models for cancer APRs. A panel of experts first agreed on the sections of the generic clinical model for cancer APR during two face-to-face meetings. In France, two online questionnaires were published in order to evaluate discrepancies between CAP and SFP cancer checklists for breast cancer and colon.

According to the Delphi method, after the first survey round, a facilitator provides an anonymous summary of the experts' responses with their comments, in order to decrease the range of answers in the second round. After achieving the consensus or stability of results the mean or median scores of the final rounds determine the results.

Step 3: HL7 CDA implementation guide for APRs

HL7 CDA Release 2.0 provides a general architecture for designing and implementing clinical documents in an electronic format that is both human and machine-readable. Because of the architectural nature of the CDA standard, individual implementations are always associated with an implementation guide (also called "HL7 CDA template"), i.e. a document that describes how the CDA standard should be implemented for a particular type of document used in a specific context. A CDA document begins with a header that states the context of care in which the document was produced, identifies the various participants involved (patient, care providers, devices, etc) and states the responsibilities regarding the content of the document. The body of the document can be organized as a hierarchy of sections. Each section lays out its text for the reader, and may in addition carry fine-grained coded machine-readable data, corresponding to that text. We mapped the various roles of professionals involved in an APR to header elements. We then defined body sections, and assigned each section a unique code, a title and a text block. Finally, we coded the fine-grained machine-readable data into entries attached to the sections. Codes have been assigned to sections and to the various entry elements (acts (observations, procedures, etc), entities (specimen)) carried within the entries.

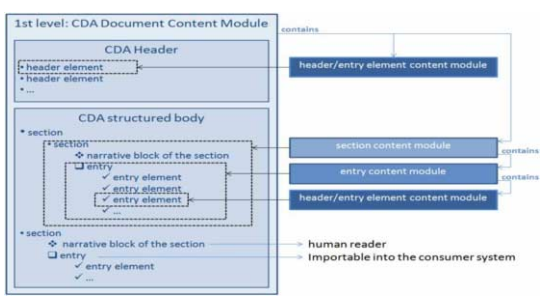

Figure 1- Hierarchical organization of CDA R2 content modules

Vocabulary domains provide value sets for coded CDA components. Some of these vocabulary domains are internally defined by HL7 V3. Others are drawn from external coding systems such as LOINC or SNOMED CT. Whether internal or external, every vocabulary domain has a unique HL7-assigned identifier (HL7 OID which is an ISO object identifier), and every concept within a vocabulary domain has a unique code and an associated display name in a given language. For some of the CDA components, the vocabulary domain is imposed by the standard. For others, the implementer is free to choose

from any relevant external source, such as LOINC, SNOMED CT or some other realm-specific vocabulary. For example, the possible values for the observation "histological type" in CAP cancer checklists are encoded using SNOMED CT values sets, while in France, SFP cancer checklists these values are encoded using ADICAP or ICD-O-3 values sets.

All the operations described above have been eased by the reuse whenever possible of relevant templates for CDA elements that had formerly been defined by the Patient Care Coordination (PCC) and Laboratory (LAB) domains of IHE.

Step 4: Evaluating HL7 CDA implementation guides

The good practice in building HL7 CDA implementation guides is driven by this key principle of the standard – "*one single xml schema CDA.xsd for all types of clinical documents*" – Therefore, like all other CDA implementation guides, this APR CDA implementation guide relies on the original CDA.xsd schema, unchanged. The set of templates that compose the implementation guide express constraints restraining the options allowed by the original CDA.xsd schema, and binding its coded elements to predefined value sets.

These constraints are expressed in formal language within the implementation guide, and will also be translated as assertions into a schematron file[9]

From that point, the process of evaluation of the implementation guide will consist in three steps:

a) Build a collection of APR instances conforming to the implementation guide, with a clinically relevant content provided by the domain experts (pathologists and clinicians).

b) Validate each APR instance against the standard CDA.xsd schema.

c) Validate each APR instance against the templates, applying the schematron file of assertions expressing the constraints of these templates.

Results

Clinical model for Anatomic Pathology Report (APR)

The generic clinical model for APR is structured into six sections; three required sections (Clinical Information, Macroscopic Observation and Final Diagnosis section), one conditional section (Intra-operative Observation) and two optional sections (Microscopic Observation, Tissue Dissection and Ancillary Tests). We defined additional constraints for the generic clinical model for cancer APR.

Table 1 summarizes the six sections and the corresponding sub-sections and entries of the generic clinical model for cancer APR (entries specific to cancer as designated by the * symbol).

In addition, two clinical models for organ-procedure specific cancer APRs (breast and colon) constraining the generic cancer model were defined. Following the consensus sessions conducted in France, SFP cancer checklists were aligned to the corresponding CAP cancer checklists in order to be defined as French national extensions of these CAP checklists.

Table 1- Sections, subsections and entries of the generic clinical model for cancer APR.

Generic cancer APR sections	Generic cancer APR sub-sections/entries
CLINICAL INFORMATION Clinical information provided by the ordering physician: reason for anatomic pathology procedure, active problems (preoperative and/or postoperative diagnosis, lab data), collection procedure(s) and specimen description(s) for all delivered specimen(s) reported separately.	**Reason for AP procedure** **History of present illness** **Active Problems** **Specimen clinical information entry** • Specimen Information Organizer o Collection procedure o Specimen(s) type o Specimen location
INTRAOPERATIVE EXAMINATION (conditional) Intraoperative diagnoses +/- images for all delivered specimen(s) reported separately.	**Intraoperative entry** • Specimen Information Organizer o Diagnostic observation o Link(s) to images
MACROSCOPIC OBSERVATION Collection procedure(s) and specimen description(s) (if not provided by the ordering physician), +/- gross findings +/- images for all delivered specimen(s) reported separately.	**Macroscopic observation entry** • Specimen Information Organizer(s) o Collection procedure o Specimen type o Diagnostic observation(s) o Link(s) to images
MICROSCOPIC EXAMINATION (Optional) Histopathologic findings (e.g results of histo-chemical and immunohistochemical stains) +/- images for some delivered specimen(s) reported separately.	**Microscopic observation entry** • Specimen Information Organizer(s) o Diagnostic observation (s) o Link(s) to images
DIAGNOSTIC FINDINGS Diagnoses +/- additional pathologic finding(s) +/- results of ancillary studi(es) (=cancer checklist(s), in case of cancer) +/- images for all specimens delivered, reported separately.	**Diagnostic findings entry** • Specimen Information Organizer(s) o Tumor location* o Tumor histologic type and grade* o Tumor extension (including pT, pN)* o Treatment effect o Additional findings o Results of ancillary techniques o Link(s) to images
TISSUE DISSECTION AND ANCILLARY TESTS (Optional) Tissue dissection (representative specimens and derived specimens dissected for other ancillary procedures (flow cytometry, cytogenetics, molecular studies, electron microscopy, etc) or biorepository) for all specimens delivered, reported separately.	**Tissue dissection and ancillary tests entry** • Specimen Information Organizer(s) o Dissection technique o Specimen type o Ancillary technique

HL7 CDA implementation guide for APR

HL7 CDA implementation guide for APRs consists in a set of CDA templates described within the IHE Anatomic Pathology content profile "Anatomic Pathology Structured Report" available on the IHE web site[10].

With regards to the header, we have defined the content modules representing the various participants involved in the documented act, and/or in the production or stewardship of the APR.

With regards to the body, we first defined CDA templates for the six sections (Clinical Information, Intra-operative Observation, Macroscopic Observation, Microscopic Observation, Final Diagnosis section, Tissue Dissection and Ancillary Tests). Each section (e.g "Clinical information") is provided with a unique code, a title, a free text zone, the description of sub-sections (e.g "Reason for anatomic pathology procedure") and entries (e.g "Specimen Clinical Information") as shown in Figure 2.

We then defined CDA templates for entries. Each entry (e.g "Specimen Clinical Information") contains a unique code and the description of the embedded entries or entry elements (e.g "specimen collection procedure", "effectiveTime" or "targetSiteCode"). One or more organizer may be used according to the number of specimens to which information is attached to. Each organizer allows identifying one specimen and describing its related acts (observation, procedure…).

```
<component>
 <section>
   <templateId root='1.3.6.1.4.1.19376.1.8.1.2.1'/>
   <code code='22636-5' displayName=Pathology report
relevant history' codeSystem='2.16.840.1.113883.6.'
codeSystemName='LOINC'/>
   <title>Clinical information</title>
   <text>
   Excision biopsy of the breast. Nodule of 1cm,
upper inner quadrant of right breast.
   </text>
    <entry>
     <!--Specimen Clinical Information-->
     <templateID root='1.3.6.1.4.1.19376.1.8.1.3.1'/>
      <!--Information related to 1st specimen-->
       <organizer classCode="CLUSTER">
       <templateId root='1.3.6.1.4.1.19376.1.8.1.4.4'/>
        <!-- Specimen collection procedure -->
        <component>
         <procedure classCode="PROC"moodCode="EVN">
           <templateId
root='2.16.840.1.113883.10.20.15.3.2'/>
            <code
code='277261002'displayName='Excision Biopsy'
codeSystem='2.16.840.1.113883.6.96'/>
          <effectiveTime><!--collection date&time-->
          <high value="201012150935"/>
          </effectiveTime>
          <targetSiteCode code='76752008'
displayName='Breast'codeSystem='2.16.840.1.113883.6.
96'/>
         </procedure>
       </component>
      </organizer>
       ...
    </entry>
    <component>
       <section>
          <templateId root='1.3.6.1.4.1.19376.1.8.1.2.1'/>
          <code code='34122-2' displayName='Reason
for referral' codeSystem='2.16.840.1.113883.6.1'
codeSystemName='LOINC'/>
          <title> Reason for anatomic pathology pro
cedure</title>
          <text>
Nodule of 1cm, upper inner quadrant of right breast.
         </text>
       </section>
    </component>
  </section>
</component>
```

Figure 2- CDA template of the section "Clinical Information"

With regards to the encoding process, in order to maintain different value sets derived from different coding systems, we have used the capacity of HL7 CDA to express any encoded element as two or more equivalent codes derived from different vocabularies (coding systems).

HL7 CDA implementation guide evaluation

A collection of APR instances of cancer APRs, including breast and colon cancer APRs, was built conforming to the implementation guide and validated against the standard CDA.xsd schema.

Discussion

Based on different initiatives for standardizing Anatomic Pathology structured Reports (APR) and as part of joint IHE and HL7 Anatomic Pathology activities, international experts defined an HL7 CDA implementation guide for structured Anatomic Pathology reports and in particular cancer structured reports. In order to ensure consistency, the organ specific HL7 CDA templates are based on a common generic template, including the constraints that apply across all APR regardless of the reporting activity, procedure, diagnosis or organ. Subsequent templates would aim to maximize the reuse of the data elements across templates whenever possible.

HL7 CDA templates support semantic interoperability of clinical data that are both human readable and machine-processable and that can be stored in databases to be further queried or mined. Furthermore, filtering algorithms may be applied on machine-processable data elements of HL7 CDA templates in order to exploit different clinical information according to different contexts of use (patient care or research).

Medical consensus is not easy to achieve at regional, national, and international levels on important features that should be reported, as well as the vocabulary or coding system to use. Although there were many similarities between, for example, the CAP and SFP cancer checklists for breast and colorectal cancer, it was impossible to achieve exact mapping between them. We found discrepancies in comparing value sets of encoded elements. Furthermore, common data elements may be encoded using different reference terminologies (e.g some data elements are encoded by CAP using SNOMED CT, while they are encoded using ADICAP or ICD-O-3 by SFP in France).

More generally speaking, due to frequent changes in the value sets, the use of ISO/IEC 11179 (Information Technology -

Metadata registries) has been proposed to allow report senders to reference externally accessible metadata dictionaries for each data element. Given the current development of various vocabulary server projects (such as the Distributed Annotation System (DAS) Server[11], LexGrid [12] and Common Terminology Services (CTS2); an additional attribute specifying the communication method with the referenced server would be necessary.

Given this issue of value set variability across countries and over time, it may be necessary to provide access to the entire current available value set for each data element. Ideally, the upcoming versions of the CDA standard would provide an attribute for directly referencing an externally accessible local (or a global) vocabulary server for each coded data element, thereby allowing the recipient of the report to query the sender's vocabulary server for a data element description and a value set belonging to the unique id of the given data element. Additionally, standardized methods for capturing form rules governing dynamic data element availability and values within the current template instance (for example using XForms) would need to be investigated and agreed upon by experts for each template, allowing for consistency across various laboratory information systems. The most appropriate method to ensure the intended layout and appearance of the transmitted report remains to be identified.

This study demonstrated that it is possible to define international IHE content profiles for both a generic cancer APR and organ/procedure specific cancer APR and to derive from these HL7 CDA international implementation guides, national extensions taking into consideration national or local constraints (e.g. local coding systems).

With regards to the evaluation step, our perspective is to make a broader use of schematrons. This rule-based validation language for making assertions about the presence or absence of patterns in XML trees is currently used to validate each APR instance only against the CDA schema. We plan to validate instances against specific APR templates, applying the schematron file of assertions expressing the constraints of these templates. Furthermore, the successful tests of the content profile at IHE Connectathons could attest the quality of the CDA templates. At last, only their adoption in real world implementation will attest their relevancy.

Further efforts are needed to provide implementation guides for the remaining organ-specific cancer APRs and also for APRs of non-neoplastic pathologies.

It is necessary to develop a tool that automates and supports the modeling process in order to cover all cancer domains in an acceptable period of time.

One of the crucial issues is not only to guarantee the consistency between APR templates at an international level but also to ensure their consistency with other clinical domains such as IHE Laboratory or Patient Care Coordination. The on-going international effort aimed at providing world-wide template repositories will allow the reuse of previously defined templates in order to avoid duplication of data elements across domains and to save time and effort[13].

The modeling methodology in its three phases of consensus achievement, modeling, and evaluation could be applied not only to the other organ/procedure specific APRs, but also to clinical documents of any type. The topic has now emerged as an important area of standards development, and a useful focus for international cooperation[14].

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Peri-operative Communication Patterns and Media Usage — Implications for Systems Design

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Abstract

Inter-hospital communication amounts for a great deal of clinicians' work time. While communication is essential to coordinate care, it can also be time consuming and interruptive, and breakdown in communication is an important source of medical errors. One contributor to the interruptive nature of communication is the use of synchronous media, and there is clearly a potential for novel technologies. To assess communication patterns and media usage we performed an ethnographic field study in the peri-operative environment at a Norwegian hospital, as well as interviews with nurses. We analyze the results with regards to choice of media, characteristics of the conversations taking place and meta-messages, and account for addressing, obtrusiveness and information richness in the message exchanges. We find a relative high degree of interruptiveness in communication, and ascribe it to 1) a lack of situational awareness between locations in the peri-operative domain, as well as 2) use of synchronous media. This suggests that design of novel technology for intra-hospital communication should aim at supporting sender-receiver awareness and signaling of availability.

Keywords:

Communication, Hospital communication systems, Qualitative research

Introduction

The amount of time spent communicating in health care is vast and still expanding [1, 2]. While communication is essential to coordinate care, it can also be time consuming and interruptive [3, 2], and breakdown in communication is an important cause of medical errors [4]. Contributing to the interruptive nature of the communication are the use of synchronous media, such as telephone and pager, and the lack of situational awareness (i.e. sender is not aware of where the receiver is or what she is doing).

For the purpose of this paper we broadly divide intra-hospital communication into two main categories: 1) clinical problem solving, and 2) coordination. (Of course, the communication serves several other more social and play related purposes, less directly work related but not necessarily less important.)

We use clinical problem solving to denote communication regarding diagnoses and treatment plans. Aimed at problem solving and decision making, this form of communication often go on for an extended period of time, and is sometimes iterative in nature (i.e. diagnoses can be changed, new treatments tested). While less rigid, this process is similar to scientific inquiry, and communicative challenges are related to sharing of complex information, documenting the clinical reasoning process, negotiating and supporting organizational memory [5].

While clinical problem solving is a ubiquitous process, which might occur anytime (it is not uncommon, for instance, that surgeries reveal physical findings which prompt new diagnoses), given the scope of this study we are more concerned with communication related to coordination. This form of communication is usually more immediate, and the need for support of organizational memory, documentation and storing of information is less pronounced. However, coordination-related communication brings its own set of challenges: due timing of messages; level of obtrusiveness; and sender-receiver awareness and feedback.

Our study is concerned with the communication patterns in the so-called peri-operative domain. Peri-operative refers to three phases: pre-operative, intra-operative, and post-operative. It starts when a decision is made to operate on the patient, and terminates with the resolution of the surgical sequelae [6]. Through a qualitative analysis, we aim to characterize the communication patterns in the peri-operative domain, and to identify areas where novel communication technologies can play a role, as well as central requirements for design of such technologies.

Background and framework

Coordination and articulation work

Coordination can be viewed as the problem of managing interdependencies between activities performed to achieve a goal [7]. The resulting joint activities are in a sense "created from the goal backwards" [8].

For each actor to be able to plan and perform his actions optimally he needs to know his team members' goals and actions. In aviation the concept of *situational awareness* has been used

to analyze accidents and improve safety, and in later years the concept has been adapted in health care. Simply put, situational awareness is the shared understanding of what is going on now, as well as what is going to happen next [9]—a prerequisite for successful coordination. To achieve an acceptable level of situational awareness each actor must ensure that his actions and plans are shared with other members of the team, and he must ensure that he himself obtains relevant information about the plans of others. This *articulation work* [10] increases when the cooperative work lacks a well-defined point of control, which is usually the case in hospital work, where the participants must themselves ensure that their combined efforts result in the desired outcome. Each participant's actions must be articulated, communicated and negotiated with the other participants (*ibid.*). Managing the distributed nature of cooperative work, in short, takes a lot of work.

Media use and communicative strategies

The nature of health work necessitates complex communication, using different media. Often the communication is characterized by a high degree of cognitive complexity, and the communicative process itself might represent several challenges (time constraints, changes during the conversation, dependency on feedback). Te'eni [11] presents several proposals about communicative strategies and choice of media in different situations. Harr and Kaptelini [12] provide an analytical tool for analyzing interruptions in social contexts and show how interruptions often spread in organizations with a ripple effect.

Communication as social action

In addition to the obvious practical reasons for intra-hospital communication, any use of language also acts on a social level. This dimension also impacts the more instrumental uses of language and needs to be accounted for, for instance with regards to choice of media, i.e. how much bandwidth a media has for this contextual information.

Conversation analysis and interactional sociolinguistics perceive language as socially structured, with set patterns, independent of the linguistic content. Pauses, overlappings, tone of voice, and gestures—meta-messages—are seen as highly relevant aspects of a conversation which must be considered in addition to the pure linguistic exchange [13].

Analytical framework

Reflecting a hierarchy of granularity, we distinguish between three types of communicative acts.

- Conversations
- Messages
- Meta-messages and cues

Our framework draws from discourse analysis, which itself encompasses a variety of analytical approaches (*ibid.*). While our definitions of conversation and message might overlap with existing concepts, they are here defined in a way we deemed useful for the analysis of this particular domain. Our definition of meta-messages is congruent with its use in pragmatics [14].

Conversations constitute the macro level, the on-going message exchange that takes place in intra-hospital coordination and medical problem solving. In principle, a conversation could span anything from seconds to years, but in our case we focus on the more immediate conversations with a shorter time span.

Messages are the building blocks of the conversation and are associated with some media used for exchange (i.e. telephone, face-to-face encounters, email). Messages are exchanged in a typical turn-taking fashion, where sender and receiver alternate between interpreting and constructing messages.

Meta-messages and cues (ibid.) are any contextual information that adds meaning to the messages and conversation. Meta-messages can be purely linguistic (i.e. an ironic email), or they can be extra-linguistic and conveyed through tone of voice, gestures, facial expressions, etc.

In addition we have identified three aspects of particular interest in message exchange in health care:

- *Addressing.* Strategies used to find and deliver the message to the right person, group or role.
- *Obtrusiveness.* The degree to which the sending of a message interrupts the receiver.
- *Information richness.* The degree of contextual information associated with a message. Ideally, the message should convey enough information to enable the receiver to interpret it without having the spend time asking for clarification or consulting other sources, but not so much information that the receiver have to filter out superfluous information.

Materials and methods

Study design and setting

We conducted a non-participatory qualitative observational study at a Norwegian University hospital in the winter of 2009. Three observations were performed over different days, for 16 hours taken together. Two of the observations were performed in the operating theatre, while one was conducted as a shadowing of the patient in the peri-operative environment. This involved following the patient from preparations done in the ward, through to surgery and admission to the recovery.

The observations were based on ethnographic methods adjusted for requirements engineering for IT systems—so called *rapid ethnography* [15]. This involves more structured and focused observations than in traditional ethnography (*ibid.*). Data from the observations were recorded using free text notes. In addition to the observations we performed two semi-structured interviews with operating nurses, which each lasted about half an hour.

The observations were performed by one of the authors. To ensure a correct understanding, the clinicians were inquired for clarifications when appropriate during the observations. We also presented some of our preliminary interpretations during the interviews to ensure their validity.

Ethical considerations

The study design was approved by the Norwegian Regional Committees for Medical and Health Research Ethics, and the Norwegian Social Science Data Services. To protect the participants in the study, the data was de-identified and stored securely. Informed consent was collected from the participants.

Results

The peri-operative domain

Our observations are limited to the different procedures during the day of an operation—i.e. they do not necessarily cover the full length of the pre- and post-operative phases, which might extend outside the realms of the hospital and for a period longer than a day. The pre-operative phase corresponds to preparations done to the patient at the ward (typically physical examinations, confirming that the patient has not eaten, and premedication for anesthesia). The inter-operative phase starts when the patient is moved to the operating room, and the post-operative phase starts when the patient is moved to the recovery ward.

As we see, the phases have spatial boundaries that involve moving the patient to different locations in the hospital. At the hospital where we conducted our observations, the wards, the operating room and the recovery ward were located in separate places in the building and on different floors. This contributed to reducing the spatial awareness of the peri-operative process as a whole, as well as to the use of communication media like telephone and intercom to facilitate coordination.

Typically, an operation would have its immediate center of control in the operating room. Surgeries were scheduled with date and time, so each of the three locations corresponding to an operative phase (ward, operating room, and recovery ward, respectively) would have an idea of what would take place when, and this facilitated what we might call implicit coordination.

The transition between the operative phases still had explicit markers. Staff at the operating room would notify the ward when it was time to pre-medicate the patient, and when the surgery was about to end the staff would likewise notify the recovery ward that the patient would soon arrive. The phases were further distinguished by handovers between the different locations: Before surgery, staff from the ward transported the patient to the operating ward; after surgery, staff from the operating theatre transported the patient to the recovery ward.

Conversations, messages and meta-messages

Conversations in the peri-operative domain were predominantly concerned with coordination. Communication regarding medical problem solving did still occur, though, in one of two ways: 1) Either as informal information exchange between clinicians regarding patients they were responsible for, as when one operating surgeon inquired the assisting surgeon about the condition of a patient who had been operated the previous day, or 2) arising as a consequence of an unexpected medical event. During one of the surgeries a bile leak occurred, prompting the clinicians to engage in conversations regarding the cause, as well as conversations coordinative in nature to correct the condition.

In general though, the conversations were of a coordinative nature, with content of limited complexity, and of short duration. Often conversations consisted of no more than notifications or prompts—one message and its acknowledgement, as when one of the operating nurses called the ward to ask them to pre-medicate the patient. The level of meta-messages was in these cases restricted by the medium—telephone or intercom—leaving only the speech pattern and tone of voice to convey emotions.

Not surprisingly, the use of meta-messages was much more pronounced in the face-to-face communication, which took place inside the operating theatre. In this setting, the coordination was highly dependent on non-verbal cues, such as what personnel was in the room, where equipment was placed, etc. Many actions were carried out without being explicitly called for. In one instance, the surgeon entered the operating room and was dressed in his operating coat by a nurse before both of them proceeded to prepare equipment—without a word having been exchanged. The verbal communication had been replaced by a set of subtle cues related to their position in the room, bodily gestures and placement of objects.

Another occasion illustrates the importance of meta-messages in addition to verbal communication. When a piece of equipment broke down, a discussion between one of the nurses and one of the surgeons arose regarding the cause. Their opinions differed, and the nurse—while not willing to give in—softened the potential aggressiveness in her insistence using several meta-messages, such as self-directed irony and smiling (in all probability also reflecting the authority gradient between nurses and surgeons).

Addressing, obtrusiveness, and information richness

Communication between the different locations in the hospital was in general characterized by unspecific and what we shall call relayed addressing. In the pre-operative phase, personnel in the operating room usually communicated with the ward where the patient resided using telephone. This involved calling the coordinating nurse at the ward, whereupon he would relay the message to the personnel concerned. By assigning a nurse to the role of coordinator other staff members were alleviated from some articulation work, but a more direct addressing scheme would be technologically feasible and could free up personnel for more direct medical work.

Incoming messages to personnel in the operating room usually came through the intercom, broadcasting the message to all personnel in the room, while the anesthesia nurse usually was the one to reply since he was the one nearest to the intercom.

Lack of information richness was to a little degree perceived as a problem in this particular domain, which should not come as too big of a surprise given the relatively straightforward and simple messages exchanged. In conversations dealing with medical problem solving, adequate information richness in

messaging would be a more important requirement.

Our general impression was that the tolerance for obtrusive communication was high. Not uncommonly, the receiver of a message was interrupted in her work and had to use time to reengage in it. The media mostly used for communication—telephone and intercom—added to the problem of interruptions. Given the synchronous nature of these media, they are often convenient for the sender, who gets immediate feedback on her request—but correspondingly interruptive for the receiver.

The interviews with nurses confirmed the problems resulting from situational awareness. A common complaint was that they lacked an awareness of what was going on in other locations, and that agreements about handovers could lead to waiting and delays.

The lack of team situational awareness between sender and receiver in a conversation also added to the problem when using synchronous media. For instance, when telephoning there is no way for the sender to know whether she will interrupt the receiver. In some cases messages were delivered personally, in the sense that personnel entered the operating theatre to engage in conversations with the surgeons. While in one sense obviously intrusive, these occasions enabled the surgeons to signal their degree of availability, and this awareness enabled sender and receiver to negotiate and adjust the form of communication literally on the spot. Even though the degree of interruptions was high, this seemed to be integrated in the work routine and a taken for given.

Discussion

As our observations were restricted to the peri-operative environment, they cannot be generalized to intra-hospital communication as such. Still, there is reason to believe the coordination problems of the peri-operative domain, and the message exchanges it prompts, are common also in other areas of the hospital. The peri-operative domain represents a scarcity of resources (rooms, equipment, and personnel), and work must be prioritized and coordinated so as best to utilize the resources available. This is similar to the situation in other domains in the hospital, like the emergency room or when using equipment and personnel for diagnosing (for instance X-ray examinations). However, the peri-operative domain is less representative of the medical problem solving communication, which is characterized by more complex conversations over longer periods of time.

To summarize our main findings:

- Physical dislocation results in lack of situational awareness in the peri-operative phase.
- The lack of situational awareness contributes to interruptions, since there is a lack of sender receiver awareness in message exchange.
- Addressing is often unspecific and relayed through several instances.
- Use of synchronous (i.e. interruptive) media is convenient for the sender, but often interrupts the receiver.
- The interruptive nature of communication seems to be accepted and integrated in the work process.

Reflecting on these findings, we think there is a potential for improving communication in the peri-operative (and similar) domains through use of novel communication technology. Problems regarding addressing and interruptions to a large degree stems from a lack of situational awareness. This could be alleviated either by enhancing awareness through changing procedures or the physical space, or by integrating a larger degree of sender-receiver awareness in communication technologies. Also, we believe that more asynchronous communication means could potentially be utilized to reduce interruptions. This is in accordance with earlier findings and recommendations [16- 18]. Again, a larger degree of sender-receiver awareness could potentially provide some of the current benefits of synchronous media also in asynchronous media. Lastly, one should keep in mind the importance of meta-messages in conversation, and we would caution against replacing information rich media or face-to-face communication with technologies that do not support the same bandwidth to covey meta-messages.

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Goal-based design pattern for delegation of work in health care teams

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Abstract

We show how a domain and language independent design pattern, defined as networks of tasks and goals, can be used to formally specify the transfer of responsibility and accountability when tasks are delegated in healthcare teams. The pattern is general enough to be applied unchanged across a broad range of different healthcare situations.

Keywords:

Clinical guideline, Goal, Design pattern, Medical error, Exceptions

Introduction

Clinical guidelines can contribute to the definition of better, safer, and more efficient evidence-based clinical care. Computer-interpretable guidelines (CIG) [1] can potentially increase the effectiveness of clinical guidelines by delivering patient-specific decision-support at the point of care. In general CIGs are defined in a particular language and lessons learned while developing them are difficult to share with groups working with other languages or different medical conditions. A possible answer is to specify generic solutions or *design patterns* [2] to recurrent common problems recognized in health informatics using a formal vendor-independent framework that allows sharing, reuse and study of patterns. The idea of creating a catalog of generic patterns that could be accessed and instantiated into particular problems using different languages has been previously suggested [3-5].

Healthcare processes, such as those modeled in clinical guidelines, are often carried out by teams. Incomplete or ambiguous specification of responsibilities and accountabilities in collaborative team work and the possible lack of accountability of medical staff working in shifts are important problems in healthcare [6, 7]. According to [8] "When delegating work to others, registered practitioners have a legal responsibility to have determined the knowledge and skill level required to perform the delegated task. The registered practitioner is accountable for delegating the task and the support worker is accountable for accepting the delegated tasks, as well as being responsible for his/her actions in carrying it out. This is true if the support worker has the skills, knowledge and judgement to perform the delegation".

In team work, delegation and assignment of tasks/goals is done based on the competences of the members of the team. During delegation, the responsibility for enacting a service and handling exceptions is passed from the requester (client) to a performer (provider); when the provider cannot cope with the exceptions he has to inform the client to transfer the responsibility. The accountability for the service outcome and exceptions arising during the service enactment is retained by the client [9].

We aim to tackle incomplete and ambiguous specification of responsibility and accountability in health care teams by formally specifying the transfer of responsibility and accountability in normal and abnormal situations during delegation of tasks/goals.

Methods

We formalize cooperative work in teams by extending a vendor-independent framework that we previously developed for specifying clinical design patterns [5]. We use the extension to define a generic pattern for delegation of tasks/goals that specifies levels of responsibility and accountability in normal and abnormal situations.

Framework for specifying design patterns for normal and exceptional behavior

In our framework [5] design patterns are specified as networks of tasks and goals (collectively termed "keystones") connected by scheduling constraints based on Petri Nets: all the incoming keystones need to be completed to enact the out coming keystone (AND join), the execution of only one of the incoming keystones is required to enact the out coming keystone (XOR join), all the out coming keystones are enacted after the antecedent keystone is completed (AND split) and only one of the out coming keystones is enacted after the antecedent keystone is completed (XOR split). As in the PRO*forma* model [1], tasks can be *decisions, enquiries, actions*, or *plans* (careflows comprising activities and goals). Goals represent temporal patterns of state variables which should be *achieved* or *maintained*. When a goal is active, a decision-support system proposes from a repository one or more candidate plans for satisfying the goal. Once the plan chosen for achieving a goal has been completed the goal is still active and its *successCondition* is checked to see if it has been achieved.

The framework allows abstraction of recurrent domain-specific scenarios as patterns, as well as abnormal scenarios originating from domain-specific or generic medical errors. Deviations from the expected process are abstracted using hierarchical definitions in a catalog of state-based exceptions, such that an exception is triggered when the corresponding state occurs, activating a goal-based pattern which abstracts commonly used strategies for repairing or recovering from the detected error. These strategies include invoking exception-handling flows and suspending or discarding affected keystones. The suspended or discarded keystones can revert to their previous state only after the exception-handling flow is completed. Exceptions are classified as hazards or obstacles. A *hazard* corresponds to a state that can *potentially* produce harm to the patient and an *obstacle* corresponds to a state where nominal execution of the guideline is not possible, either because the task cannot be completed or if its completion is no longer beneficiary to the patient.

Extending the design-pattern framework by specifying roles and actors

We extend the framework of [5] by proposing four new types:

type Role= <name, competences, restrictions, constraints>

Name uniquely identifies the *role; competences and restrictions* are sets of keystones that the *actors* performing the *role* can and cannot perform, respectively; *Constraints* are predicates that an *actor* must satisfy to play a *role*. For example to play the *role* of general practitioner (GP) the role player must be a registered practitioner. Role competence of health professionals is regulated by statues and professional bodies.

type Actor= <name, roles, competences, restrictions, attributes >

The *name* uniquely identifies the *actor; Roles* are set of *role* names that the *actor* is playing; *Competences* and *restrictions* specify those different from the ones inherited from the roles played by the actor. The sets of competences and restrictions should be based on the *actor*'s attributes. For instance in general nurses are not allowed to provide service X but nurse Ana can do it because she has taken a recognised course. Finally the *Attributes* are set of predicates that can be used to check if the *actor* satisfies the *role*'s constraints (e.g., has_degree_GP) or to select the actor for service delegation (e.g., based on the attributes experience, other_medical_specialities).

The competence, accountability, and delegation of services for some health registered professionals are regulated by statutes and regulatory bodies. In the UK regulatory bodies include the Nursing and Midwifery Council for nurses, midwives and health visitors, the Health Professions Council for physiotherapists, dieticians, speech and language therapists, and so on. Roles not regulated by statutes are accountable for their actions in three ways: civil law (duty of care), criminal law, and employment law. Therefore there are good sources of information that can be used to specify, in the way proposed above, the competences of the roles played by health care professionals. Once the *roles* and *actor* specifications have been completed the following functions can be used to determine (1) conflicts between two sets of competences and restrictions, (2) an actor's competence to perform a service (keystone), and (3) the set of actors who can provide a service for a client based on their competences and the client's constraints.

1. Boolean **function *areConflicting***(keystoneSet Compentences, keystoneSet Restrictions)=
```
{ If intersection (Competences, Restrictions)!=null
        then return true else return false;  }
```

2. Boolean **function *isCompetent*** (Actor actor, Keystone service)=
```
{ roleCompetences, roleRestrictions==emptySet;
 roles=actor.GetRoles() ;
  While roles!=null
  {  roles.GetFirst()=role;
     roleCompetences= union(role.GetCompetences(),
                                roleCompetences);
     roleRestrictions= union(role.GetRestrictions(),
                                roleRestrictions);
     roles.remove(role);
  }
allCompetences= union(roleCompetences,
                          ator.getCompetences());
allRestrictions= union(roleRestrictions,
                          actor.getRestrictions());
If not areConflicting(allCompetences, allRestrictions) &&
   allCompetences.contains(service) &&
   not allRestrictions.contains(service)
          then return true
          else return false;
}
```
An actor is competent to perform a service if and only if: there is no conflict between the restrictions and competences defined for actor and role, the actor is competent to perform the service (actor's and roles' competences satisfy the requirements for the service), and the service is not included in the actor's and role's sets of restrictions.

3. ActorSet **function *ObtainCompetentProviders***(Keystone service, Proposition constrains, ActorSet staff)=
```
{ providers=emptySet;
 While staff!=emptySet
 { staff.Retrieve()=staffmember;
   If isCompetent(staffmember, assignment) &&
      canSatisfy(staffmember, assignment, constraints)
         then
            providers.add(staffmember) ;
            staff.remove(staffmember);
  }
 return providers;
}
```

The function ***canSatisfy*** takes as arguments an actor, a service, and a constraint and it returns true if the actor can perform the service satisfying the constraints. Examples of constraints include time restrictions, place where the service should be provided, etc.

Each delegation starts with a service request:

type request = <client, provider, service, service type, satisfyCompletion, constraints>

Client identifies the agent that requires the service; *provider* corresponds to the agent that agrees to provide the service; *service* is the task that is assigned/delegated to the provider by the client; *service type* indicates the type of service requested and can take the values *assg, deleg, sdeleg* indicating assignment, delegation without supervision and delegation with supervision; *satisfyCompletion* is a function given by the client of an assignment to the provider to check if the service satisfies the client's criteria of service completion; *constraints* can be defined by the client to restrict the way the service should be provided. For instance the time constraint that the service should be provided in less than 3 hours.

If a provider accepts a service request a contract is defined:

type contract= < service request, startTime, finishTime>

Service request is the identifier of the service request that originated the contract; *startTime* is the date the contract starts; *finishTime* corresponds to the date the contracts finishes. Always *finishTime>startTime.*

Figure 1 shows the relationship between the new introduced types and the already existing types from the framework [5] used for the specification of the delegation pattern.

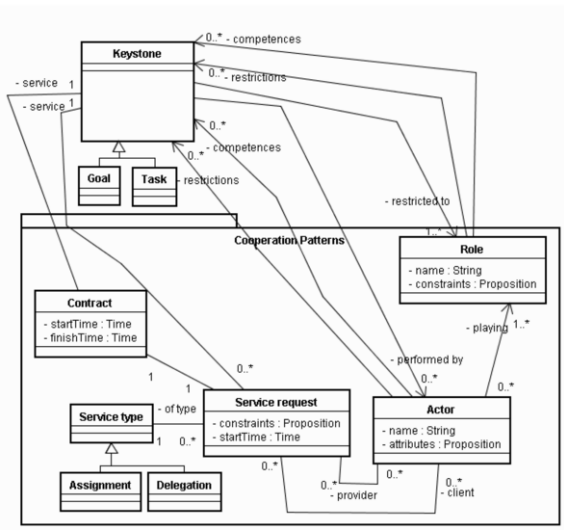

Figure 1- Class Diagram showing the connection between the terms used for the specification of the Delegation Pattern

Definition of service delegation

An actor called *client* delegates the enactment of a task or the achievement of a goal to a competent actor called *provider* such that:

Property 1. The provider is competent and responsible for providing the service.

Property 2. The client retains accountability for the service's outcome and any exceptions arising from the service enactment.

Property 3. The provider is responsible for handling any exceptions arising during the service enactment. When the provider cannot handle an exception the provider must transfer responsibility back to the client.

Property 4. The client is responsible for managing any exceptions that the provider cannot handle (whether detected by provider or client).

Design pattern for delegation of services

We define the delegation pattern based on formal approaches for delegation of tasks (services) between collaborative agents [10] from agent-oriented software engineering.

The delegation pattern is divided between the client's delegation workflow (Figure 2.1) and the provider's delegation workflow (Figure 2.2).

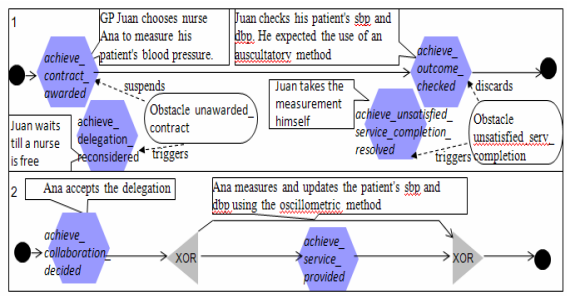

Figure 2- Delegation Pattern: 1) Client_delegation 2) Provider_delegation. In Figure 2.2 the first scheduling constraint corresponds to an XOR split, and the second constraint is an XOR join.

Table 1 contains the formal specification of the *Client_ delegation* workflow. As specified by the *precondition* of the client's workflow, a *service* can be delegated if the client has the competence to do so (according to function *isCompetent* the client can pursue the goal *achieve_ delegated*) and the service is not already assigned to another provider (there is no open *contract* and the service has not been requested according to *serviceRequest*). For instance the role general practitioner (GP) is competent to delegate the measurement of the patient's blood pressure to members of the hospital staff competent for that task, only if the same request is not being processed.

As shown in Figure 2.1 first the client tries to achieve the goal *achieve_contract_awarded*. For instance, the GP Juan can check the set of competent staff and delegate the task of measuring the patient's blood pressure to nurse Ana because she is available at the time he is requesting. In the exceptional case where no provider is willing to provide the requested service or a timeout has elapsed and no contract has been awarded, the discarding obstacle *unawarded_contract* is triggered, which discards the goal *achieve_contract_awarded* and triggers the

goal *achieve_delegation_reconsidered*. Thus Juan may decide to relax his delegation condition delaying the task to the first time when there is a nurse available.

In the best case a contract is awarded between client and provider (goal *achieve_contract_awarded*) and the client waits for service completion. In our example Juan can check the service completion by accessing the patient's record that contains the latest measures of the patient's systolic and diastolic blood pressure (sbp, dbp).

It may happen that after the provider has completed the service the client's criterion of service completion is not satisfied; in this case the suspending obstacle *unsatisfied_service_ completion* is triggered. For instance, Juan specified that he wanted to have his patient's blood pressure measured using the auscultatory method, but according to the patient's records the measurement has been done by an oscillometric method. The obstacle *unsatisfied_service_completion* suspends the goal *achieve_ outcome_checked* and triggers the goal *achieve_unsatisfied_ service_completion_resolved*. In our example Juan decides to make an appointment with the patient to take the measurement himself.

Client Juan is responsible and accountable for both exceptions *unawarded_contract* and *unsatisfied_service_completion* because they happened before and after the service enactment, respectively. If any exception had happened during the service enactment nurse Ana should be responsible for dealing with it.

The workflow *Client_delegation* is completed when the goal *achieve_outcome_checked* is achieved and, as described in Table 1, the contract between client and provider has been closed, and the client's completion criteria is satisfied.

Table 1- Client_delegation

Attribute	**Client_delegation**
Parameters	service, contracts, staff, preferences, isComplete, serviceRequests
Precondition	isCompetent(actor, achieve_delegated((service, contracts, staff, preferences))) & not contracts.contains(service, anytype, actor, anyProvider, start, null) & not serviceRequests.ObtainAll(). contains(this.GetActor(),anyProvider, service, anyType)
Success Condition	ObtainProviders(service,preferences,staff). contains(provider) & contracts.contains (service,deleg, this.GetActor(),providers,start, finish) & isComplete (service.GetSuccessCond())

We now turn to the provider's workflow in the delegation pattern (Figure 2.2). For the sake of brevity we do not provide the formal specification for the provider's workflow. The provider's workflow is activated when an actor receives a request for service delegation from a client and there is no contract between the client and any provider for this service. The provider decides whether he wants to collaborate, in which case he satisfies the goal *achieve_collaboration_decided*. If he does not want to collaborate the provider's workflow ends without activating the goal *achieve_service_provided*. For instance Ana receives a request from Juan to make an appointment to measure a patient's blood pressure at a time she is available. Ana is competent to perform the task so she accepts the appointment. If as in this example the provider accepts the *achieve_contract_awarded* is achieved, the provider's first goal is achieved and the provider's second goal *achieve_ service_ provided* is activated. The provider's workflow finishes when according to his completion criteria the service has been completed. The provider's criteria for service completion are not necessarily identical to the client's criteria for service completion. For example for Juan the blood pressure should be taken using an auscultatory method, while for Ana the task is achieved when any accurate measuring method is used. Because of possible differences between the client's and provider's completion criteria after the workflow *Provider_ delegation* has been completed the contract between client and provider is still open until the client checks that the service's outcome is the desired one (goal *achieve_outcome_checked*).

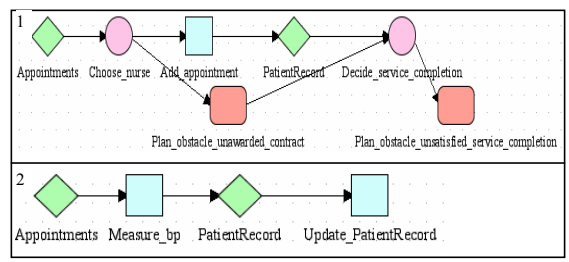

Figure 3 - Implementation of the delegation pattern in the Tallis toolset.

Results

Properties satisfied by the pattern

Property 1: In the case of the client the pattern is defined in terms of the goal *achieve_contract_awarded*. Therefore providing the service has not been assigned to anyone else, the provider is *competent* to provide the requested service and accepts the delegation (as specified by goal *achieve_ collaboration_decided*) then a contract is opened between them, which makes the provider *responsible* for providing the service.

Property 2: As specified by the delegation pattern, the goal *achieve_outcome_checked* is part of the client's workflow, therefore he checks that his completion criteria is satisfied after the provider has finished the delegated service. Only if the client's completion criteria are satisfied is the delegation contract between the client and provider closed. Because a delegation contract is signed between the client and the provider when the goal *achieve_collaboration_decided* is achieved, the client becomes *accountable* for any exception arising from the service enactment.

Property 3 can be proved only if the following property is satisfied by the catalogue of exceptions provided by the exception manager:

Property to be satisfied by the catalogue of exceptions: *Each exception from the provided catalogue is specified such that the actor responsible for meeting the goal that was triggered in order to handle the exception is the actor who enacted the keystones or goals that triggered the exception.*

For any catalogue of exceptions provided for the patterns this property must be checked.

Property 3: If the repository of exceptions satisfies the property explained above then the provider is responsible for enacting exceptions arising from the service enactment. But in case the provider cannot cope with the exception he can inform the client and transfer to the client the responsibility of dealing with the exception. A hazard can be triggered to inform the client about the exception and the recovery strategies that he has unsuccessfully tried.

Property 4: When the provider achieves the goal *achieve_exception_informed* the provider has been informed about the unresolved exception which arose during service enactment and responsibility for enacting a plan to recover from the exception has been transferred the provider. Once the provider has been informed about the unresolved exception he can activate the goal *achieve_exception_recovery_decided.*

Pattern enactment

Design patterns have proved to be very powerful generic and abstract mechanisms for software analysis, design, and comparison, provided they can be mapped to concrete executable languages. In Figure 3 we show an implementation of the delegation pattern in the Tallis[11] toolset used for enacting PRO*forma* guidelines. Each component from the delegation pattern is mapped into one or more Tallis components. Figure 3.1 corresponds to the *Client_delegation_pattern*. To pursue the goal *achieve_contract_awarded* the GP starts querying the existing appointments (query *Appointments*) and chooses an available nurse (decision *choose_nurse)* to delegate the task of measuring his patient's blood pressure. When a nurse is chosen a new appointment is created (action *add_apointment*). Both GP and nurse roles and the actors playing those roles are specified as described by the types *Role* and *Actor* that we introduced to extend the design-pattern framework. To satisfy the goal *achieve_outcome_ checked* the GP activates the action *check_patient_bp* after the appointment date. Possible exceptions are: the case when no nurse is free, which activates the plan *Plan_obstacle_unawarded_contract;* or the case when the service has not been completed according to GP's requests, which activates the plan *Plan_obstacle_unsatisfied_ service_ completion*. Figure 3.2 corresponds to the plan *Provider_ delegation_ pattern.* In this hospital the nurses cannot refuse to take appointments, therefore the goal *achieve_ collaboration_ decided* is always satisfied after the GP chooses a nurse. The provider's plan starts when the nurse pursues the goal *achieve_service_provided* by taking the blood pressure measurement the date chosen for the appointment (query *Appointments* followed by action *measure_bp*). The delegated service is completed when the patient's record is updated with the measurement (query *PatientRecord* followed by action *update_ PatientRecord*).

Discussion

The delegation and assignment patterns have been enacted by mapping them into the Tallis tool used for running PRO*forma* guidelines. In addition a simplification of the patterns, which does not include exception detection and recovery, has been implemented and enacted in a COGENT prototype. What remains to be done is to fully explore the practical benefits of the use of these patterns, by mapping them into a real clinical-based application.

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Participatory interaction design in user requirements specification in healthcare

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Abstract

Healthcare information systems are accused of poor usability even in the popular media in Finland. Doctors especially have been very critical and actively expressed their opinions in public. User involvement and user-centered design methods are seen as the key solution to usability problems. In this paper we describe a research case where participatory methods were experimented within healthcare information systems development in medicinal care in a hospital. The study was part of a larger research project on Activity-driven Information Systems Development in healthcare. The study started by finding out about and modeling the present state of medicinal care in the hospital. After that it was important to define and model the goal state. The goal state, facilitated by the would-be software package, was modeled with the help of user interface drawings as one way of prototyping. Traditional usability methods were extended during the study. According to the health professionals' feedback, the use of participatory and user-centered interaction design methods, particularly user interface drawings enabled them to describe their requirements and create common understanding with the system developers.

Keywords:

User interface design, Interaction design, Usability, User requirements, Participatory design, Medicinal care

Introduction

This paper describes a research case where a few traditional usability methods were used to specify end-users' requirements in the demanding context of medicinal care. At the same time the methods were further developed to fit better with domain of healthcare information systems (IS) development. The researchers were user interface and interaction design professionals with a strong background in industrial art.

Health services are an information-intensive field across the world. A huge amount of information in different forms is constantly needed by various professionals to support their work. A range of software products, as well as traditional tools for information processing and communication, are utilized. The quality of these tools varies and not all of them support the actual work processes or mutual aims in this highly complex environment. There is a great deal of available health information management software. However, doctors and nurses are still using traditional paper forms, for example, for planning and following up on medicinal care in university hospital units.

According to the public discussion in Finland, healthcare professionals are dissatisfied with current tools, such as patient record systems and other software products. Doctors and nurses are complaining that current software products do not help them enough with their everyday work with complex patient data. [1,2]

Even the most common tasks take too long and are illogical to complete. It seems that the users' point of view has been ignored and the usability of the systems has not been tested before implementation. Particularly, doctors have been very critical users and they have actively expressed their opinions in public, for example, in the Finnish Medical Journal [1- 3]. Problems in the usability of clinical information systems are also known world wide [4].

User participation in information systems development is considered to be an answer to usability problems. According to the ISO standard 9241, usability is "*the extent to which a product can be used by specified users to achieve specified goals with effectiveness, efficiency and satisfaction in a specified context of use*" [5].

Participatory Design (PD) is an approach to designing technological and organizational systems that attempts to actively involve workplace practitioners, future users of the system, in the design and decision-making processes [6].

Interaction Design (IxD) defines the structure and behavior of interactive products and services. Interaction Designers create compelling relationships between people and the interactive systems they use [7]. Design practices typically alternate between user research, analysis, and actual design work.

There have been only rather few studies in the healthcare IS world using usability methods [8]. But a result of these studies confirms that usability methods are also effective in the healthcare domain [9, 10]. More often usability methods are used in consumer product development such as mobile phone software and computer game development.

Smelcer et al. have argued that "usability work with EMRs is not straightforward":clinicians use foreign terminology, there are different specialties in medicine, and every specialist has different needs for using EMRs [4]. Also, observing clinicians' work is challenging because of privacy regulations [4].

The development of healthcare information systems differs from the development of consumer products. The main differences to mainstream usability studies are:

- The end-users are not those who purchase products, which can cause problems, especially when developing the usability aspects of products.
- Some usability methods, e.g. observations in actual patient care situations, are difficult to use because of the confidentiality of patient records.
- The context of use of software products is highly complex. Physicians' workflows are difficult to understand without medical education.
- The new products are usually only one part of the larger (hospital) IS infrastructure, not "independent products."

Medicinal care in hospital units is based on co-operation between the patient, physicians, nurses, and other professionals. At its best, medicinal care crosses the dividing lines between units and organizations. Medication information should be available in various care situations. It is an important part of electronic patient records and it is crucial that the information is up to date.

Information systems for keeping the patients' medicinal care up-to-date (medicinal information systems) need to be integrated with many other EPR products in Finnish hospitals. This will bring challenges to the IS and usability development.

Objective and research questions

The primary goal of the research was to experiment with how the participatory, usability, and interaction design methods would work in the field of user requirements specification for healthcare software.

The usability methods to be experimented with were heuristic analysis with end-user participation, observations combined with simulations, artifact analysis, contextual inquiries and analysis, and prototyping with use cases.

The more detailed research questions were:

- How can the end-users' requirements and needs for the healthcare software be collected?
- How can end-users be involved in the software development process?
- How can common understanding on the future software be achieved between developers and end-users?

There was a need to find out how to specify health information systems for both software engineers and healthcare professionals to understand the future software. The study started from the premise that user interface drawings could be a base of shared understanding and would be a good method for defining user requirements. This requires more than an ordinary software developer's education to design the future product as well as the future software user interface. Designerly knowing skills are needed. [11].

Materials and methods

The research case was carried out as part of the ZipIT project, the aim of which was to narrow the distance between the different worlds of work improvement and information system development. The project produced the Activity-driven Information Systems Development (AdISD) model [12, 13].

The research case presented in this paper was called: "Planning and following up medicinal care in hospital wards." The researchers participated in the work of the medicinal care documentation development group of the Finnish hospital. The group consisted of healthcare professionals, physicians, nurses, and pharmacists. The primary working method of the group was workshops. The group was established because of end-users' poor experiences with the medicinal care software that had been in pilot use in the hospital. The users found that the software was inappropriate for use in real-life patient care situations and, with the software, patient safety issues could not be assured. The primary goal of the work group was to produce development ideas for the new version of that medicinal care software.

The empirical research work can be divided into four phases. Firstly, there was a need to find out about and to model the present state of medicinal care. Secondly, the goal state was defined. The third phase consisted of modeling the use of the would-be software package in the goal state with the help of user interface drawings. Finally, feedback was gathered from the end-users.

Present state survey

To understand the present state, it was important to become familiar with the literature of the basic principles and terminology of medicinal care and care processes. An experienced nurse was interviewed to achieve a more concrete understanding of the medicinal care system in the hospitals. Based on those actions, the acquisition of information, a flowchart of medicinal care in a hospital unit was drawn. The nurse also reviewed the flowchart.

The researchers also found out about how software development of healthcare systems in general had been done. Specialists were interviewed about the common methods of user involvement. According to those specialists, the end-users participated in workshops organized by software providers; no other participatory methods were used commonly.

To identify the usability problems of the existing prototype of the medication information system, heuristic analysis was carried out with user participation. After the analysis, users rated the findings. It was impossible for the researchers to perform the severity rating of the standard heuristic evaluation method because usability problems were deeply involved with the users' tasks. The analysis and rating built an atmosphere of trust with the end-users and removed prejudices against researchers.

To researchers the purpose of the early workshops of the medicinal care documentation development group was to collect information and verify their understanding of medicinal care in

hospitals. The results of the analysis of the information from the workshops were different kinds of data structure charts. This analysis phase can be called data analysis and an Affinity Wall was used as a working method from Contextual Design, a user-centered design process developed by Karen Holtzblatt and Hugh Beyer [14].

The researchers figured out what data the physicians needed for making decisions about the patients' medicinal care. The users' goals in that data processing were also determined.

In between workshops participatory observations, interviews, and simulations of both manual and digital systems were conducted in the hospital wards. The observations were related to medicinal tasks, e.g., doctors' rounds and nurses' medicinal preparations and deliveries. These were documented by photography and taping. It was also important to collect empty and used paper forms that were used in the medicinal tasks, for artifact analysis: "*Artifact analysis may be used to supplement observational data and to gain a more thorough understanding of people's tasks, and may lead to the design of improved artifacts*" [15].

A member of the hospital development group modeled the present workflow of medical care in the hospital. The flowcharts were drawn from the patient's point of view (care pathway). The researchers noticed that there was also a need to describe the end-users' processes, e.g., physician process, nurses process, etc. It was very important to find out which points of the workflow professionals needed information about a patient's medications. Modeling those workflows produced the understanding of work activities in the hospital. It is important to know the entire work activity in order to understand a specific part of it.

After finding out about and modeling the present state, it was possible to define user needs and design challenges. For instance, when writing a prescription, a doctor must be able to see every piece of information related to the patient, not just medicinal notes. Both doctors and nurses have to see medicinal notes in a chronological order; they must be able to write medicinal notes, riffle through previous notes, and document the prescribed and given medicine. These basic requirements were detailed during the design process.

Goal state survey

The primary aim of this phase was to describe the human-computer interaction and user experience with the help of use cases and user interface drawings. The researchers wrote use cases with the help of Laakso's model [16]. The written use cases were goal-based use cases because writing the use case without a goal does not generate enough information for interaction and user interface design.

Each written goal-based use case described one work task and all the information needed for making decisions concerning that work task. It was important to separate those facts that the user already knew from those that the user needed to know.

Interaction design and user interface design

The user interface (UI) and interaction design process itself was interactive. Briefly, the users' needs for medication information were discovered and the user interface was designed to service these needs. All user interface design solutions were discussed with the users in workshops, and corrections were made as needed. This can be seen as low fidelity or paper prototyping [17, 18].

This process made it possible to define almost all of the user requirements with user interface drawings or a series of drawings.

It was important to design the UI drawings with real patient data. In this phase, the previously collected and analyzed artifacts and the workflow charts that included the medication data were very important. The researchers produced series of user interfaces based on the user workflows. The user's interaction with these series of drawn UIs was tested with the help of the goal-based use cases. This made it possible to avoid the worst design mistakes.

The design principles that emerged for the medicinal information system are as follows. What physicians need to see to be able to decide on how to continue medicinal treatment (and what was lacking in the previously existing system): all of a patient's medications; changes in medication, medication history; current medication and planned changes (e.g., operation day). All of these must be confined to time. The problem with the previously existing system was that it did not have enough support for the user to understand the relations between medication and time.

The drawn UI proposal was split into three parts. The first part was patient information because of patient identification and the need to see critical information in some care situations. Afterwards the researchers realized that the designed proposal followed one of the main principles of MSCUI: "*Correct identification of a patient and the matching of a patient to their care elements*" [19].

The second part, in the middle of the user interface design, was a view of the actual medication list. This view was combined with a calendar view. The calendar view was split into two parts, daily and weekly. Below that there was the third part, a row of information on the history of a selected medication. This three-part solution appealed to the users.

Feedback gathering

After the research, feedback on the working process and the methods was gathered from the end-users who participated in the work. The feedback gathering was done with the help of a web-based questionnaire form. Every respondent thought that it was very useful to model the collected user needs as user interface drawings. The expressed thoughts and needs for the software were seen immediately in the user interface drawings.

To that point, the work of the researchers was completed and the development of the medicinal care software continued in the product development team of the software provider.

Results

The results of this research can be divided into two groups: practical user interface proposals and methodological results.

We were able to define medicinal care user requirements with user interface drawings or a series of drawings, as expected. We also developed standard usability and user-centered design methods to fit better with the demanding field of medicinal information system development.

Graphical user interface proposal

The graphical user interface proposal came about through the process of developing an effective communication tool between all participants of the required specification team. The user interface drawings were an unambiguous way to see how the future software was supposed to look and feel. With the help of those drawings, it would also be possible to check whether or not the specified system will support the users' goals.

Methodological results

According to this research case, standard user-centered design and usability methods seem to be suitable to complex medicinal information system development, too. Putting those methods into practice in this field, however, demands a lot of collaboration between end-users and developers to ensure that the healthcare professionals' needs are taken into account properly.

In addition, it was realized that the end-user working process is very different from the patient process. Doctors and nurses are normally repeating some small piece of the patient process throughout their work day with different patients, but current software development methods are not taking this into account. Understanding the everyday work of clinical practitioners with several patients at the same time is an important, but often ignored, starting point for the development work.

During the project, the researchers developed two extensions to existing usability methods:

1. **Heuristic evaluation with end-user participation**. Instead of the evaluators rating the severity of the usability findings by themselves, the researchers organized a web survey to collect the professional end-users' opinions on the severity ratings. In that way, it was possible to cover the professionals' point of view and it also helped the researchers to build an atmosphere of trust between the interaction designers and the clinical professionals.
2. **Method to conduct simulation workshops with professional end-users**. The end-users prepared themselves for the simulation workshops by bringing real patient data with them (without personal information). During the workshop we simulated how the designed user interface would work with that data and we discovered several possible patient safety and usability issues to be corrected during the next design iteration. It was a cost-effective way to validate the planned user interface solutions with real patient data. This method also gave us a good understanding of the co-operation between physicians and nurses.

Lesson learned

Afterwards we realized that there should have been two more phases of the development process after where we stopped:

First, the user interface drawings and the prototype developed on the basis of the drawings should have been tested with the help of end-users. To get valid results, the end-users should not be the same ones that participated in the development group, because the latter already knew too many of the compromises and decisions made in the development phase.

Second, after careful usability testing, the interaction designers should have provided usability support to the developers; there seems to always be a need for compromises between the usability objectives and technical limitations in the development phase. If the same designers take care of the implementation compromises, too, this prevents any big new usability problems.

Discussion

The results were quite similar to other research in this subject area. Complex design problems require more knowledge than any single person possesses. Participatory and collaborative design methods are useful in producing a shared understanding of the target area and can lead to favorable and unexpected ideas and solutions.

Nowadays there is a huge amount of data in health records; the problem is not data input, but the access to the relevant information in the right situation in the right format. To understand better what information needs to be seen when and how, we need a better understanding of the users' work tasks and work flows and the information they need in various care situations.

It is hard to develop only one part of a large information system without a really good understanding of the entire picture. Users in hospitals have to work with many types of software and these software products should be integrated well enough to support the whole work path of the user. That cannot take place through technical integration only, it has to be "logical" integration. System developers should study the users' work. The developers' world is too different from the hospital environment. Doctors do not sit next to the computer in the same place all day. They do rounds and visit patients' rooms and operating rooms. They handle the data of lots of different patients at the same time – their work is not like a "logically" ordered timetable.

With this specific research case, the researchers were able to confirm the ideas of participatory interaction design, describing user requirements in a more efficient and understandable way with user interface drawings. Common understanding between designers and end-users was achieved through the user interface drawings. Without seeing user interface drawings – the first prototype of the future software – it is hard for users to participate in requirement specification. Continuous usability testing throughout the design process is needed to ensure that the process moves into the right direction.

User participation is very important, but almost as important is the way how the users are involved. Listening to the end-users is the most important thing, but it is crucial to keep in mind that they are not designers. By presenting some ideas, users typically point out problems even though their design solution might be insufficient. This is a good starting point for developing new

methods for collecting and verifying user needs and requirements in healthcare information systems development.

Conclusion

In this paper we reported on an experiment in applying participatory interaction design methods in healthcare information systems development in medicinal care in a case hospital. The process and the results of four phases of the case study were reported: (1) modeling the present state; (2) defining the goal state; (3) modeling the use of the would-be software package in the goal state with the help of user interface drawings; and (4) gathering the feedback from the end-users.

The results show that participatory and collaborative design methods are useful when aiming for usability in the complex domain of healthcare. Systematic further research is required to develop practicable methods for system developers.

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Cognitive Evaluation of a Physician Data Query Tool for a National ICU Registry: Comparing Two Think Aloud Variants and Their Application in Redesign

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Abstract

Applying usability methods in formative evaluations of interactive healthcare information systems design is recognized as of extreme importance to the final success of these systems. However, it seems that the merits of specific methodological approaches for conducting these studies have received little attention. This study reports on a cognitive evaluation of a Physician Data Query Tool, which offers physicians the opportunity to query quality of care data collected by the Dutch National Intensive Care Evaluation (NICE) foundation. A comparison in terms of usefulness and utility of two variants of the Think Aloud method is addressed, the Concurrent and Retrospective Think Aloud. These methods are well known in the field of Human Computer Interaction in the context of usability evaluation. The results of this research indicate that though both methods have their disadvantages and benefits, in redesigning the Physician Data Query tool the Retrospective Think Aloud provided more useful input to the Tool's redesign. However, in deciding which method to apply in a formative evaluation study, end users' cognitive workload of performing the system's tasks and the system characteristics need to be considered as well.

Keywords:

User-Computer Interface, Usability Study, Cognitive Evaluation, Health Care Quality Evaluation, Physician Data Query.

Introduction

Understanding the cognitive processes of clinicians, such as the processes by which they (learn to) comprehend and interact with interactive programs, is a prerequisite for building tools that support clinical practice in an appropriate manner [1]. The think aloud method is generally recognized as a major source of data on subjects' cognitive processes and has been applied in studies on computer program comprehension in the field of Human-Computer Interaction (HCI) for decades. Its application in usability testing of health information systems aims to improve clinician system interaction and to develop more usable interfaces [2]. Ericsson and Simon (1984) have presented two variants of the think aloud methods which have been applied in the context of usability testing in recent years; Concurrent (CTA) and Retrospective (RTA) Think Aloud [3,4]. When applying the CTA method, subjects are instructed to verbalize their thoughts while conducting a task. In contrast, the RTA method instructs users to recall their thoughts or actions after they have finished the task by for example reviewing a video recording of their actions. Analysis of the verbal protocols and video recordings has the purpose of revealing the contents of the subject's working memory and his corresponding action, thus providing a unique insight into the subject's cognitive processes in relation to experienced system usability. Controversy exists, however, about the utility and validity of these two methods in usability testing of interactive health information systems [4,5]. It seems that the choice of application of these methods should be based on the nature and complexity of the task to be performed by the subject [4]. Also, which method best to apply in a formative evaluation study of an interactive health information system is still unclear.

This paper explores the use and utility of both the Concurrent (CTA) and Retrospective (RTA) Think Aloud method in a usability study of a Physician Data Query Tool for a national ICU quality of care registry in the Netherlands. We address a comparison of the methods in task completion time and task performance with tasks of differing cognitive difficulty, and type and number of usability problems detected. We discuss the implication of these results for system redesign in general and in light of the efforts that are currently undertaken in redesigning the Physician Data Query Tool.

Materials and Methods

Test object: NICE Online, a Physician Data Query Tool

In 1996 the Dutch National Intensive Care Evaluation (NICE) foundation started collecting data on patients admitted to Dutch ICUs. The NICE database, also called NICE registry, contains information on demographic, physiological and clinical variables required to calculate mortality risk predictions according to the Intensive Care prognostic models [6]. The NICE registry aims to detect differences and trends in quality and efficiency of ICU care and provides quality reports and benchmarking information to its participating hospitals on a quarterly basis. In 2004 the request was made by participating hospitals if the NICE database could be queried by them to answer more specific clinical questions for their own ICU management or scientific reporting. To provide participants with the opportunity to query the NICE database

while protecting the privacy of the participating hospitals, a Physician Data Query Tool called **NICE Online** was developed in 2004 by a group of software engineers.

A standard software design cycle was applied in this project with the primary focus to develop a graphical interface for querying purposes. The user's view on query commands was reduced to a designer-customized browser, with a structured query model (figure 1) to support clinicians in developing queries, assuming that they have no or little experience in database query command development.

Figure 1-Screenshot of the Physician Clinical Data Query Tool: NICE Online.

Nice Online can only be used by participants with a user account. When entering the system, a large list of 'standard queries' is presented to the user. He/she can decide to select one of these queries and directly view the query's resulting table or graph or he/she can chose to change the query by adding (data) elements to the query model. Another possibility is to start a new query, also called 'custom query' in the system. A user is then presented with a blank query model, in which he/she must add all (data) elements needed for the query. The query model consists of four components: functions, splitting/intersection, benchmarking/mirror and selection of subpopulation. For each component the user can select from a large list of elements that are either statistical models or data elements collected by the NICE Registry. For example, functions are Intensive Care prognostic models which may form the basis of a clinical query. 'Benchmarking' refers to at least the user's 'own hospital data' for example in comparison to the element 'national data'. The splitting/intersection and selection of subpopulation components offer the user the possibility to split the data for example in gender categories or to create a subpopulation with regard to for example a certain time period. When a user is finished with the query model, he/she can select the 'graph/table' button to create the resulting graph or table.

Not all participants have yet requested a user account of NICE Online. In July 2008, NICE Online registered 80 users. A log file analysis, performed to gain insight into NICE Online usage patterns, showed that only 17% of the participants with a user account actually used the query functionality on a regular basis. Telephonic information needs analysis provided insight into user experiences with NICE Online. It showed that users were willing to use the tool but the structured interface for query development was not appreciated by them. However it did not become clear in what way the cognitive burden of a query development by use of the Tool was influenced by a potential lack in the Tool's usability. Next to this, planned expansions to the NICE Database, such as the collection and reporting of structure, process and outcome quality indicators of ICU's, required a high level of user-friendliness of NICE Online, which made it necessary to redesign the Tool and improve on its usability.

Subjects

Our study involved 16 subjects. Subjects were categorized on basis of a log file analysis of NICE Online usage patterns in order to select a number of representative target users. Subjects were assigned to one of the two conditions in a matched-randomized way with tool experience as matching factor. For testing of the Physician Data Query Tool formal agreement to contact the users was given by the NICE Foundation. The selected subjects were then contacted by email with an accompanying letter. All agreed to participate to the NICE Online evaluation study.

Tasks

To evaluate the cognitive workload and the usability of the Physician Data Query Tool (NICE Online), six tasks were developed which were divided into two to six smaller subtasks. Input into the development of these tasks was given by two data managers of the NICE Foundation. They where highly experienced in ICU clinical query development and were able to provide generally relevant tasks of varying difficulty with a golden standard for how to perform and finalize each task. The tasks were preceded by a query description, or short clinical question, which could be answered by data in NICE Online. The usability test started with two standard query tasks, randomly given. These tasks provided the subject with some experience in NICE Online, and for the CTA method it provided participants with practice in verbalizing their thoughts while performing a task in the system. Then four tasks were randomly presented to the subject with a varying degree of difficulty. These four tasks consisted of two custom query tasks, in which the user had to enter a query statement as described in NICE Online, and two tasks consisting of a clinical question to be translated into a query in NICE Online. An example of both tasks is given in Table 1.

Table 1- Examples of the usability Tasks

	Examples Main question
Custom query task *easy*	*'Please select the percentage of patient admissions which are split by admission type for the data of your own hospital within a sub selection of the last two years'*
Translating a clinical question task *easy*	*'The annual NICE report shows you that there exists a difference in the mean length of stay for patients in the age category 60 to 70 year in the year 2007 compared to 2008. You whish to find out if this is correct by making a graph of these data in NICE Online.'*

CTA and RTA experiment

The experiments took place in the actual clinical working area of the subjects. A portable usability laptop with Morae software made it possible to record all the subjects' verbalizations in combination with a screen recording of their (mouse) actions in the system and a video recording of the subjects performing the actual tasks in NICE Online on the usability laptop. In both the CTA and RTA condition, the experimental procedure started with the subject answering questions about his or her general computer experience, experience with statistical knowledge and calculations, and experience in formulating queries in other systems. Hereafter the subject received the tasks as well as oral instructions on how to carry them out on the laptop. In the CTA condition, the subject was instructed to think aloud while performing the tasks. In line with the Think Aloud procedure described in [3], it was made clear that the accompanying researcher, the facilitator, would not interfere with the session by giving assistance, but would only remind the subject to keep thinking aloud if the subject would fall silent for a while. Finally, the subject was told that the goal of this test was to gain insight into the problems he/she might encounter in using NICE Online, and to understand in what way he/she translated a clinical question to a NICE Online query. In the RTA condition, the subjects received the tasks and short oral instructions. They were instructed to carry out the tasks in silence on the laptop, without assistance of the facilitator. After the session, video recordings of their actions in the system were shown to them and they were asked to verbalize their thoughts retrospectively. The analysis of the think-aloud sessions was done in the Morae Manager from Techsmith. Additional validation of the subjects' task performance was performed by the research and database manager of the NICE Foundation.

Results

General results

The 16 experiments resulted in over 24 hours of recordings. The CTA testing lasted approximately 1 hour, while the RTA testing lasted about 2 hours, including the time for retrospective reporting. The transcription of the verbal protocols of subjects in the CTA condition resulted in 3 times as much data compared to the transcription of the verbal protocols of subjects in the RTA condition. Of the subjects, 12,5% was female. Of all subjects 62,5% mentioned that they considered themselves expert with regard to computer experience, 50% considered themselves expert in statistical calculations and 56,25% regarded themselves expert in query development. The analysis showed that subjects who considered themselves as experts were somewhat equally divided between the two methods.

The verbal protocols of subjects were transcribed and all actions of subjects were linked to the comments made by them as reflected in the protocols. Two analysts went through all verbal protocols and video recordings and separately coded the usability problems, experienced by the subjects, in usability categories described among others by Kushniruk et al. [7]. Inter rater reliability was measured by Cohen's kappa (.83) which constitutes to a substantial agreement between the two analysts. In total 43 singular usability problems were analyzed.

Task completion and performance

Table 2 shows a comparison of the CTA and RTA method with respect to 1) task completion time in minutes and 2) task performance in terms of incorrect tasks (N/E) per difficulty level. Analysis showed that development of a custom query in the system took slightly more time in the CTA condition than in the RTA condition. Yet, there was only one clear difference in task completion time between the two methods. The translation of the clinical question to a query in NICE Online in the easy category took exceedingly more time in the CTA condition than the RTA condition. Also, this task was more often performed incorrectly by subjects in the CTA than in the RTA condition. Analysis of the verbal protocols revealed that subjects in both conditions experienced much difficulty in translating a clinical question to a query in the Tool and commented on this task to be cognitively complex. This translation proved however more difficult for subjects in the CTA condition than in the RTA condition. In total, 24 tasks were incorrectly performed in the CTA condition whereas 12 were incorrectly performed in the RTA condition. Overall, the CTA condition had lower task performance than the RTA condition.

Table 2 - Overall task completion time in minutes, N/E tasks not executed correctly

	CTA			RTA		
	Mean	**SD**	**N/E**	**Mean**	**SD**	**N/E**
Standard Query						
Easy	4.8	1.8	1	5.0	0.3	0
Difficult	7.3	1.8	2	6.9	2.0	0
Custom Query						
Easy	6.1	0.1	3	4.5	0.7	2
Difficult	7.5	2.0	4	6.8	2.1	3
Translating Question Query						
Easy	11.3	1.8	5	7.5	0.8	2
Difficult	11.7	0.9	9	9.4	3.3	5

Usability problems

Table 3 gives an overview of the mean number of usability problems detected for each usability category per think aloud method. Table 3 also shows the number of problems per category that was uniquely detected by one of the two methods (CTA or RTA) and those problems that were detected in both the CTA as well as the RTA condition. The CTA condition provided insight into several types of usability problems. Analysis of the verbal protocols revealed that subjects in the CTA condition, when confronted with usability problems of a minor or cosmetic nature that directly obstructed the performance of a task, directly commented upon that issue. In contrast, the verbal protocols of subjects in the RTA condition showed that subjects did not report upon

these minor usability problems. Instead, subjects' comments in the RTA condition focused more on the complex usability issues they had experienced during the test.

Table 3 - Usability problems per category and total number of problems per think aloud method.

Problem types	CTA		RTA		CTA	RTA	Both
	Mean	SD	Mean	SD	#	#	#
Navigation	4.9	1.2	4.2	1.1	2	0	3
Graphics/ symbols	5.6	1.8	3.4	0.5	4	2	2
Layout/screen organization	4.8	1.4	2.9	0.8	2	0	4
Meaning of labels/ terminology	5.0	0.5	7.2	1.2	0	4	4
Error messages/ help instructions	4.9	1.7	4.7	1.4	2	0	3
Overall ease of use	6.0	2.8	4.1	1.2	1	1	6
Visibility of system status	3.8	1.5	3.2	1.1	1	0	2
Total number of usability problems	36.0	-	31.0	-	12	7	24

Overall, it can be stated that the CTA condition revealed more usability problems than the RTA condition. The RTA method however provided more usability issues concerning the terminology and meaning of labels. Also, the verbal protocols of subjects in the RTA condition, subjects' verbalizations proved more explanatory towards these problems. For example, one subject in the CTA condition did not completely understand what the term splitting/intersection meant in the query model, he showed irritation and commented there upon, while the subject in the RTA condition explicitly described what the problem was, and how to resolve this terminology issue, which was of high importance to redesign of NICE Online. The analysis of the CTA and RTA verbal protocol data showed that subjects' verbalizations in the CTA and RTA method differed considerably. The golden standard for task completion provided by the NICE data managers proved useful in analyzing the verbal protocols of subjects. When tasks were commented upon by subjects in one of the two conditions, the numbers of statements made by a subject was classified in terms of 'experienced Tool usability', 'explanatory Tool usability', 'task statistical reasoning', 'task comprehension', and 'task query complexity' and were subsequently counted. The verbal protocols showed that comments made by subjects' about 'statistical reasoning', 'comprehension of the task' to be performed, or comments made about the 'complexity of the query' were of a different cognitive nature then the comments made on the experienced Tool usability. Table 4 shows the mean number of these 'cognitive' problems detected per method. In the CTA condition during the usability test subjects explicitly verbalized when they did not fully comprehend a statistical model or the task to be performed or the query to be made in the Tool. Subjects in the RTA condition did not comment upon a potential lack in their statistical knowledge, or in their (in)comprehension of the task at hand.

Table 4 – Mean number of statements of a cognitive nature per method

	CTA		RTA	
	Mean	**SD**	**Mean**	**SD**
Problems in statistical reasoning	5.3	1.0	1.0	1.1
Problems in task comprehension	5.1	1.7	2.3	1.2
Problems in query design complexity	5.1	1.4	4.5	2.2

Discussion

This study shows that task completion in the CTA condition for standard and custom query tasks did not take more time than task completion for standard and custom query tasks in the RTA condition. The task of translating a clinical question to a query in NICE Online took generally more time in both methods, but took exceedingly longer in the CTA condition than the RTA condition. In the Human Computer Interaction literature it is under debate if the CTA and RTA methods offer similar results in terms of task completion time [8,9]. The results of this study seem to indicate that subject's task completion time in the CTA method is influenced by the task complexity. Apparently task completion time of the translation of a clinical scenario to a query seemed to be affected by the cognitive workload of both query translation and direct verbalization of the corresponding actions in the system. Also, the number of tasks completed correctly was lower in the CTA than in the RTA condition. This might point out that the double workload of verbalizing thoughts and performing actions in the CTA method causes subjects' to make more errors or less easily recover from usability problems experienced in performing a task in the Tool. The cognitive complexity of translating a scenario to a query might affect subjects' task performance

In discussing the type of problems detected per method, it becomes clear that each method revealed unique usability problems. The CTA uncovered more usability issues in general, and more specifically it revealed problems concerning system graphics, navigation, error messages and the layout and organization of the computer screen. The CTA method also seemed to uncover more usability issues of a more cosmetic nature than the RTA method. In comparison, the RTA method uncovered more usability problems related to terminology and meaning of labels, and uncovered more usability issues of a complex nature. Also, its verbal protocols provided more explanatory verbalizations which were considered useful by the software engineers as they provided

information on how to resolve such usability issues in redesign of the NICE Online tool.

Another interesting finding of the RTA method in contrast to the CTA method was the fact that subjects did not verbalize potential problems they had experienced related to statistical, task and query comprehension. Therefore, a slightly positive bias towards the NICE Online tool could be seen in the RTA condition, suggesting that subjects made their comments more positive, thus disguising their 'not so good' result caused by a lack in statistical knowledge, or their possible incomprehension of the task to be performed. The subjects involved in this study were clinicians. A reason for this 'disguising behaviour' might be found in that a 'hospital culture' could exist which prevents them to comment on errors made following their lack in knowledge on for example clinical statistics [10]. However, if the RTA subjects indeed did not express their experienced difficulties and their need for more computer support in certain phases of task execution, then the results of the usability study may be less valid, and could for example lead to missing important insights into additional functionalities required in a system redesign. For example, NICE online is specifically designed to provide its users the opportunity of analyzing ICU data, also from a statistical point of view. While subjects in the CTA condition expressed their need for additional support in statistical reasoning to adequately make use of the Tool in the CTA condition, this requirement was not expressed by subjects in the RTA condition. Based on the verbalizations of the subjects in the CTA condition, the conclusion was drawn to provide additional functionality in the help and information support of the NICE Online Tool.

Our study not only showed that the cognitive difficulty of tasks influenced the total completion time, but also that subjects' task performance in terms of correct tasks was lower in the CTA condition than in the RTA condition. In this case, subjects were not supported by the Tool in adequately performing the task of translating a clinical question to a query, mainly because of the many usability problems that they surfaced. However, for NICE Online, not all of these usability problems might prove to be of importance in redesigning the cognitive model of clinical querying.

Conclusion

Overall, the conclusion can be drawn that the RTA method provided more useful information for the Tool's redesign, because of the more explanatory nature of the verbal protocols, and the provided insight into complex usability issues, Subjects had more time to articulate why they were having problems and they did not focus on the irritations caused by the experienced usability problems in performing their tasks. While the CTA method provided a useful overview of a large number of usability problems experienced including minor usability issues, some of its resulting verbalizations did not provide enough detail to support the Tool's redesign. Also, it is not clear if all these problems in redesign need to be coped with. However, these results also indicate that the RTA method might lead to missing input on additional functionalities in system redesign, because statements concerning physicians lack in task and statistical comprehension were nor adequately made. Though CTA has as its benefit that its subject testing takes less time than RTA, it is of importance to decide which method best to apply in revealing the usability issues that provide enough insight needed for a system's redesign. In light of these formative results, the Physician Data Query Tool is currently under redesign. A future study will focus on a comparison of these two methods in a pre-post design in usability testing of the redesigned Tool.

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Can Brain Computer Interfaces Become Practical Assistive Devices in the Community?

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Abstract

A Brain Computer Interface (BCI) provides direct communication from the brain to a computer or electronic device. In order for BCIs to become practical assistive devices it is necessary to develop robust systems, which can be used outside of the laboratory. This paper appraises the technical challenges, and outlines the design of an intuitive user interface, which can be used for smart device control and entertainment applications, of specific interest to users. We adopted a user-centred approach, surveying two groups of participants: fifteen volunteers who could use BCI as an additional technology and six users with complex communication and assistive technology needs. Interaction is based on a four way choice, parsing a hierarchical menu structure which allows selection of room location and then device (e.g. light, television) within a smart home. The interface promotes ease of use which aim to improve the BCI communication rate.

Keywords:

Assistive technology, Brain-computer interface, User centred design, Graphical user interface

Introduction

Communication and control of the environment is vital to everyday life. In many cases disabled people have gone to extraordinary lengths to communicate. Consider the memoir of Jean-Dominique Baub (Diving Bell and the Butterfly; Le scaphandre et le papillon [1]), which depicts Bauby's life after suffering a massive stroke that left him with amyotrophic lateral sclerosis (ALS) or 'locked-in syndrome'. Bauby developed a system of communication with his speech therapist by blinking his left eye as she read a list of letters to spell out the text and completed his book. Scott Mackler, a neuroscientist in the Veterans Administration Medical Center, also succumbed to ALS and is completely paralyzed, retaining only eye movements. He now communicates through a Brain Computer Interface (BCI), which has led public awareness of the technology (CBS news 60 minutes documentary [2]).

In 2002, Wolpaw et al. [4] offered the following vision: "BCI systems could eventually provide an important new communication and control option for those with motor disabilities and might also give those without disabilities a supplementary control channel or a control channel useful in special circumstances". Allison updated on the prospects of BCI in a 2007 review [5], stating: "BCI systems have just begun to provide significant assistive communication technology to people without other effective means of communication in their home environments." BCI could also be applied in applications where existing communication is desirable, e.g. noisy industrial applications, or as a gaming or entertainment interface [3].

A BCI provides communication from the brain to a computer or electronic device. Communication is achieved by collecting the subject's brain waves, known as the electroencephalogram (EEG), and then translating some information contained within these signals. Currently the information that can be obtained from the EEG is quite limited, as the EEG is inherently noisy containing endogenous and exogenous components, relating to sensory, motor and cognitive activity in the brain. Certain motor and sensory EEG components may be induced or enhanced, revealing the person's intentions when performing some activity, for example moving a cursor on a monitor, in order to control an application. This is potentially powerful when combined with interaction and control of a smart environment [6].

There are three main paradigms: the 'odd ball' paradigm to elicit an event related response (known as the P300 response) from the EEG; an 'imagined' movement paradigm; and the steady state visual evoked potential (SSVEP),. The P300 is a positive exogenous potential which occurs approximately 300mec after a 'rare' or unexpected auditory, visual or somatosensory stimulus and can be used to infer a subject's attention to the stimulus. It requires the average of a number of stimuli to enhance the signal to noise ratio. A component in the motor area of the brain (known as event related synchronization or mu rhythm) can be used to determine if the person is 'imagining' that they are moving, for example, their left or

right hand. SSVEP requires an external visual stimulus to evoke a steady oscillatory component in the EEG, at the same dominant frequency as the stimulus. It is primarily located at the occipital region of the brain. A summary description of these paradigms and possible disadvantages are listed in Table 1. In each case the EEG must be analysed to produce distinct classifications which can be used to navigate an interface, and hence potentially interact with the environment. Misclassification of EEG, of course, results in errors in interface control.

Table 1- Comparison of BCI paradigms

BCI paradigm	**Description**	**Disadvantages**
P300	Stimulus: The Bremen 'speller' uses 6 flashing rows and 6 flashing columns to cover the alphabet and numbers. A number of repeat flashes are performed for the rows and the columns. The evoked potentials are extracted from the EEG for the rows and the columns. Then the classifier uses the row and column to determine the value.	It requires concentration by the user on the screen. The user may become distracted or focus on a wrong symbol/tile. Approximately 16 repetitions are needed to determine the class, due to the small signal to noise ratio. Over familiarization can lower the P300 response.
Imagery	No Stimulus: Imaging the movement of: right hand, left hand, right foot, left foot enhances motor potentials in the brain. Many researchers consider this the 'purest' BCI as there is no external input required	Imagery requires significant training of the user. It also requires concentration. The user has to relate a certain imagined movement to a particular decision. They could easily make a mistake in this process.
SSVEP	Stimulus: A tile or symbol flashes at a defined rate (8-50Hz). Decisions are dependent on the number of stimulating frequencies being used. (Usually between 4 and 10).	It requires concentration by the user as they need to look at the correct flashing tile. It is tiring and suffer5s from possible habituation effects.

The recording of these components for use in a BCI has many challenges. An individual may be better suited to one of these approaches or may be completely BCI illiterate. The recording parameters (electrode location, spatial filters) also need to be 'personalised' to the individual and may be affected by ambient conditions, environment, habituation and fatigue. For people with complex problems the situation is obviously more difficult due to brain injury, additional movement artefacts and reduced periods of concentration. However already, spelling devices can be used to enable those without means of communication to 'voice' their thoughts, by linking to a speech synthesizer.

BCIs are difficult to set up. For example recording constrains the user to be close to an amplifier, requires different approaches, and lacks recognised standards. Placing electrodes on the scalp can be arduous and unpleasant to the user, and requires expertise by an assistant. The equipment comprising electrodes, cap, amplifier, computer and stimulus device is expensive and is not aesthetically appealing. Furthermore, solutions hitherto have been geared towards technical demonstrations to showcase scientific advances without specifically focusing on the needs of the users. However for inclusion in society, a BCI could have a major impact, particularly for those with severe physical disabilities. For the small number with ALS, it may be the only technology that could achieve this.

BCIs with Rapid Automated Interfaces for Nonexperts (BRAIN, [7]) funded by the European Commission's Framework 7 programme, addresses the accessibility of BCIs. In order for BCIs to become practical assistive devices it is necessary to take BCIs into the community. In particular; to make BCIs accessible to a non technical user and their care giver and to ensure that operation is sufficiently robust so that constant intervention is not a requirement. By doing this the BRAIN project intends to make the performance of day to day activities accessible to users for whom this has not previously been the case, thereby promoting the social inclusion of those most in need.

In this paper, we report on the design of generic interfaces [8, 9] for the user, built upon an architecture that will allow a wider variety of applications to be supported. Two threads of development exist. The first is the interface that the user sees and interacts with. Secondly, there is a range of possible applications that could be included and will need to be handled within the same BCI system. For example, enabling BCI control of the television, a music player, a speller; or control over assistive devices within a smart environment.

This is an example of pervasive computing, an emerging research area where sensors and computers support people in their home environments. In these environments, it is highly desirable that the systems and services must be able to adapt and react without the need for people to intervene to configure them.

Methods

BCIs have benefited from improved sensors, smaller amplifiers, better signal processing techniques and a move towards standardization of interfaces. However, it is important that research is focused upon applications that the potential user groups actually want, so the design methodology is to allow users to influence the development. There are two groups: users with complex communication needs and users who may use a BCI as technology of choice for work or entertainment.

User Surveys

BRAIN has adopted a user-centred design approach, involving 2 separate groups of participants in two countries. The user study comprised quantitative and qualitative techniques. In Northern Ireland (United Kingdom), the Cedar Foundation convened workshops and surveyed the needs of six tenants of sheltered smart housing. They expressed an appreciation of the value of the BCI system and a sense of satisfaction of being involved in the development process. One participant was unsure if they would use the technology, but the others were keen to try it. A total of fifteen people participated in the user sessions at a Telefonica site in Spain. The qualitative research was conducted by focus groups, of 8 and 7 participants each and the quantitative part was gathered from surveys delivered to users. The results of the user survey (see below) influenced the design of the user interface, and the target applications.

Interfaces

Interface design is key to uptake of technology, and this is particularly important for BCI, which suffers from a slow communication bit rate. There are three interfaces: (1) An electrical interface via electrodes and amplifiers, which collects EEG from the user; (2) A Graphical User Interface (GUI) which provides feedback to the user regarding the state of the application; and (3) An Application Interface, which provides actuation from the computer to the environment. It is important that a number of applications can be controlled and thus we aim to produce a Universal Application Interface (UAI). The BCI comprises software for paradigm control, signal processing and feature extraction (called BCI2000, Schalk [10]), GUI and UAI, with drivers appropriate to different domotic devices. The user views a GUI and dependent upon the paradigm (SSVEP, P300 but not imagined movement) will view stimuli, presented via external light emitting diodes (LEDs) or on a computer screen.

A number of BCI user interfaces have been reported. These include: the 'Hex-o-Spell' mental typewriter [11], BCI2000 implementations [10], an SSVEP speller [12] and Milan's Adaptive Brain Interface [13]. The current GUI is influenced by the SSVEP work of Piccini [14], and has been adapted to higher frequency LED stimulation [15]. The GUI consists of two modules:

- Display Requirements Module, which adapts the graphical interface to limitations, imposed by the BCI protocol and user preferences.
- Device Interface, which handles the interface between the GUI and the BCI2000-based BCI system.

The BCI system performs signal acquisition and processing, resulting in events that the GUI is able to map to actions of the UAI applications. During operation, BCI2000 stores data, along with event markers and information about system configuration. Additional signal processing routines (written in Matlab) provide classification into four categories (right, left, up, down). Communication between the various modules is by classified user datagram protocol (UDP) packets over a socket connection. The GUI menu structure is defined in extensible markup language (xml), which facilitates the declaration and description of structured classifications. In this manner a menu hierarchy is defined and menu icons associated with appropriate commands. By using xml in this manner the GUI becomes a menu parsing facility. This makes it possible to harness the interface for many different purposes or to facilitate the tailoring of the interface according to individual user needs. The GUI provides the user with navigation through various locations in the smart home. In Figure 1, the menu indicates current location as the "back garden". The down arrow can then select 'controllable' smart devices in this location.

Figure 1- IGUI showing high level location menu within the Smart home

If for example, a room was selected then devices within the room that the user could operate become available. For example, Figure 2 shows the current state of the door. This 'device' can be toggled by selecting 'down', i.e. if the door is currently 'open', it will be closed by actuators associated with UAI.

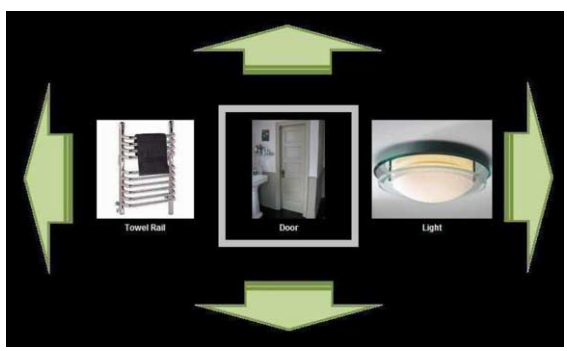

Figure 2-IGUI showing activation of the door open/close (within a room/location)

Results

From the CEDAR workshop and the questionnaire, user requirements were obtained. In terms of physical requirements, all CEDAR participants are wheelchair users with a range of seating postures and positions. It is important therefore to establish the acceptable working distance of the individual when wearing the BCI cap, in relation to device that will house the system. All participants required significant assistance from

care staff for activities of daily living. For BCI, assistance will be required to fit the cap and electrodes. A practical requirement is the importance of training and support, for participants.

In terms of user preferences, communication is the prime function users wish to try, although using the system to support phone calls was not well received. Accessing multimedia content is of interest. Television is the most important entertainment device to participants, and integration of the BCI software into the television or vice versa may support access and usage.

From the Telefonica workshops and questionnaire (N=15; 10 male; 5 female, 21-52 years old) further user requirements were obtained which pertain more towards BCI as an additional technology. Time spent at home was dominated by watching television (TV: 3 hours, Internet: 2.5 hours; work/study: 2 hours; phone communication 2 hours; housework: 1 hour; other: 1 hour).

Requirements for Automation Control: (Video:13 users/ 15; Heating:13; Audio:12; Security:5; Doors:3; Lights:2;). The main concerns of automation systems within the home environment included high prices, the early stage of the technology, reliability and maintenance, security and the new infrastructures (i.e. need for wiring).

Requirements for Multimedia devices (TV:15 users / 15; PC:15; Mobile Phone : 15; DVD: 11; Tuner:6; others:3). The users expressed desire for an entertainment system which can manage multimedia formats, and whose content can be stored in any media server in the home network. Interoperable systems are desired. The system should support the control of many devices, from media players and servers, to domotic devices/sensors, and communication devices, all coming from different technologies. In case of people who need special care, this is considered essential. The television is one of the most valued devices to be controlled by BCI system. The context environmental information should be taken into account to handle smart services.

The BCI system is considered by users as a possible 'remote control' to access to home applications. For a skilled BCI user, this could be a simple task. Techniques to make training easy are requested. The majority remarked that improvements of graphical interfaces are needed to make them more usable. This work has influenced the design of the Graphical User Interface (GUI). The GUI should be implemented on a multimedia workstation which could also function as a television and communication device.

Software and Hardware Testing

Testing has been carried out to ensure that the GUI can interact with the BCI recording system and the domotic applications. Extensive unit testing of menu operation and the ability to issue a command has been completed. Integration testing of the GUI has been successful concerning:

- Demonstration of the correct traversal of the GUI menu via mouse operation. This offers a good test environment and provides the facility for a care giver to operate the GUI should the user require additional assistance. For instance GUI shut down, should the user become tired.
- Demonstration that the GUI will successfully receive and unpack BCI2000 generated, UDP Package content, thereby providing the user with a mechanism to traverse the GUI menu structure via BCI.
- Demonstration that the GUI can issue commands to the UAI which are received and invoked. Commands are invoked as a web service offering the potential for remote control where necessary.

A television (TV) control application has been completed, which allows the user to control the most used functions of a TV set: power on/off, change channel, change volume. A TV set that natively supports the required universal plug and play (UPnP) functionality does not exist in the market place. Most Digital Living Network Alliance (DLNA) compliant TVs are limited to browsing and playing the content found in the Media Servers connected to the home network. However, set top boxes exist that provide remote control features through the ethernet port, e.g. Dreambox 7025 TV tuner (https://www.dream-multimedia-tv.de/en/dm-7025), which allows streaming, electronic program guide retrieval, and schedule of recordings. When the TV input is connected to the Dreambox, the channel displayed and the volume can be controlled from the UAI. A UPnP light emulator was implemented for integration testing. Initial supported devices include UPnP PowerSwitch service and wireless X10 controller. New devices are supported by means of a UPnP wrapper around the native application programming interface (API) of the device.

Initial testing with subjects indicates that the high frequency SSVEP paradigm is feasible in the research laboratory. However, it is necessary to calibrate frequencies for each subject under test and work is underway on a software wizard to facilitate and expedite this process. At present, interface metrics regarding usability in the two target groups still have to be collected.

Discussion and Conclusions

The User Interface uses a 4 way interaction: left, right, up, down. Currently menu items are grouped by space and function in order to ease identification and selection. These groupings can be adjusted within the xml declaration in order to balance depth and breadth of navigation, to facilitate the accessibility of final commands by reducing the number of menu navigation steps required to reach them. Primary grouping is made by the rooms associated with the users' housing environment: living room, bedroom, hall etc. and then by function: lighting, television, heating. An additional classification of menu item 'Sticky' is used to ensure that significant applications such as a Speller, or the ability to answer the door or phone are always available. The environment to deploy UAI applications as web services has been set up under the Equinox OSGi framework. UAI applications are implemented as OSGi bundles that are easily installed in the system. The UAI is able to filter the discovered UPnP devices so that only authorized devices are operated. The software light emulator and

light control application has been successfully tested, and indicate the potential for more complex domotic device interaction. Additional user trials will allow us to collect information which can then be used to impart intelligence into the menu structure. This can improve the effective bit rate of the BCI.

The Graphical User Interface is intuitive and can be personalized. The menu is based on photographs of the intended location/device, which may be personalized to the specific environment, and so should be intuitive in use. It does not rely on literacy. The size of the menu could be scaled, appropriate to poor visual acuity. The menu structure may be easily extended for further rooms/devices. Each device can have additional menus appropriate to the complexity of operation, e.g. a media player will have more controls than a simple switch. Interaction with the UAI is via web services, and a queue of current events. GUI and devices can communicate with this queue to indicate their current state, e.g. turn a light off, if already on. Communication with the BCI is via UDP network packets. This provides a decoupling of technologies, enabling independent development (e.g. BCI200 has been developed in C++, whereas the IGUI has been developed in JAVA). This provides an IGUI which is potentially open to the wider community for enhancement.

In conclusion, we are in the process of implementing a BCI system designed to be used in the community. Paradoxically initial testing has occurred in a controlled setting, and hence our overall rationale still requires validation. However, we believe that the approach allows us to deploy a system to deliver a number of services, which the users desire, with familiar control using a consistent extendable (and in the future) context aware intelligent GUI. These advances are necessary for BCI to become practical assistive devices, but are not sufficient, and we need further progress in electrodes, caps, signal processing, convenient set-up and detailed understanding of user interaction with the system.

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Supporting Human Interaction and Human Resources Coordination in Distributed Clinical Guidelines

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Abstract

Clinical guidelines (GL) play an important role in medical practice: the one of optimizing the quality of patient care on the basis of the best and most recent evidence based medicine. In order to achieve this goal, the interaction between different actors, who cooperate in the execution of the same GL, is a crucial issue. As a matter of fact, in many cases (e.g. in chronic disease treatment) the GL execution requires that patient treatment is not performed/completed in the hospital, but is continued in different contexts (e.g. at home, or in the general practitioner's ambulatory), under the responsibility of different actors. In this situation, the correct interaction and communication between the actors themselves is critical for the quality of care, and human resources coordination is a key issue to be addressed by the managers of the involved healthcare service. In this paper we describe how computerized GL management can be extended in order to support such needs, and we illustrate our approach by means of a practical case study.

Keywords:
Clinical guidelines, Human interaction and communication, Human resources coordination.

Introduction

Clinical guidelines (GLs) are defined as "systematically developed statements to assist practitioner and patient decisions about appropriate healthcare for specific clinical circumstances" [1]. GLs exploitation is meant to improve the quality and to reduce the cost of healthcare, putting evidence based medicine into practice, and is progressively spreading in several countries. As a matter of fact, a lot of national and international institutions have recently been engaged in developing and disseminating GLs. Moreover, the medical community has started to recognize that a computer-based management of GLs can further increase GL advantages, providing relevant benefits (e.g. automatic connection to the patient databases, and decision making support) to care providers and patients. Many different systems and projects have been developed to this hand (see e.g. [2-4]).

The goals of these systems are mainly the ones of supporting physicians in patient care by representing and executing a GL. However, it is worth noting that some GLs, mainly dealing with chronic diseases, require that patient treatment is not completely performed in a single location (e.g. the hospital), but is continued in time, often in a life-long perspective, and distributed in *different contexts* (e.g. at home, or in the general practitioner's ambulatory), under the responsibility of *different actors*. In this situation, the *correct interaction and communication* between the involved actors is critical for the quality of care, and *human resources coordination* is a key issue to be addressed by the managers of the involved healthcare services. None of the available computerized systems for GL management explicitly addresses these needs, and interaction is nowadays completely demanded to the different actors. Sometimes the responsibility of notification is even demanded to the patient, without a check of communication completeness and correctness. For instance, in Italy, the discharge letter is given to the patient, who has to notify it to her general practitioner.

In this work, we propose an extension of a computerized GL management tool in order to support coordination of multiple actors operating on the same GL. In particular, we first introduce an extension of the GL representation formalism with new dimensions, meant to *color* the GL actions with *context, role* and *competence* information. Then, we describe how human resources coordination and human interaction and communication can be supported through notification and query answering services. The querying facility, in particular, can help both during GL execution and off-line (e.g. before execution, and independently of any specific patient's data). A practical implementation of this work is represented by an extension of the GLARE system, a domain-independent system for GL acquisition and execution [5], that we are developing since 1997. Resorting to the GLARE formalism, we will illustrate the application of our approach to the "Management of harmful drinking and alcohol dependence in primary care" GL developed by the Scottish Intercollegiate Guidelines Network (SIGN) [6], which we have adapted to the Italian context. However, although we have implemented our approach in GLARE, it is worth stressing that the methodology we propose is completely general and application-independent.

The paper is structured as follows: in the next section we describe the extension to the basic GL representation formalism required by our approach, as well as the notification and the query answering service. In the Results section, we exemplify a practical application of our approach considering the alcohol-related disorders treatment GL. Finally in the last section we address some concluding remarks.

Materials and Methods

Colored Guidelines: representation formalism

In the literature, the majority of the GL representation languages share the same basic primitives, from which we will start to describe the extensions we propose in this paper. Obviously this grants for generality: despite the fact that our approach is being integrated with GLARE, all the considerations could be easily adapted to other GL management systems.

In particular, a GL is typically represented by a graph, where nodes are the statements/actions to be executed, and arcs are the control relations linking them. Actions can be *atomic* or *composite*, defined in terms of their atomic components via the has-part relation. Three main types of atomic actions can then be identified[1]: *work actions,* which describe a procedure which must be executed at a given point of the GL; *query actions*, which represent requests of patient data; *decision actions,* which embody the decisional criteria that can be used to select among alternative paths in a GL. *Control* relations establish which actions can be executed next, and in what order: *sequence, parallelism*, *alternative*, and *repetition* constructs are typically available. In some systems (e.g. in GLARE) temporal constraints, such as the delay between two actions in sequence, can also be provided. Such notions will be used in the examples in the Results section.

In order to deal with human interaction and human resources management, we propose to extend the semantics of each action by *coloring* it with three new dimensions:

- **context:** it specifies where the action can be executed (e.g. in-patient care, community medicine). Observe that a context is not necessarily a physical place, but it is an operative environment. For instance, community medicine can refer to the patient's home or to the general practitioner's ambulatory;
- **role:** it specifies who can execute the action (e.g. physician, nurse);
- **competence:** it specifies that the action can be executed only by actors with some specific abilities (e.g. pharmacological treatment of abstinence syndrome).

It is worth noticing that not all combinations of values of the three parameters are usually possible. Moreover different actors may share the very same competence. However a competence may assume different meanings according to the role.

[1] In the following, without loss of generality, we will use the GLARE system terminology for action names.

At design time, the specification of a list of possible contexts and of a list of possible roles is mandatory for every action in the *colored* GL; on the other hand the competence dimension specification is not always required. In the case that the competence list is empty, no specific restriction needs to be applied; otherwise, only the actors having the required competences will be allowed to execute the action at hand. Moreover, all dimensions are represented by a list of values, but the interpretation of such lists is different. Context values must be interpreted as alternative ones: in the case that two or more contexts are specified, it means that the action can be executed in any one of the contexts. The same consideration holds for role values: if two or more roles are provided, the action can be executed by any one of the actors. On the other hand, the competence values must be interpreted in conjunction: if two or more competences are specified, the actor responsible for performing the action at hand will need all the abilities.

Example. The action "Brief intervention for hazardous and harmful drinking" (see action 11 in Figure 1, Results section) in the alcohol-related disorders treatment GL [6] is color as follows:

- *context: community medicine, SERT medicine (i.e. an Italian service similar to the Mental Health Service in U.S.A.), in-patient care, hospital care ambulatory;*
- *role: physician, nurse;*
- *competence: psychological support.*

Notification service

As observed in the Introduction, in many real world situations no automatic notification exists to the different actors involved in the execution of a GL on a chronic patient. The issue is particularly critical when an action is followed by another action to be executed in a different context, like, e.g. when a patient is discharged from a hospital, and must be cared by her general practitioner. The absence of an automatic notification exposes the patient to the risk of being "left alone", without any healthcare operator who is formally in charge of her monitoring or treatment procedures; especially when dealing with pathological conditions involving low compliance patients (like e.g. alcohol-addicted ones), it is not really acceptable that the notification to the new responsible actor is up to the patient herself.

Our approach allows to properly deal with this issue, since each action is *colored* with information about context, roles and competences required for its execution. In particular, we have implemented a notification service, which is automatically activated at execution time. By means of this service, as soon as a GL action is completed, all the contexts, roles and competences *coloring* the next action to be executed are collected, and a notification is sent to the proper person or service manager. In this way, the patient is constantly under the responsibility of a proper healthcare operator, and communication with the responsible is always possible for the other people involved in the GL execution.

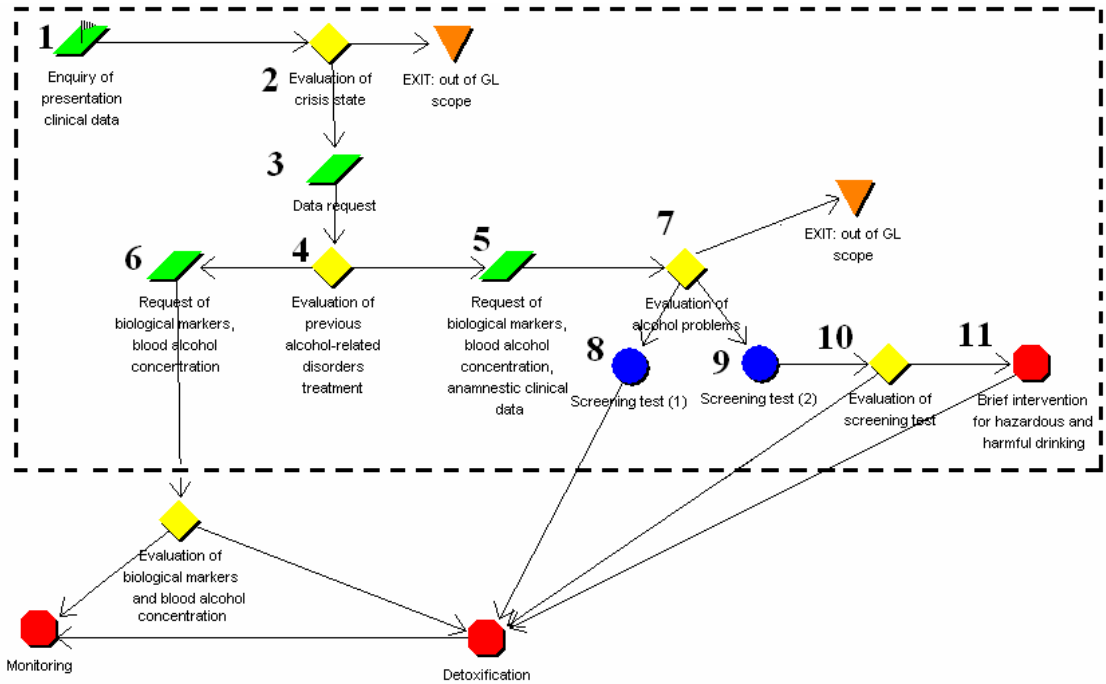

Figure 1 - Part of the alcohol-related disorders treatment GL acquired in GLARE

An example of the notification service use will be provided in the Results section.

Query answering service

In addition to the notification service, we have also defined a query answering service, which may help both individual actors involved in the GL and healthcare service managers.

An individual actor (e.g. a physician, a nurse) represents one instantiation of the three dimensions used to *color* a GL: she works in a context, covers a specific role, and has (or can have) a set of competences (actually the instantiation may be partial, since specific competences may be absent).

By means of our approach, given her "*colors*" the actor is allowed to issue some queries, with the aims of:

- focusing on **what** actions she will **necessarily/potentially** be asked to be responsible of; this type of query can be issued both during GL execution, referring to future actions, or off-line, considering the overall set of actions composing the GL;
- scheduling **when** she will **necessarily/potentially** be involved in the GL execution, and referring to what actions; this kind of query will obviously be issued at execution time;
- discovering **with whom** she will **necessarily/potentially** be involved, i.e. who are the actors responsible for the actions to be executed before/after the ones she is in charge of. This type of query, which can be useful both at execution time and off-line, strongly facilitates interaction and communication.

On the other hand, healthcare service managers (like e.g. hospital administrators, or social services directors) may be interested in issuing queries with the aim of:

- verifying **what human resources** are **necessarily/potentially** involved in a GL execution, and **when**; this type of query, which is useful off-line, allows the manager to properly coordinate and allocate human resources themselves. The information about the list of people covering the same role or having the same competences helps the manager to optimize human resource allocation also when people in the context she manages are involved in different distributed GLs at the same time.

Note that temporal queries are answered resorting to advanced AI techniques integrated in GLARE [7]. Examples of the different query types will be provided in the Results section.

Results

As an example, we present an application of our approach to a GL for alcohol-related problems [6], adapted to the Italian context. We have acquired and *colored* such GL in GLARE. The possible values of the three dimensions used to *color* all GL actions are the following:

- context: Community medicine (C1), SERT medicine (C2), in-patient care (C3), hospital ambulatory care (C4), social services (C5), social voluntary work (C6), family (C7);
- role: physician (R1), nurse (R2), healthcare assistant (R3), social assistant (R4), social worker (R5), patient (R6), relative (R7);
- competence: pharmacological treatment of abstinence syndrome (CO1), psychological support (CO2), family and group approach (CO3).

For the sake of brevity, we will focus on a subpart of the GL, shown in the dashed box in Figure 1. The GL starts with a request of some clinical data (query action 1), used in the following decision action (decision action 2), which is meant to diagnose if the patient is currently experiencing a crisis state. Alcohol-related crisis is outside the GL scope. If, on the other hand, the patient is not experiencing a crisis, her history is collected (query action 3), in order to distinguish whether it is the first time that the patient is in treatment for alcohol-related problems, or not (decision action 4). New patients require the collection of biological markers, blood alcohol concentration and anamnestic data (data request 5), while anamnestic data collection is not needed for patients who were already cared for alcohol related disorders (data request 6). Focusing on new patients, a diagnosis about alcohol-dependence is performed (decision action 7), on the basis of the collected information. In the case that the patient does not show alcohol-dependence, the GL execution is ended. Otherwise, two different treatments can be applied, on the basis of the severity of alcohol-dependence; both start with a screening test (work actions 8 and 9 respectively). Focusing on patients who show a mild alcohol-dependence (work action 9), evaluating the screening test results (decision action 10), the patient can be selected for the brief intervention for hazardous and harmful drinking (composite action 11), which basically consists in a set of motivational interviews. Actions 1 to 11 in Figure 1 are *colored* as described in Table 1.

We now provide an example of the notification service use. Suppose that, during a specific GL execution on a new patient X, the "Evaluation of previous alcohol-related disorders treatment" action (action 4) is performed by actor Y, being Y a social assistant (R4), who is employed in social services S (C5). Being X a new patient, action "Request of biological markers, blood alcohol concentration, anamnestic clinical data" (action 5) will be scheduled for execution next. All the possible responsibles for action 5 (i.e. all physicians (R1) in contexts C1-C4) are notified by the GLARE facility about the fact that one of them should take care of the patient for the needed data collection. If temporal constraints about the action execution are specified in the GL (e.g. if data collection must start as soon as possible, for instance within one day from the completion of action 4) such constraints are provided in the notification message as well. As a matter of fact, they can be of help for the potential actors in scheduling their commitments.

Table 1 – GL actions in dashed box of Figure 1 and their "colors".

Action number	Action description	Context	Role	Competence
1	Enquiry of presentation clinical data	C1, C2, C3, C4, C5	R1, R2, R4	-
2	Evaluation of crisis state	C1, C2, C3, C4, C5	R1, R2, R4	-
3	Data Request	C1, C2, C3, C4, C5	R1, R2	-
4	Evaluation of previous alcohol-related disorders treatment	C1, C2, C3, C4, C5	R1, R2	-
5	Request of biological markers, blood alcohol concentration, anamnestic clinical data	C1, C2, C3, C4	R1	-
6	Request of biological markers, blood alcohol concentration	C1, C2, C3, C4	R1	-
7	Evaluation of alcohol problems	C1, C2, C3, C4	R1	-
8	Screening test (1)	C1, C2, C3, C4	R1, R2	-
9	Screening test (2)	C1, C2, C3, C4	R1, R2	-
10	Evaluation of screening test	C1, C2, C3, C4	R1, R2	-
11	Brief intervention for hazardous and harmful drinking	C1, C2, C3, C4	R1, R2	CO2

Observe that the patient is free to choose among different contexts for being visited and for taking her lab exams, as requested by action 5: she can go to the hospital (C3 and C4), as well as to the general practitioner (C1), or to the SERT centre (C2). The added value of our facility is that all contexts know that the patient is meant to contact one of them; as soon as one context is chosen by the patient, one physician employed there will explicitly accept the responsibility of action 5, and all her

colleagues in the same as well as in the other contexts will be automatically contacted and properly informed by GLARE. It is also worth noting that, if the patient does not contact any context, the notification service can work as a reminder for all potential responsibles. In this way, one of them will then proactively contact the patient, and finally accept the responsibility of action 5.

A set of queries, of the types introduced in the previous section, are now provided as an example of the query answering service use.

Query1: social assistant *Y* (R4) asks off-line **what** actions she will **necessarily/potentially** be required to be responsible of in the alcohol-related GL.

Answer1: she will be potentially involved in the following actions: "Enquiry of presentation clinical data" (action 1), "Evaluation of crisis state" (action 2).

Query2: during a specific GL execution, social assistant *Y* (R4), who has determined that the treatment path will start with "Request of biological markers, blood alcohol concentration, anamnestic clinical data" (action 5) asks for information on the actions to be executed next, in order to verify **with whom** she will **necessarily/potentially** be involved.

Answer2: "Evaluation of alcohol problems" (action 7) is the next, mandatory action to be executed, and can be performed by a physician (R1), in any of the contexts C1, C2, C3 and C4. Depending on the evaluation results, "Screening test (1)" or "Screening test (2)" (action 8 and 9) which are mutually exclusive, will be executed next. Both can be performed by a physician (R1) or by a nurse (R2) in C1, C2, C3, or C4 contexts.

Query3: the responsible of a hospital ambulatory care (C4) asks for information concerning the execution of the "Brief intervention for hazardous and harmful drinking" (action 11) in order to discover what **human resources** are **necessarily/potentially** involved in its execution (take from the GL colors), and **when** (inferred by temporal reasoning [7] on the constrains in the GL).

Answer3: The action is not mandatory during the GL execution, it has a minimum duration of 1 day and a maximum duration of 3 days, and in the case that it will be performed, its execution will be done by a physician (R1), who has the competence of alcohol-related disorders management (CO1), within the 9th day from GL start.

Conclusion

In this paper we have presented an extension of the basic computerized GL management support, meant to deal with human interaction and communication. Such extension is strongly needed when dealing with distributed GLs, which ask for a continuous patient monitoring and treatment, operated in different contexts, under the responsibilities of actors covering different roles and having different competences.

To the best of our knowledge, the existing GL management systems have not explicitly considered this issue yet. It is just worth noting that Fox's group has recently proposed an extension of the PROforma representation formalism [8] in order to specify who will execute an action. However their goal is not the one of managing actor interactions in different contexts: they exploit actor information for better contextualizing GLs taking into account local human resources, and for flexibly adjusting them through delegation.

Our approach is currently integrated in the GLARE system - even though it is general enough to be easily transferred to other GL management systems as well. In the future, we will complete the implementation, and add further facilities. First, we will structure the available contexts, roles and competences information in a hierarchical fashion, by acquiring the needed knowledge from domain experts. This will allow us to better structure the *color* information in the GL actions. Moreover, we have implemented a user-friendly graphical interface, in order to allow the different actors involved in a distributed GL execution to easily and quickly obtain the answers to their typical queries, and to properly deal with communication and resources coordination needs.

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Chapter 5.

Regional and National Information Systems

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LuMiR: The region-wide EHR-S in Basilicata

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Abstract

The Lucania – Medici in Rete (LuMiR) project aims to support the shift from organization-centric to patient-centric healthcare in Basilicata, a region in the southern Italy. Main objective of the project is to foster collaborative, multidisciplinary and cross-organizational healthcare processes by developing and stimulating the adoption of a region-wide, software infrastructure, the LuMiR system,. It is a suite of e-services that facilitates the sharing of patient related clinical data among authorized professionals, by enabling the interoperability among Electronic Medical. In the paper the LuMiR project approach is discussed, pointing out the methodology adopted in the design and development of the LuMiR system, the peculiarities of the system architecture and interventions scheduled to mitigate the risks related to the large scale adoption of the LuMiR system itself.

Keywords:

Electronic health record system, Service oriented architecture.

Introduction

Recent trends in healthcare service delivery promote integrated and patient-centric care, i.e. the continuity and coordination of care, provided by multidisciplinary teams, along the continuum of a disease, and across multiple points of care (e.g. [1]). In these complex processes the timely availability of patient related medical information assists professionals in recomposing the fragmented activities, taking more informed decision, delivering more appropriate care and preventing medical errors. In this perspective the systematic adoption of Healthcare Information Technologies (HITs) is a promising opportunity to innovate the healthcare sector, to protect the economic sustainability of healthcare services and to improve their quality. The LuMiR project[1] intends to support the shift from organisation-centric to patient-centric models of service delivery in Basilicata, by promoting collaborative, multidisciplinary and cross-organizational healthcare delivery processes and supporting them with a software infrastructure that provides services for sharing patient related clinical data among authorized healthcare professionals.

[1] The Lucania – Medici in Rete (LuMiR) project is jointly carried out by the Institute of Biomedical Technologies of the Italian National Council of Research and the Basilicata Region (website (in italian): www.sanitaelettronica.cnr.it/lumir).

Our format introduces the Italian e-Health institutional initiatives which frame the LuMiR project, followed by describing the Basilicata region, its healthcare system, and the heterogeneous environment in which the LuMiR system is to be deployed. The next section describes how the LuMiR approach is presented together with its incremental three-phased life cycle. Architectural details on the LuMiR system are then provided, and additional details on the ongoing implementation activities conclude the paper.

eHealth Institutional Initiatives in Italy

The planning and programming of strategies to innovate the healtcare sector (e.g. [2]) has well as their carrying out has been keeping busy many industrialized countries all over the world. e-Health applications are pervading both the back-office and the front-office of the healthcare delivery systems. At the heart of many complex platforms there is the Electronic Health Records System (EHR-S) [3], a system for recording, retrieving and manipulating information in electronic health records. Such an EHR-S serves a variable set of interdependent clinical, relational, administrative, and managerial needs, according to the specific implementation goals and business processes to support.

Numerous eHealth programs and projects have been carrying out in Italy. The precursors started by regional or local autonomous initiatives (e.g. [4, 5]). The more recent are following European directives and national roadmaps (as described e.g. in [2]). Actually, since 2005, a national permanent eHealth Board (Tavolo di Sanità Elettronica, hereby TSE), was established to carry out a national strategy for eHealth in order: i) to harmonize the eHealth initiatives individually promoted by each of the 23 federated regional governments; and ii) to support a coordinated implementation of a cross-regional interoperable HIT infrastructure.

To this aim the TSE issued an high level conceptual framework [6], as well as an architectural specification for a software infrastructure for distributed healthcare processes, namely the eHealth Basic Infrastructure (Infrastruttura di Base per la Sanità Elettronica, hereby IBSE) [7].

The LuMiR project is the enactment in Basilicata of the GP's Network Pilot Program (Rete dei Medici di Medicina Generale, hereby RMMG). The RMMG program targets the primary care settings in 9 regions of the central and southern Italy. It was funded by the Ministry of Economy and Finance in 2006 and managed by the Department of Technological Innovation

of the Presidency of the Council of Ministers. It aims to foster the implementation and adoption of interoperable regional software infrastructures in order to stimulate and support the cooperation among general practitioners (GPs) or paediatricians and the other healthcare professionals in the delivery of ICT-enhanced integrated healthcare services.

The Basilicata region and the LuMiR Project

The Basilicata region covers 9,992 km², has a population of 596,546 citizens and a very low population density compared to that of Italy as a whole (in 2001about 61 vs 192)[2]. It is the most mountainous region in the southern Italy with citizens mostly concentrated in the major cities and the hinterland villages under-populated. Transport infrastructures are scarcely developed with railroads nearly completely lacking, and only five important highways serving the street traffic.

The Regional Healthcare System has been recently reorganized in two Provincial Health Authorities (PHAs) (the ASP and the ASM), which are entitled of managing and carrying out the delivery of healthcare services for all the welfare beneficiaries. The PHAs directly manage respectively 3 and 4 hospitals, each of which providing both inpatient and outpatient care, as well as many other smaller clinics for outpatient care disperse in the territories. More in details in the Basilicata region primary care is in charge to a total of 510 general practitioners, 70 paediatricians and 140 points of medical guard. Secondary outpatient care is also provided by 108 among public ambulatories and laboratories as well as many more authorized private ambulatories[3]. Secondary and tertiary care is also provided by the San Carlo Hospital Trust, a public hospital autonomous from the PHAs, and by the Crob Oncology Regional Hospital, a regional institute for research and care.

The healthcare processes supporting the daily services delivery sensibly vary from site to site, reflecting the geographical and demographical peculiarities of each area, as well as the distribution and organization of the local healthcare facilities. Also the diffusion of HITs and the level of automation in the healthcare value chain is heterogeneous, even if many local software vendors operate in the market. The software systems deployed in islands of automation include: (i) a certain number of specialized applications supporting operational and clinical activities in hospital departments and/or ambulatories, each one isolated from the others; (ii) only one fully integrated Hospital Information Systems, and (iii) several different EMR for GPs and paediatricians offices. The more relevant existing systems for the LuMiR project are: a registry of welfare beneficiaries' personal data; a cross-organization booking system for outpatient services; a networked service for the management of first aid/hospital admission, discharge and transfer; a distributed authoring tool for medical reports connected with a centralized repository; and a specialized asynchronous cardiac teleconsulting system. In this heterogeneous environment the LuMiR project targets the design, development, and deployment of the LuMiR system, an interoperable EHR-S which interconnects at application level both software-intensive information systems running in individual points of care (Figure 1) and existing repositories which support specific regional information flows.

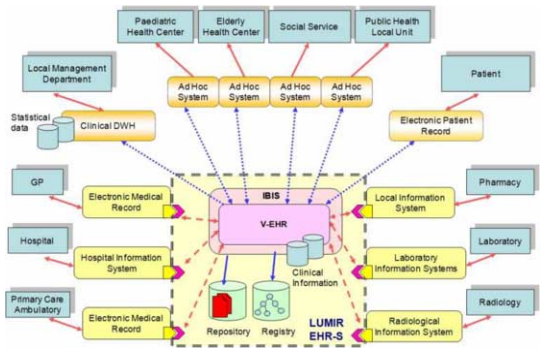

Figure 1- The LuMiR system conceptual architecture

More in general the LuMiR project intends to promote the diffusion of eHealth all over the region, accelerating the modernization process in all the points of care, stimulating the reengineering of business processes and the development of novel services for professionals and citizens. According to the LuMiR project vision, in the long term all the public points of care in the region will be interlinked together via the LuMiR system and all the citizens will be able to freely access the information on their own health status. Other business activities which will indirectly benefit of the LuMiR system are those related with the secondary use of de-identified and aggregated clinical data and information (e.g. management and governance of healthcare organization, epidemiology studies, biomedical and healthcare research, etc.).

The LuMiR System approach

The design of the LuMiR system was influenced by the business requirements described above. It was also constrained by the guidelines issued by the TSE and the technical specification issued by a restricted RMMG harmonisation workgroup, part of which under development at the beginning of the project, and in continuous evolution during the project lifetime. The more relevant principles inspiring the LuMiR system design are: (i) use of multiple views on EHR contents; (ii) promotion of technical and semantic interoperability; (iii) integration of legacy applications; (iv) enforcement of national guidelines and international standards; (v) promotion of reusability; (vi) easy adaptability to changes in the environment; and (vii) assurance of information security and privacy by policy-based configurable models.

Due to the many institutional, organizational and technological issues, the development of the LuMiR system has been based on an incremental life cycle model. In this way a prototype implementing the core functionalities was early available.

[2] 56% of the citizens live in the 12 major cities of the region, 27% live in medium towns (with a population comprised between 5,000 and the 9,999 inhabitants), and the remaining 17% live in the smaller villages which are under-populated.
(Data from the EC DG Regio "Portraits of the region" series http://circa.europa.eu/irc/dsis/regportraits/info/data/en/index.htm)

[3] Data from the Italian Ministry of Health.

It was used to better elicit the LuMiR system requirements with the direct involvement of the end-users following a socio-technical approach. Actually three incremental releases of the LuMiR software infrastructure were scheduled as described in the next section.

The LuMiR system was developed with the aim not only to receive the TSE guidelines and technical specifications, but also to extend them with some additional functionalities, in order to overcome some limitations they present.

The EHR-S is, in the TSE specification, a document-oriented healthcare information system. Actually the core component of IBSE is the Health Individual Broker (InfoBroker Individuale Sanitario, hereby IBIS), which implements an efficient storage of digitally signed clinical documents, by referencing, routing, notifying, retrieving and making them proactively and/or on-demand available to the authorized healthcare providers. This approach is compliant with the Integrating the Healthcare Enterprise initiative's Cross Enterprise Document Sharing profile (IHE-XDS) for cross-organization exchange of patient related clinical documents. In addition, the mandatory requirement that each document circulating in IBIS have to be digitally signed (e.g. by its author) reflects an important business rule in the healthcare domain. Actually it is intended to enforce the legal value of clinical documents (e.g. prescription, referral, certificates) which, in the paper-based daily working practice need to have handwritten signatures. At the same time this approach is coherent with the larger process of paper dematerialization. Nevertheless, it is not completely responding to the end-user need as emerged in the real environments observed in Basilicata. Actually the number of clinical documents related to a single citizen can grow sensibly, especially if a chronicle disease affects him/her. This means that healthcare professionals need value added services through which classify and organize, from a clinical perspective, the huge amount of IBIS contents. Actually if these services are missing the search and collection of a restricted set of meaningful patient related clinical information could reveal not sufficiently efficient and effective. This in turn implies that the overall software system runs the risk to be refused by healthcare professionals. Thus, in order to overcome these limitations, in the LuMiR approach the IBIS specification was extended in two opposite directions:

[1] some additional concepts, i.e. Contact, Episode of Care and Health Issues, were introduced to support different level of classification ;

[2] other additional functionalities were introduced with the objective to refine the course granularity of documents.

In respect of the former intervention, a Contact is a set of Healthcare Services (HCService), each of which provided by an healthcare professional during an encounter with the patient, considered relevant for the patient's healthcare status documentation and described in one or more clinical documents. An Episode of Care is a sequence of correlated and chronologically ordered HCServices associated with a patient Health Issue. These concepts have a quite long tradition in the healthcare literature [8] and also recur in some healthcare standards (e.g. CEN TC/251 EN 13940-1:2006). They offer a mean to classify and organize patient related clinical documents, and can be used to simplify the consultation of a certain patient's IBIS content. In order to support these concepts in the LuMiR system an additional component, namely the LuMiR Infobroker, was introduced. It is described in the next section.

On the other side in order to answer complex and longitudinal user-requests, as for instance in the synthetic grouping or charting of some biological parameters, a set of documents can reveal hard to process. For these kinds of user-request it is preferable to manage smaller chunk of content or atomic structured data and aggregate them according to pre-defined or on-demand forms. In order to cope with this additional requirement, in the LuMiR architecture the Virtual Healthcare Record (VHR) component has been introduced [9]. The description of this component is outside the scope of this paper

Phasing the LuMR system development

In the following LuMiRp0 and LuMiR1 are briefly discussed. LuMiRp0 is an early prototype where large part of the non-functional requirements (e.g. security, privacy and reliability) were neglected. It was rapidly developed in order to be used as a sort of trial environment to carry out a field experiment. It served small groups of selected healthcare professionals, providing them with all the medical information and documents about a restricted set of volunteer patients that where easily collectable, because already archived in digital format in some regional or local healthcare information systems. To this aim the LuMiRp0 system integrates minimal services for sharing and storing patient related clinical data, but introduces to the end-users the key concepts of Contact, Episode of Care and Health Issue described above.

Figure 2 presents a screenshot of the Viewer that physicians operate for browsing patient related medical data. Thanks to the release of the LuMiR p0 prototype, care providers were involved in the project since the early phases, and this made possible to:

- better understand in which situations GPs (paediatricians) and clinicians effectively cooperate together in the care of their patients;
- identify how and in which contexts the LuMiR system could promote a paradigm shift toward integrated care, more centred on communication and collaboration among professionals; simplifying and empowering the daily working practices; and
- identify some measurable quantitative indicators to evaluate the improvement resulting from the new approach to patient care.

LuMiR1 is a distributed, component-based system focused on the interoperability, security, privacy and reliability issues. It is based on a peer-to-peer communication infrastructure and implements a Service Oriented Architecture (SOA). To integrate legacy as well as new client-applications LuMiR1 promotes a standard adapter and various specific drivers that adjust the peculiarities of any of these client-applications at the uniform, standard-based LuMiR1 internal space requisites.

On the server-side the LuMiR1 components include:

Figure 2- Screenshot of the LuMiR p0 system

- the Public Cooperative System software infrastructure (SPCoop);
- the IBIS components for sharing of digitally signed clinical documents;
- the LuMiR Broker which provides high-level services of message dispatching, event notification, document management, and security.

SPCoop is a technical and organizational nationwide large scale e-Government SOA providing network, communication, basic interoperability, application cooperation and security services among jurisdictionally independent public administrations (Domains). IBIS is the document-oriented federated Registry/Repository system in which: *(i)* a federated ebXML-based Registry stores document content metadata; *(ii)* Repositories are storages where electronic documents (pointed at by Registry records) reside and are retrieved by their name or properties; and (iii) Access Gateways (AG) demarcate jurisdictional domains by controlling accesses in/from the domain . According to the TSE recommendations, in the actual implementation of IBIS, the exchanged clinical documents are compliant with the HL7 CDA r2 standard and the ad-hoc restriction defined by the RMMG harmonisation workgroup. Figure 3 depicts the functioning of the LuMiR Infobroker.

From a behavioral point of view, the interaction among the LuMiR1 system, any PoC EMRs (whatever a legacy system or an ad-hoc application), and the IBIS AGs is described in the followings.

During the storage phase:

- The doctor captures with his/her PoC application all the medical information about each encounter with his/her patients. For each encounter he/she, produces one or more correlated HL7-CDA documents, and via an ad-hoc software driver passes them to the LuMiR standard Adapter;
- The standard Adapter encapsulates in an HL7 v3 message the information on the Contact, the Episode of Care and the Health Issue, as well as the HL7-CDA document(s) in attachment, and forwards it to the LuMiR Broker via a dedicated, document-style web-service interface. The standard Adapter is implemented by using messaging-based integration patterns [10];
- The LuMiR Broker processes the received message, extracts the attached document(s), asks to the appropriate AG to store them in appropriate repository and register their metadata in the ebXML Registry. Then the Infobroker stores the information related to Contact, Episode of Care and Health Issue, together with the unique identifiers of the stored documents in the Viewer's repository;
- The LuMiR Broker also notify the information related to Contact, Episode of Care and Health Issue and document(s) metadata to all PoCs who subscribed their interest in receiving the notification ,.

During the retrieval phase

- Healthcare professionals consult the contents of a patient EHR via the Viewer that, apart from technological changes transparent to the end users, looks and behaves as the LuMiRp0 Viewer. More in details the information related to Contacts, Episodes of Care and Health Issues are retrieved from the LuMiR1 Registry, the documents metadata from the IBIS Registry and the documents by the IBIS Repository (Figure 2).

Due to the fact that also the IBIS AG internally contains another Infobroker, this infrastructure actually realizes a two level broker-based architecture in which:

- multiple distributed IBIS AGs, one for each of the SPCoop Domain, interact with each other via the IBIS Infobroker, and
- a centralized LuMiR Infobroker plays the role of an intelligent mediator between PoCs software applications and the IBIS AG infrastructure.

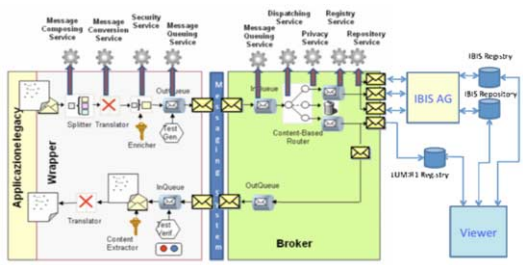

Figure 3-The LuMiR1 InfoBroker

For the system development two different software houses were entrusted of the implementation of different component. Also those software houses providing one of the legacy systems running in the PoCs enrolled in the project, were involved in order to implement software adapters for the integration of their products with the LuMiR system.

Discussion and Conclusion

At the moment the field experiment with LuMiRp0 is concluded in two different public healthcare organizations of the Basilicata Region. The development of the LuMiRp0 and its adoption in the field experiment were burdensome but fundamental activities. On one side, the simplification of the technological aspects facilitated the tasks in charge to the software vendors and allowed a rapid development of the integration adapters. Also the involvement of the software vendors since the early stages of the project has been profitable for the establishment of a collaborative environment and business partnerships, strategic for the subsequent more complex phases of the project. On the other side, the design and development of the LuMiRp0 system, supported with narrative scenarios and focus groups, put the focus on the socio-technical dimensions and the actual business processes, enabling to elicit important system requirements. Also, the set up and execution of the field experiment provided important lessons learned on possible hindrances for the final adoption.

The LuMiR1 system is released this summer, and the field experiences brought us to define a specific roadmap for the large scale adoption of the LuMiR system, in which key activities and their interdependencies were pointed out, and to organise a task force, in charge to support and monitor the adoption process. Actually, at the beginning the LuMiR project was mostly driven by the goal to develop and deploy a software platform implementation, nevertheless the additional efforts spent in disseminating and fertilizing the ICT-enhanced patient-centric idea, in supporting the redesign of more patient-centred primary care business processes, and in assisting and coordinating the software vendors for integrating their legacy application during the field study revealed even more important.

The design of LuMiR2 system, which will integrate data from the clinical documents into a VHR for each citizen, is in progress.

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Experience Implementing OpenMRS to Support Maternal and Reproductive Health in Northern Nigeria

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Abstract

In Northern Nigeria a deteriorating health system has resulted in one of the World's highest rates of maternal and infant deaths. The dire situation in Northern Nigeria is only amplified by the lack of an effective health information system, leaving hospitals and clinics to make decisions about patient care with only uninformed guesses about medical history and access to unreliable and unintelligible patient registers and summary reports. In 2009 we implemented an electronic medical records system using OpenMRS for the Family Health Unit of the Shehu Idris College. The three-month process resulted in electronic forms for all clinical areas, greatly reduced data duplication and a monthly reporting process that takes minutes instead of days. This system provides not only access to the first patient-based health indicators in Nigeria (as opposed to previously error-prone aggregate data) but is also an example of the potential to overcome the harsh computing environment in Nigeria to implement eHealth systems that will improve the quality of patient care.

Keywords:

Computerized medical records systems, Nigeria, Reproductive medicine

Introduction

The Problem of Maternal/Child Health and Information Management in Northern Nigeria

The risk of a woman dying while giving birth in Nigeria is 1 in 18. In the poorer Northern parts of the country it can be as high as 1 in 13. For every woman that dies giving birth there are another 30 who suffer long-term and chronic ill health [1]. The story of child survival in Nigeria parallels that of motherhood with as many as 71 neonatal deaths in 1000 live births. A complete collapse of this system is only hindered by numerous NGOs and private foundations that in 2000 accounted for almost 90% of all health care spending [2]. While there now exist free or low-cost maternal and child health clinics, supported by several local and international agencies, these clinics are burdened by various paper-based "health information management systems". A typical data point is recorded 3-4 times and manually summarized monthly and quarterly. It can take weeks just to find the number of patients that attended a particular clinic. If it is not a research hospital or clinic (or specifically required to keep track by external funders) this information might not exist at all [3].

Towards a Viable Health Information Management System for Reproductive and Maternal Health with OpenMRS

To address the problem of maternal and child health and this crisis of information in Northern Nigeria, a team from the University of California Santa Cruz and the Shehu Idris College for Health Sciences and Technology (SICHST) put together an electronic medical records pilot at the Demonstration Clinic for the Family Health Unit (Asibitin Yara) in the Tudun Wada area of Kaduna. This pilot system, based on OpenMRS, is a complete clinical data system collecting information on antenatal visits, labor, child health, immunization and family planning. Between 60-100 clients and patients visit the clinic each week day and have their patient records created and updated without hindering or slowing patient care.

Methods

We describe the process to initiate a electronic medical records pilot and briefly explain how we identified the information "flows", technical literacy of clinical staff and the clinical use of computers and other technology. We then describe the process of converting the forms from each clinical area into OpenMRS, how the training was carried out, the design of the data entry procedures and how various technical and infrastructure issues were addressed.

Lastly, as of the writing of this paper, the pilot process is ongoing and in the process of expanding. We will describe the future expansion plans as well as plans to enhance the system to support clinicians at "point-of-care".

Results

A Clinical Information Needs Assessment

Beginning in June 2009, Evelyn Castle carried out an information needs assessment for staff of the SICHST Demonstration Clinic. The process began with a self-reporting survey to identify the use of information technology as well as skill and comfort level in both personal and clinical settings. The surveys were accompanied by in-context interviews and participant observation with ethnographic fields notes. Other clinical information needs studies have found the desire for "just-in-time" information at point-of-care and generally a need for ready access to patient-centric data [4, 5]. However in the Nigerian context there were significant barriers to information access including illegible handwriting, frequently missing patient cards, missing or broken equipment (ie for weight, blood pressure, etc) and social stigma especially around reporting HIV status, alcohol use and sexual history. These barriers resulted in a clinical culture where most types of data were rarely sought after, regularly seen as unavailable, and often not collected in the first place. The ONLY motivation for data collection, storage and reporting was because of mandate by the state government which sponsored this free clinic for women and children.

The SICHST Demonstration Clinic

The SICHST demonstration clinic is a government funded clinic in Tudan Wada, Kaduna. It provides free antenatal care, labor services, immunizations, child health care, family planning services, and reduced prices on pharmaceutical drugs.

Table 1 – SICHST staffing and workflow

Staff		Patients/Clients	
Doctors	0	Antenatal	60/day
Nurses	9	Child	40/day
Consultants	3	Immunizations	100/wk
Records Clerks	3	Family Planning	10/wk
Pharmacists	4	Labor	3/wk
Midwives	2		
Nannies/Guards	6		
Other Staff	3		

The staff at the clinic is made up of mainly women. Their age range is from straight out of school (22) to near retirement (65). The clinic is also frequented by young students doing practicals for their degree from SICHST. The technical experience of the staff is very limited. All of the staff owns a cell phone which they use frequently. The matron has a computer in her office, however she is unable to use it. Two of the Records Keepers have used computers in the past. Two of the consultants have used computers in the past and one is currently attending a computer programming class. Also, one of the pharmacists uses a computer for recreational purposes. Of the five staff members who are familiar with computers, 4 of them are male. No staff member had any knowledge of electronic medical record systems.

The use of technology in the clinic is non-existent. It contains one computer, which is not used. The only other technological devices it has is a television, a broken autoclave, a generator, and lights. The clinic receives light from PHCN infrequently and irregularly. When PHCN did supply power the voltage is too low to run many devices. The only reliable source of electricity came from the generator, which is often being refueled and repaired.

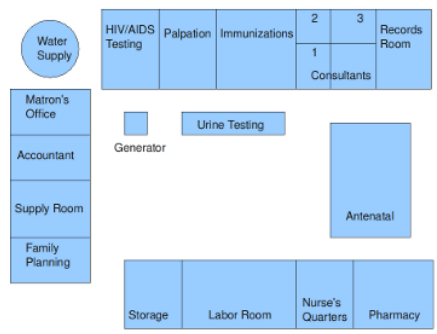

Figure 1-Layout of SICHST Demonstration Clinic

Clinical Records

Record Keeping at the clinic is all recorded on government forms or in hand-made log books.

Table 2 – Record keeping

Forms	Log Books
Antenatal, Immunizations, Family Planning, Child Health Care	Antenatal Check-in, Immunization, Out-patient register, labor and delivery

At the end of each month, the staff in charge of Record Keeping goes to each department and collects the information required by the Kaduna State Government. The information is gathered by going through the log books and counting each entry, one-by-one. The Kaduna State Government Monthly Summary consists of 7 pages with 76 questions, and 8 pages of tables. Each month the clinic is only able to supply answers to about one-third (1/3) of the questions.

Implementing OpenMRS

OpenMRS was quickly chosen as the platform from which to develop an electronic health information system to support maternal and child health because of it's existing deployments in similar low resource environments (ie Rwanda, South Africa and Kenya) [6, 7]. OpenMRS also existed in a range of deployment sizes from small clinics and large hospitals to networks of care centers. In addition OpenMRS was quickly able to be customized to support not only patient-based data

management but also aggregate data at the clinic, district and state level [8].

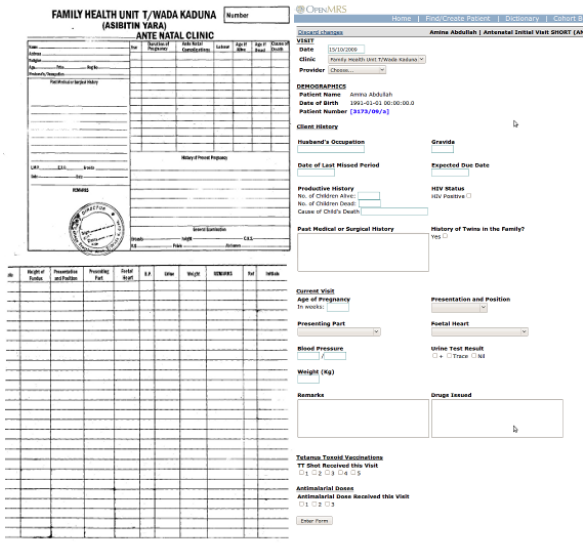

Figure 2- Antenatal Paper Card vs eForm

At the SICHST Clinic, the focus was to record Antenatal, Immunizations, Family Planning and Labor forms using OpenMRS. Two other departments, Child Health Care and Pharmacy would not be converted at this time since (1) there were no permanent paper forms and (2) in order to record these areas without extra burden, other equipment would be needed that there was not yet sufficient budget and training time.

The form conversion process did not result in an exact electronic copy of the paper form as is common for other OpenMRS implementations [7]. Instead since the patient cards were rarely completed in a correct or systematic way the electronic forms were made to match data that was ACTUALLY collected by the clinician. These electronic forms were revised over several iterations that involved simplifying data entry, adding drop down lists and check boxes whenever possible to speed up data entry. As well as creating alternative "short forms" to remove the clutter of other data fields that simply were not collected on the patient cards or registers.

To manage the data entry process a schedule was planned out after observing how the clinic runs and which services are offered each day. The volume of each service on particular days was such that the two data entry clerks could not keep up with the volume of data entry. Thus data entry was spread through the week and other staff that had computer skills would assist with back-log when time permitted.

	MONDAY	TUESDAY	WEDNESDAY
IMMUNIZATIONS	Enter all given today Enter all given Friday	Enter all given today	Enter all given today
ANTENATAL	Finish Thursday	Enter all from Monday	Enter all from Tuesday
LABOR	Enter all from Friday and over weekend	Enter all from Monday	Enter all from Tuesday
FAMILY PLANNING			

Figure 3- SICHST Demonstration Clinic Data Input Schedule

Reaction to OpenMRS and the Trainings

The initial reaction by the staff to OpenMRS was very positive. Most people at the clinic had never used a computer before but all claimed to be willing to learn. The people with past computer experience were more interested in learning OpenMRS.

Initially, training began with the two men in the Records Department, both who had previous experience with computers. They were able to understand OpenMRS and navigate the patient creation, patient look up and encounter form entry after only hours of introduction. The problems encountered while teaching were: language barrier, spelling errors, typing speed, and overall speed on computer. The clinic handles a large volume of clients each day and the overall speed of the two Records Keepers was not fast enough to record all the patients every day.

One of the causes of the overload of input data was because patients were coming for return visits. The Records Keepers not only had to input the information from the current visit, they were also required to enter the information from all the prior visits. We tried to combat this problem by focusing on entering in immunizations first (only the shots that children received during their current visit), then first time Antenatal clients, then second time Antenatal clients, and so on. Normally, we were able to finish all immunizations, and all first and second time Antenatal clients. However, in order for the Monthly Reports to give an accurate number of Antenatal clients and services, they will need to enter in the visits for all patients. This is projected to ease slightly with time as more and more of the clients/patients will have existing records in OpenMRS.

The other staff that received training were two women from Family Planning and two women from the Labor Department. After experimenting with teaching methods, it was concluded that it was most effective to have one of the men from Records do the teaching. The language barrier was too difficult to overcome and the staff seemed more at ease learning from one of their own colleagues.

OpenMRS Technical Setup

The computing environment even within the State's capital (Kaduna) proved to be very challenging. Another review of health informatics systems in Nigeria found the technical barriers to be the primary reasons for little to no adoption of these systems [3]. To combat the inevitable power and

maintenance issues, a simple setup was designed that used an OpenMRS server running on a single low-power Inveneo computer with a 500mhz processor, 1Gb RAM and a 40G hard drive. This server was connected to a network with another identical Inveneo machine. Another low-power ASUS Eee Laptop was connected via wireless when another data entry clerk was available. Both desktops were connected to battery backups that provide for two or more hours of work time when electricity from the "grid" or the generator were unavailable. Besides being simple to maintain, the equipment cost was under $1500 (USD). Other technical barriers revolved mostly around the clinic facility itself where several rooms did not have doors, locks, or correctly wired electrical outlets.

Discussion

Feedback from Clinical Staff

The implementation of OpenMRS proved to be very beneficial overall. Not only was the staff excited to learn OpenMRS, but they were also determined to keep the system running and up-to-date.

The clinic staff identified the following benefits of OpenMRS on their work in the clinic:

1. Saves time each month over gathering information manually
2. Gives an accurate report without human mistakes
3. Allows for more detailed analysis of data
4. Encourages staff to collect completed forms
5. Increase in clients because computers are associated with an advanced clinic

The feedback and buy-in from clinical staff was important early on. Having feedback rapidly implemented in the system created a high-level of personal and organizational investment into the system even after the main project implementors were no longer in-country.

Expansion Beyond the Demonstration Clinic: eHealth and Information Systems Nigeria

Nigeria is currently undergoing a public health crisis with regards to maternal and child health [9, 10]. In order to address this crisis, Nigerian clinics, hospitals and policy makers will need access to timely and accurate health information that can both influence policy as well as support patient care. To this effect it will be necessary to address the lack of an eHealth "ecosystem" in Nigeria. To support a robust health care information system, equipment vendors will need to exist that can provide low-cost, low-power equipment. Software and support service professionals will need to have the skills and expertise in implementing, customizing and extending platforms like OpenMRS. The authors of this paper are working towards these ends by (1) working with the SICHST to update a national diploma curriculum on Health Information Management Systems to include much more in-depth knowledge and hands-on experience with OpenMRS and other eHealth systems, (2) working with local vendors and software developers to understand the eHealth environment and provide equipment and services at reasonable costs and (3) creating effective partnerships with academic institutions, local and international NGOs as well as government institutions, to ensure a viable and sustainable health information system (see [11] for more discussion on creating effective eHealth partnerships).

Future Plans

Currently the Pathfinder International staff in Nigeria are evaluating our OpenMRS implementation and working with us to plan an expanded pilot in several clinics and hospitals that they manage and support financially. The goal is to have an "OpenMRS Nigeria Express" setup that will have ready to deploy hardware, software and power sources to extend the reach of important health informatics work into even rural parts of Northern Nigeria.

Conclusion

This project is a demonstration of the dramatic potential to revolutionize health information management in Northern Nigeria, possibly effecting millions of women and children over the next few years, with very little extra required in terms of resources, time and money. In many cases an effective and expanded use of OpenMRS will save time and money while opening up completely new possibilities for improved quality of care. The data collection alone will provide a never before seen view into the maternal and child survival crisis allowing the local and international community to come together and stay motivated and updated with important near real time information.

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We thank the SICHST for all of their support and guidance as well as the entire team of the Demonstration Clinic that quickly took ownership and are committed to improving maternal and child health. We also thank Dr. Mairo Mandara for providing so much support and guidance. We thank the staff at Pathfinder International in Kaduna for showing interest early and providing helpful guidance and critique.

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Using Electronic Medical Records for HIV Care in Rural Rwanda

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Abstract

Partners In Health (PIH) implemented an electronic medical record (EMR) system in Rwanda in 2005 to support and improve HIV and TB patient care. The system holds detailed patient records, accessible to clinicians through printed reports or directly via a computer in the consultation rooms. Ongoing assessment of data quality and clinical data use has led multiple interventions to be put in place. One such evaluation cycle led to the implementation of a system which identified 15 previously undiagnosed pediatric patients with HIV. Another cycle led to an EMR intervention which helped to decrease the proportion of completed critical CD4 lab results that did not reach clinicians by 34.2% (p=.002). Additionally an automated data quality improvement system reduced known errors by 92% by providing local data officers a tool and training to allow them to easily access and correct data errors. Electronic systems can be used to support care in rural resource-poor settings, and frequent assessment of data quality and clinical use of data can be used to support that goal.

Keywords:

Computerized medical records system, Developing countries, Information systems, HIV

Introduction

EMR in Rwanda

PIH has eight years of experience implementing EMR systems in resource-poor rural settings where meeting infrastructure, logistics and human resources needs is challenging [1,2]. The deployment of an EMR in Rwanda is a single intervention designed to meet multiple needs including improving direct patient care and decision making through access to summary chart data, printed summaries, using automated alerts and reports to ensure consistency of care and to aid follow-up. The system also allows the efficient production of aggregate data for administrative, monitoring and evaluation purposes, and to enable both research and reporting as required. Since the original implementation of PIH's EMR in Rwanda, the system has undergone numerous improvements and expansions. The current system is based on OpenMRS, an open source web-based EMR system that was co-developed by PIH and the Regenstrief Institute [3,4]. It is currently used in 16 PIH-supported health centers in Rwanda, as well as the government's HIV clinic in the capital city. By early 2010 the PIH Rwanda EMR held over 10,000 HIV, TB and heart failure patient records. This system is currently being expanded for general primary care use to support the Rwandan Ministry of Health's planned national implementation of OpenMRS across health centers.

Database setup

The EMR system is used in two provinces in Rwanda, and a separate database is maintained for each of these regions. In the Eastern Province, where solar power systems and internet access exist in the remote health centers, each health center runs a local server which is synchronized over the internet to the district hospital-based 'parent' EMR server. In the Northern Province, where electricity is not yet at all health centers, and only the district hospital has internet, data officers travel to the district hospital to enter the health center data into the shared database, and then return to the health centers with printouts of the upcoming week's consultation summaries.

Software Development

The PIH Rwanda EMR program currently employs two programmers who are based on site at one of the rural district hospitals, and develop modules and system improvements while immersed in the context in which the technology will be used. A key feature of OpenMRS is the modular nature of its architecture which allows programmers to develop and add additional functionality to the EMR without impacting on the code base of the system. This arrangement has allowed the software development to be adaptive, which is particularly beneficial in a complex low-resource environment.

Staffing

The organizational structure of the program is designed to maximize collaboration between PIH and the Ministry of Health (MOH) and build capacity within the MOH structures. All data officers who are based at the health centers, while currently funded by PIH because there is not yet a national EMR program, have employment contracts with the MOH. This allows the program to be part of the normal health center activities, which will increase the sustainability of the program. Employed by PIH centrally and providing support across all sites are a Data Quality Coordinator, Reporting Coordinator, Team Coordinator, Program Manager, Program Director, IT Officer and Software Programmers.

Data Collection

Almost all data collected by the EMR system is unambiguous, coded data. Collecting high quality data in the field is of critical importance to ensuring patient safety and quality of aggregate data. Input from clinicians, data managers, and researchers was incorporated into the design of the encounter forms that are currently in use in the field and are able to be updated to accommodate changing circumstances.

Clinical Use of Data

By prioritizing quality of care and placing an emphasis on clinician-oriented data tools, PIH's EMR program is currently working to maximize the amount of benefit from the system that flows back to clinicians, and therefore patients. In doing so, the system provides incentive for clinical staff to feel invested in the system and to prioritize accurate data collection as well as detection and correction of existing errors. Currently HIV clinicians at all 16 sites that use the EMR receive a printed consultation summary report each morning for patients scheduled for a visit that day. The summary sheet contains the patients' name, age, gender, program, three most recent recorded weights and CD4 counts, as well as their treatment regimen, and community health worker. An alert column indicates if the patient has a declining weight or CD4 count, and if their CD4 count is overdue. In addition to regular EMR reports, other data is provided to clinicians on request, such as lists of underweight patients, those at high risk requiring cervical screening, patients with renal failure. Lists of patients who are lost to follow up are provided to allow community health workers to make contact with the patients and encourage them to return to care.

Aim

The aim of this paper is to document the process of identifying areas within the electronic medical record program requiring improvement and implementing interventions to improve the quality of the patient data and to increase the usage of the clinical data for directly improving care in sixteen rural health centers in Rwanda. Brief case studies of four identified areas of need and the implementations and outcomes are described. These areas include decreasing errors in electronic data used by clinicians, improving transmission of CD4 results to clinicians caring for HIV patients, increasing clinician direct access to electronic patient summary data and increasing detection and program enrollment of HIV positive children.

Materials and Methods

Program auditing and process analysis were used to determine areas of the EMR program which could be modified to improve clinical care. The process in each case was the identification of needs through discussion with clinicians and the data team and analysis of existing data and workflow. Following identification of need areas the technical aspect of the intervention was undertaken, which included drafting necessary software tool requirements, and designing, developing and implementing the software though an iterative process between program manager, data team, clinicians and software developers. Other aspects of the intervention were also undertaken including provision of equipment, data officer training, clinician training and workflow adjustment. Each area identified for intervention was then evaluated.

Data Quality

This assessment focused on data which was directly used by clinicians for decision-making. In response to the identified needs, an automated data quality tool with emailed data quality report was developed for and implemented in OpenMRS. The developed tool allowed for customized definitions of data errors, for example people currently registered in the TB program that do not also have a current anti-TB drug regimen prescribed in their record. Each health center had a separate link to a data error report, which provided a real time list that linked to all patient files with a known data error. Additionally a weekly report was sent to the Data Quality Coordinator and data officers which listed the progress of data error correction in each site. Eight data errors types were defined and programmed in July 2009, and data officers and managers were trained to utilize these software tools to efficiently identify errors and initiate processes to correct them in collaboration with clinical staff when necessary. Incorporating input from data officers, a second round of error types were identified and automated lists were created.

To evaluate the impact of this intervention, the total number of errors detected was tracked on a monthly basis beginning with the implementation of the first automated lists. The total number of errors corrected was also tracked.

Access of laboratory results

The current process in place to support clinical decision making is based on patient summary data being available to clinicians along with alerts and reminders. Among the key variables for decision making for the clinicians that we support for HIV are patient drug regimen, weight, height, and CD4 count. CD4 count testing is a critical measurement to gauge the state of the patient's immune system and for clinicians to initiate antiretroviral HIV therapy (ART) or to identify treatment failure. Measurement of CD4 levels indicates how far the disease has advanced and the risk to the patient of complications or opportunistic infections. This test is usually performed every six months and is critical that clinicians be able to access the results of this test during a patient's consultation.

The existing method of communicating CD4 laboratory results to clinicians was identified as requiring improvement. The Rwinkwavu District Hospital laboratory processes CD4 count tests for two district hospitals and all health centers in the Kayonza, Kirehe and Ngoma districts in eastern Rwanda. CD4 count test result follow-up visits are scheduled a minimum of seven days after the test sample is obtained to allow sufficient time for transport of the test sample from the health center to the laboratory site and for sample processing and result return.

Before the introduction of the OpenMRS laboratory system, these paper-based laboratory results were entered into a static database on the laboratory workstation, which was stored locally and not integrated with the EMR system. Test results were then printed and transported back to the health center by hand or emailed to those health centers with internet connectivity available. At worst, printed test results were delayed in transit, and at best, clinicians were required to cross-reference

an individual patient's record with multiple laboratory result reports during the clinical visit to be recorded on the encounter paper form. Patients with lost ID cards often had a new patient record created in the laboratory system due to an inability to easily cross patient data in the EMR, making their CD4 data difficult to access.

Problems identified from this nonintegrated system were that clinicians did not always receive the most recent CD4 result on patient summary sheet printed from the EMR. The solution devised was to develop and implement a laboratory order and entry system in OpenMRS tailored to the clinic workflow, and to conduct a quality improvement evaluation. Based on a detailed requirements document, a new module for OpenMRS was developed to allow laboratory orders and results to be entered directly into the EMR system by data officers based in the Rwinkwavu laboratory and these results are being recorded directly into the patient's electronic record.

The usefulness of migration to the OpenMRS-based laboratory information system in reducing use of outdated CD4 count test results in assessments for HIV patients was also evaluated. Laboratory CD4 count test result data was collected from laboratory paper register logs for a 30 day period in January 2008, prior to the implementation of the OpenMRS laboratory system, and for an additional 30 day period in June 2009 following the completion of the implementation period. A period of one month was chosen based on power calculations which indicated a sample size of 474 would be sufficient for 80% power based on a 2 sided test with alpha = .05.

Each HIV patient encounter at the clinic required the clinician to complete a paper initial or return visit encounter form for the patient's chart – which included a space for recording the patient's most recent CD4 count. A CD4 result from the January 2008 and June 2009 date range was included in the sample if the patient with the test result also had a return visit encounter in the EMR and did not have an initial visit (where finding the initial CD4 is crucial to conducting the encounter) within 60 days after the test result. The clinical data was collected from the paper return visit encounter forms in the patient chart. For the purpose of this exercise, successful receipt of an up-to-date CD4 count test result was confirmed by a matching CD4 count value in the laboratory paper register as entered by the lab technician and on the return visit encounter paper form as entered by the clinician. Assuming the laboratory result registers are correct, this frame of analysis allows for the capture of all possible errors occurring throughout the transmittal process that could prevent successful delivery of the result. All cases of non-matching CD4 count values were investigated to attempt to identify the source of the error.

Data for all sites and for both pre-ART as well as ART patients were included in the evaluation. Exclusion criteria for patients with a CD4 result during either examination period were if a follow-up visit did not occur between 7 and 60 days following the test sample date, if the laboratory register recorded "no result," and if the patient had multiple CD4 counts in the 30 day period. The data was collected by EMR data staff with existing full access to patient medical records as part of their employment, and names were removed for analysis. Data officers were unaware of the CD4 count result from the lab register when recording the CD4 count that the clinician had written on the form.

Clinical Decision Making

After the conclusion of the intervention to improve access to laboratory results, the assessment was made that while an integrated laboratory system can help to improve the transmission of the data, relying on paper copies to be produced from the EMR still allows room for lost results. Patient consultation summaries were already being produced from the EMR that included brief pertinent information that could fit across a page and accommodate data for all patients scheduled to attend the clinic that day. This however did not account for patients who arrived at the clinic for an unscheduled visit. It was also limited to only providing a minimal set of information due to the format and space available. To expand clinician access to data for decision making, including access to graphs of key care indicators like CD4 count and weight, direct access to the system was required.

Training for HIV clinicians was conducted in June 2009 on how to log in to the EMR, look up patients, and use the data in patient summary. The training was led by data officers from several of the sites in which the clinicians work, so that they could serve as the onsite trainers when needed. Another required step for implementing direct look up was the purchase of laptop computers specifically for this purpose and configured and supported by the EMR IT officer for low maintenance (i.e., running Ubuntu, unneeded audio/visual componentry removed, locked to the desk). Due to a delay in acquiring the equipment, laptops were unable to be placed in all consultation rooms until September 2009.

A need was identified within the EMR program to assess if clinicians and data team were using the system to access patients files, how the system was being used, and to examine periods of heaviest system use. A usage auditing module was developed for this purpose, and deployed on one EMR server.

Targeted High Risk HIV Testing

A key benefit of the EMR system is the ability to automate real-time reports that would take many hours of work to compile under a paper-only system. A need was identified in enabling the EMR to support earlier identification of pediatric HIV cases in children of known HIV infected adults. The impetus for this is that early initiation of HIV care and ART in pediatric patients is associated with decreased mortality [5].

In April of 2008, an automated report was created to track untested children of HIV positive parents who were newly enrolled in the HIV program at any of seven PIH-supported health centers in Rwanda. If a parent's test result was positive, they are enrolled in an HIV treatment program and their paper intake form is entered into the EMR system. On a weekly basis, an automated report is produced that lists all children of HIV positive parents enrolled in the program who have not been tested for HIV as reported by their parent. This report is automatically emailed to the pediatrics department where the Pediatric Coordinator manages the database and the then work with the social workers and village-based community health workers to contact the family and have the child attend the health center for HIV testing.

Children who test positive are immediately enrolled in the pediatric HIV program, through which they are provided with comprehensive HIV care. To evaluate the impact of this intervention, the total number of children identified has been tracked on a weekly basis beginning with the implementation of the first automated lists. Of these children, the number tested and the number that tested positive was also tracked.

This study was approved by the Brigham and Women's Hospital Investigational Review Board

Results

Data Quality

The development and implementation of the automated data quality improvement tools, along with the training of data officers, led to a 92% decrease in eight pre-defined data quality errors (1064 errors corrected) in the first four months of implementation (Figure 1). Limits and ranges applied to concepts within the EMR identified existing errors including over 9,000 observation dates in the future, and will prevent such errors in the future. Feedback regarding use of the data quality OpenMRS tools was positive, and the training was well received by data officers. A user-friendly interface and automated weekly reminders have helped keep these tools in use.

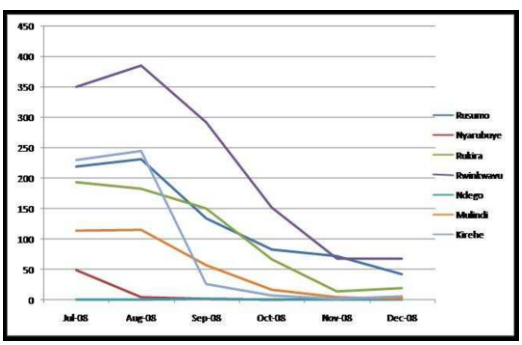

Figure 1 –Defined Data Quality Errors by Health Center Before and After August 2008 Data Quality Tool Implementation

Access to laboratory results

After patients who did not have a visit within 60 days of their CD4 test were excluded there were 457 patients in the January 2008 sample, pre-intervention and 545 in the June 2009 post-intervention sample. Exclusions due to incomplete charts and multiple CD4 counts in the same month decreased the sample size to 412 for and 493 respectively. The proportion of patients who completed CD4 counts within 60 days prior to their visit whose recent result was unknown to the clinician at the time of consultation was 24.7% pre-intervention and 16.7% post intervention, representing a 32.4% reduction in CD4 loss, a change which was found to be statistically significant ($p=.002$, $\chi^2=9.146$). There was no statistically significant difference for either sample period between lost CD4 counts and the age, gender or CD4 count range of the individual patients.

Clinical Decision Making

The response to clinician training on the EMR was positive, with over 30 HIV clinicians attending. In addition to this training, data officers at each health center were instructed to provide ongoing clinician support for computer and EMR use.

The equipment was successfully placed at each site and clinicians were able to access the EMR providing electricity and the local network were functioning. Prior to any additional formal training for clinicians, the usage audit tool was launched, showing that over a 21 week period between October 2009 and March 2010, 18 HIV and TB clinicians directly accessed the electronic records of 1752 patients. The number of patient records accessed ranged between two and 520 per clinician, with seven clinicians accessing over 100 records.

Targeted high risk HIV testing

In an assessment period covering six months the automated report of untested children with HIV positive parents resulted in 178 children being tested, with 41 currently awaiting results, 122 testing HIV negative and 15 who were found to be HIV positive. Due to their identification through the EMR, the HIV positive children are all now receiving comprehensive care, with seven of them receiving ART.

Table 1 – Summary of Audit Case Study Findings

Issue	Description	Intervention Method	Outcome
Data quality	Data errors existed in variables used for clinical care	Developed automated data quality tool and report and provided training	92% reduction in defined data errors
Access to laboratory results	Clinicians not having access to patients' most recent CD4 count during consultation.	Developed an integrated laboratory system in the EMR	32.4% decrease in CD4 counts that did not reach clinicians
Issue	**Description**	**Intervention Method**	**Outcome**
Clinical decision making	Clinicians not having direct access to comprehensive electronic patient summaries	Improvement of a patient summary module, development of an EMR-use audit tool, placement of laptops in consultation rooms	1752 patient records looked up by 18 HIV/TB clinicians in a 21 week period
High risk screening	Missing opportunity to used medical record data from HIV+ adults to ensure screening at their at-risk untested children	Developed an automated email report alerting weekly of any new untested at-risk	15 patients found to be HIV positive and enrolled in pediatric HIV program

Discussion

Each of the four areas of intervention led to a change in behavior and practice in the health centers. Efforts in training and changing workflows were very important in accomplishing this. In particular in each of these cases it was key to understand the user's needs, and ensure that a technological solution alone was not implemented. Data problems decreased sharply once data officers were aware of the existing problems. From this experience we learned that what is needed to continue to improve quality is to add additional pre-defined data errors to the data quality tools, and to increase automation of error reporting as well as primary prevention of data errors. Similarly with increasing detection of the pediatric HIV patients we saw that this type of report being automated from the EMR, with a documented process of what actions are taken when the report is received, can lead to improved program quality and have real clinical impact. Automated high risk patient screening reports are likely to have a clinical impact, provided that the processes and workflows surrounding them are sustainable.

Clinician access to information was addressed in both increasing access to laboratory results and allowing direct lookup of patient data. In this regard many of the hardware and software challenges have been overcome, but training clinicians on using the system and ensuring it is designed to respond to the clinician's needs remain the challenges. In particular there was a long unintended gap between training clinicians on looking up patients in the EMR and in providing the equipment for them to be able to do so. Some clinicians used the system only infrequently, and discussion with them will be required to better understand if there are hardware, software, training or workflow changes that could increase the usefulness or ease of use of the system. Due to the development of the audit module as part of this process, it is now possible to observe if there are changes following trainings or after the addition of clinician-requested features to the EMR. An additional need for a re-evaluation of clinician access to CD4 counts will take place after the clinicians have had further training on direct access to the system. Establishing a cycle of audit and quality improvement in the EMR program will allow for faster progress towards having the most effective and useful system possible.

Conclusion

Multiple strategies have been employed to improve EMR data quality and use of the data to improve patient care. Experience from the capture of HIV, TB and chronic care patient data has shown that as the PIH OpenMRS program in Rwanda continues to expand, in particular to include capture of all primary care data, the need for automated and user friendly tools to assist in data quality and clinical care will increase.

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Key Common Determinants for Adoption of Wireless Technology in Healthcare for India and Pakistan: Development of a conceptual model

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Abstract

This study explores the perception and views of healthcare professionals in the subcontinent (India and Pakistan) towards the wireless handheld technology in the healthcare setting. A mixed methodology was adopted to explore the determinants of the wireless handheld devices in the healthcare setting. Interviews were conducted with 30 healthcare professionals to explore the initial themes. This was followed up with a survey instrument, specifically developed for this study, and distributed to 300 healthcare professionals in Pakistan and India. 200 useable surveys from India and 97 from Pakistan were received. The results of the study indicate that healthcare professionals felt that to use the wireless technology, the integration of the clinical and operational process is essential. Factor analysis through SPSS showed that any development of technological solutions for handheld devices would benefit, by considering the clinical, technological, and operational influences of the wireless technology in addition to clinical influences, clinical preference, training, and technical support. The study culminated in the development of an initial conceptual framework. The scope of this study is restricted to wireless handheld devices such as the smart phones, handheld PCs and PDAs.

Keywords:

Wireless technology, Healthcare, PDA's, Handheld

Introduction

Technology Acceptance Model (TAM) asserted 'perceived ease of use' and 'perceived usefulness' as the determinants in predicting the acceptance of technology in a given setting. These constructs were found reliable in many Information Systems studies. However, when these models were tested in a healthcare environment, the perceived ease of use was not found to be significant [1, 2]. Furthermore, other studies also established that the perceived ease of use was not a significant predictor of technology acceptance in specific clinical domains [3, 4]; Hu et al., [5]. While studying the dynamics of IT adoption in a major change process in health delivery, TAM was found inadequate [6]. In introducing electronic patient records into hospitals, it was found that relative advantages, available strong network externalities, and the rich availability of information through different communication channels influenced technology adoption [7]. While measuring the physician's understanding of online systems use, the physicians' behaviour, their workflow practices and their perceptions regarding the value of specific information systems were found to be more significant than the perceived ease of use and perceived usefulness [8]. Therefore, there is a need to revisit the factors that determine the adoption of wireless technology in healthcare.

Research Problem/Design

Literature identified various factors that can influence the acceptance/usage of wireless handheld devices in the healthcare environment. For example, mobility, real time access, reduction in cost, improved patient care, and reduction in error [9-14] are factors identified using wireless technology in terms of improving healthcare. There are limited studies that have investigated the views and opinions of healthcare professionals in terms of wireless handheld devices in the Indian and Pakistani healthcare environment. In order to identify themes that may be applicable to the Indian and Pakistani environment, we conducted a set of 30 interviews in the Indian healthcare environment. We omitted Pakistan from the interviews as the two countries come with similar healthcare settings and it was convenient for the interviews to be conducted in India. Participants for the interviews were selected from private and public hospitals that were involved with patient care and had some exposure to wireless technology. In order to ensure the interviews were conducted on time, the local health district was approached by an author of this paper and suitable candidate groups were identified. The interviews were conducted in such a fashion as to minimize any disruption to the participants' work schedule, to ensure comfort in answering questions, to minimize any travel time by interviewees, to synchronize the 'interview' language with participants and to prompt participants when unknown aspects were encountered by participants. Prior to the interviews, the line managers were approached for permission to release staff for the interviews. Initially a consent letter was distributed to obtain consent for interviews and the list of people to be interviewed was provided to the Health District. The interviews were recorded using a digital recorder and

catalogued as per the ethical requirements. These interviews were then transcribed for data analysis. Participants for the interview were selected from the healthcare professionals in the Southern Region of India. The participants were initially screened for suitability, and previous workings with technology were considered for this purpose. Any staff involved with 'administration only' was eliminated from the interviews to avoid any unforeseen bias. As the healthcare professionals belonged to the Health Department, no further screening was employed for the sampling.

The instruments of this research consisted of two broad categories of questions. The first category of questions was related to the adoption and usage of wireless devices in hospitals for data collection purposes. In this category, questions were asked in terms of usage, perceived benefits, perceived problems, management issues, performance issues and operational aspects. The second category consisted of demographic variables. Open-ended questions were included in the instrument to obtain unbiased and non-leading information. Prior to administering the questions, a complete peer review and a pilot study were conducted in order to ascertain the validity of the instruments. The specific research problem investigated during this stage of the study is as follows

- What are the factors of acceptance of wireless technology in a healthcare environment for India and Pakistan?
- What are the emerging challenges in adopting wireless handheld devices for the Indian and Pakistani healthcare environments?

Survey Data Collection

In order to extract opinions about technology in a specific domain such as healthcare, the choice of sample is crucial. This is because the opinions expressed by healthcare professionals should be unbiased and should pertain only to the technology and not the effects of the technology on their current workflow. The samples for this project were drawn from the health department of both Pakistan and India, where each participant is currently holding a practicing license. Furthermore, the participants chosen were working in clinical wards. People in administrative roles were eliminated from this stage to avoid any unforeseen bias. While Information Systems research identifies a range of sampling techniques such as random and clustering, the sampling technique used for this study was 'purposive' sampling. As healthcare staff with special knowledge of technology were needed, this sampling technique was employed in this study. The samples were chosen through the local medical district on their advice as their opinions on wireless technology were extracted based on their knowledge. Therefore, the samples needed to exhibit certain attributes that are related to technology adoption.

This study developed a specific survey instrument from the interview data. The main reason for this approach was that previously tested instruments were found to be inadequate in the healthcare settings of Pakistan and India. The data from the interviews was used to develop a specific range of questions to gather a more detailed view from the wider population, such as the usefulness of wireless handheld devices in healthcare, participants' knowledge of wireless handheld technology, their views about error reduction and cost reduction, and the clinical efficiency as well as performance factors. This survey instrument (contains 5 point likert scale) was pilot tested to capture the information reflecting the perceptions and practice of those adopting the wireless technology in the Pakistani and Indian healthcare system, particularly focused on what internal and external environmental factors shape the adoption of wireless and the extent of influence.

This survey was then randomly distributed to over 300 healthcare professionals from the Southern Region of India, and in the Punjab province of Pakistan. A cover letter explained the objectives and goals of the research. In order to improve the response rate a telephone reminder was sent two weeks after the initial date of survey distribution. A total of 200 surveys were received from India and 97 were received from Pakistan. When the instrument was tested for reliability, the Cronbach Alpha was over 0.89, confirming reliability. Table 1 provides a summary of the demographics. It can be inferred from the table below that for the Pakistan sample, there was an equal number of males and females, and the median experience was less than 10 years, as most of them had a bachelor's qualification, and many of them were under 25 years of age. The demographics for the Indian sample were inconclusive as many participants did not fill in this information.

Table 1- Summary of demographic data

Category	Descriptions	Pakistani	India
Gender	Male	50.5%	70%
	Female	49.5%	30%
Education	Bachelor degree	73.2%	50%
	Diploma/Certificate	4.1%	16%
	Other	10%	15.5%
Experience	Less than 2 years	17%	27.5%
	Less than 10 years	69%	51.0%
	More than 10 years	11%	20.5%
Age	Less than 23	52.6%	40.9%
	Between 23 and 29	26.8%	17.0%
	Between 30 and 36	10.3%	5.5%

Once the instrument was found to be suitable, a factor analysis as "Principal Component Analysis" with "Varimax Rotation" was run on the data. Results of the factor analysis for the Indian sector are shown in Table 2, below.

Table 2- Results of factor analysis on the Indian survey data

Indian Data	Component		
	CP	CM	TB
Reduce-workload	.651		
Improve-public-image	.684		
Improve-clinical-	.695		
Attract-more-practitioners	.596		
Save-time	.762		
More-training	.706		
Save-effort	.754		
Tech-support	.769		
Reduce-overall-cost	.633		

Table 2 (continued)

Indian Data	Component		
	CP	CM	TB
Reduce-medical-errors	.644		
More-contact-time-with-	.721		
Improve-clinical-workflow	.801		
Efficiency-in-communication	.728		
Better-quality-of-service	.747		
Improved-delivery-of-	.740		
Delivery-of-high-qual-info	.762		
Reduce-inaccuracies	.659		
Easy-access-to-data	.692		
Positive-impact-on-patient-	.686		
Time for training barrier			.518
Poor technology barrier			.656
Legal barriers			.538
Tech expertise barrier			.710
Technical support barrier			.597
39-Medical database referral		.655	
Daily scheduling of		.661	
Obtain lab results		.611	
Billing and accounting		.621	
Disease state management		.610	
Administrative purpose		.686	
Note taking		.738	
Drug administration		.629	
Communication with		.647	

CP = Clinical Performances, CM = clinical management, and TB = Technology Barrier

The Indian data returned three factor groupings. These factors were titled clinical performance, clinical management, and technology barrier. Similarly, the factor analysis as "Principal Component Analysis" with "Varimax Rotation" was run for the Pakistan data and resulted in three specific factors, namely data management, clinical performance and usage barrier as is shown in Table 3. As a result of factor analysis, the initial framework did not distinguish among positive and negative factors and did not incorporate the mediating factors either, as this was not the scope of this paper.

Table 3- Results of factor analysis on the Pakistan survey data

Pakistani Data	**Component**		
	DM	**CP**	**UB**
Reduce-workload		.673	
Improve-clinical-performance		.716	
Attract-more-practitioners		.607	
Save-time		.548	
Save-effort		.604	
Tech-support		.523	
Reduce-medical-errors		.580	
Improve-clinical-workflow		.695	
Efficiency-in-communication		.672	
Better-quality-of-service		.738	
Improved-delivery-of-		.640	
Delivery-of-high-qual-info		.654	
Reduce-inaccuracies		.668	
Easy-access-to-data		.667	
Positive-impact-on-patient-		.714	
Resource barrier			.507
Tech expertise barrier			.565
Device usage barrier			.561
Device comfort barrier			.538
Generating exception list	.804		

Table 3 (continued)

Pakistani Data	**Component**		
	DM	**CP**	**UB**
Patient education	.608		
Drug administration	.618		
Communication with	.670		
Communication with	.569		
Communication with patients	.598		
Electronic medical records	.785		
Medical database referral	.816		
Electronic prescribing	.783		
Daily scheduling of	.591		
Obtain lab results	.776		
Billing and accounting	.697		
Disease state management	.717		

DM = Data Management, CP = Clinical Performance, and UB = Usage Barrier

Combined Pakistan and India Data Analysis

We also conducted an exploratory factor analysis to investigate the combined data. The combined data resulted in four distinct factors, namely clinical performance, clinical data management, technology barriers, and clinical communication. When a correlation analysis was conducted, most of the factors correlated with their group items positively and significantly, indicating the cohesive nature of these groupings. As the nature of the study is exploratory, once the data reduction technique was adopted, the factor analysis was saved as component factors with the following labels: Clinical Performance (CP), Clinical Data Management (CDM), Technology Management (TM), Clinical Communications (CC) and the predictor variable Intention to use (ITU). The strategy was to combine related items of the factor analysis into a single item. Further before conducting the regression analysis, a correlation analysis was conducted among the independent variables CP, CDM, TM, CC, and the predictor variable ITU.

As can been seen from Table 4, the correlation analysis shows a low correlation among the independent variables. The correlation between the composite variable is positive and is not significant ($r < .5$ and $p < .05$), where as the correlation for the composite variable technology management and the predictor ITU is low with a negative direction ($r < .5$ and $p < .05$). Therefore, multicollinearity does not exist for the composite variables, and according to [15] multicollinearity exists only if there is a strong correlation between the independent variables (as $r < .5$).

Table 4- Summary of correlation (2-tailed) analysis

	ITU	CP	CDM	TM	CC
Intention to Use	1.000	.791**	-.030	-.285**	.087
Clinical Performance	.791**	1.000	.000	.000	.000
Clinical Data	-.030	.000	1.000	.000	.000
Technology	-.285**	.000	.000	1.000	.000
Clinical	.087	.000	.000	.000	1.000

To understand the role of each composite variable and to explain the variation in the predictor a regression analysis was conducted. The linear regression analysis was conducted as the "Enter" method with ITU as the dependent variable and CP, CDM, TM, and CC as dependent variables to understand the variation in the ITU. The 61.2 % variation in the ITU is explained by the predictors CP, CDM, TM, and CC ($R = .786$ and Adjusted R-Square is .612). From the regression analysis, independent variables "Clinical performance", "Technology management", and "Clinical Communications" for the subcontinent healthcare professionals are quite significant and uniquely contribute to their views about uses of wireless handheld devices in a healthcare setting ($\beta = .74$, $t = 20.3$, $p < .05$, and $\beta = .08$, $t = 2.2$, $p < .05$). Whereas the independent variable "Clinical data management" seems to not be providing any unique contribution in explaining the healthcare professional intention to use wireless handheld devices in the sub-continental healthcare environment ($\beta = -.03$, $t = -.8$, $p > .05$). Once it was clear that the independent variable CDM was not contributing to explaining the variation in ITU wireless handheld devices, another linear regression without the CDM variable was conducted and the regression results were not much different from the previous analysis ($R = .79$, Adjusted R-Square = .613, df (293,3) = 157, $p < .05$ and $\beta = .74$, $t = 20.3$, $p < .05$, and $\beta = .08$, $t = 2.2$, $p < .05$). The standardized coefficient of multiple regression analysis provided the relationship of the independent variables (CP, CDM, TM, and TM) for the dependent variable of intention to use wireless handheld devices for the subcontinent's healthcare environment.

The above framework shows the relationship between the dependent and independent variables, the analysis shows that healthcare professionals in the subcontinent see variables such as "clinical performance" and "clinical communications" as having a positive effect on the intention to use the wireless handheld devices in the healthcare setting.

Discussion

The data analyses indicated that clinical performance and clinical data management are common to both countries. However, as can been seen, both countries have concerns about the barriers. Indian healthcare professional perceived the existing status of the wireless handheld technology itself posing some barriers, whereas, Pakistani healthcare professionals perceived the barriers in terms of usage context. In the combined context, communication is an additional factor contributing to the usefulness of wireless technology in healthcare. The combined data clearly indicates the clinical performance, clinical data management and technology barriers to realize the usefulness of wireless technology in a healthcare domain as the three main contributors of acceptance of wireless technology. This indicates that in order to be accepted, technology should be useful in a given context. In terms of clinical performance, the factors such as reduced workload [8], the saving of time [16], the reduced overall cost [17], the reduced medical errors [18], the reduced inaccuracies [19] and the easy access to data [20] have already been identified in the literature. This study has confirmed these factors, perhaps for the first time, using empirical evidence. However, factors such as improved public image and improved clinical performance attract more practitioners, more contact time with patients, better quality of service and the delivery of high quality information are new factors. The set of these factors indicate that medical staffs perceive the wireless technology to provide direct benefits in these areas in order to realize better clinical performance. These respondents have also identified the positive-impact-on-patient-safety in addition to the above factors, subtly indicating their concern on patient safety due to the current inferior standards of data quality. These factors are new and have not yet been established in the literature.

In terms of technology barriers, this study established system migration, benefit evaluation, time for training, poor technology, incomplete health standards, legal, technical expertise, technical support, security, device usage, device comfort and device access as barriers to the clinical usefulness of wireless technology. While some of the factors such as the poor technology have been identified in the literature, the device access and device usage aspects are surprising. One would expect that due to the relative affordable cost of the devices, access and usage would be drivers rather than barriers. The views expressed by the respondents indicate this not to be the case. This may be due to the fact that the current health system budgets are predominantly allocated to salaries and clinical services rather than investment in technology. One would expect that by investing in technology and the prevalence of telemedicine concept, it would be possible to reduce the queues in hospitals. This does not appear to be the case. The third set of factors, clinical data management, is interesting because for the first time certain specific factors were identified to highlight the usefulness of wireless technology for healthcare. These factors include medical database referral, electronic prescribing, obtaining lab results, note taking, and drug administration. While previous studies have highlighted the usefulness of wireless technology, most of them have focused on the management aspects, clinical usefulness was very seldom covered in the literature. This study has identified specific factors that contribute to the usefulness of wireless technology in a clinical setting. In addition to identifying these factors, this study was able to identify the common factors between two radically different medical systems, namely India and Pakistan. Despite the relative differences between the countries, this study has been able to establish a set of common factors that bind the clinical usefulness factors of wireless technology for these two healthcare systems.

Conclusion

It can be concluded from this study that technical, clinical and management/operational factors are the driving force behind the intention of the healthcare professional to use the wireless handheld technology in the subcontinent.

It can be also be summarized that drivers are the factors with the potential of improving the clinical process and

management of the patient care, and the inhibitors are due to lack of wireless solution, infant stages of the technology, and management support. There is clear evidence that healthcare professionals in the subcontinent are motivated and keen to use the wireless handheld technology in the healthcare environment. This study has identified factors such as clinical performance, clinical management, clinical communication, and data management as major factors for the intention to use wireless handheld devices. The main challenge that has emerged from this study is that even though healthcare professionals are motivated, they would like to see the usefulness of the technology and availability of the appropriate healthcare applications for wireless handheld devices.

Future studies can use these factors in order to develop a regression model so that the factors identified can be regressed into a smaller set. The main purpose of the study was to identify initial factors and hence the data collected was not found to be suitable for a second order regression model. Therefore, this was not attempted in this study.

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Factors associated with health information system success: Results of a survey of hospitals in South Africa

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Abstract

A survey of computerised hospital information system (CHIS) use was conducted in two South African provinces, in order to test a conceptual model of CHIS use developed in previous phases of this study. Relationships between factors of the conceptual model and user assessment of CHIS success; and between pairs of conceptual model factors, were derived from the survey data.

The results confirmed that factors of the conceptual model were associated with CHIS success. Analysis of the relationships between factors yielded results which supported some of the conceptual model relationships, and were inconclusive for others. None of the conceptual model relationships was contradicted by the survey results. Further investigation is required to demonstrate statistical relationships between factors of the conceptual model more conclusively.

The results to date support arguments for the applicability of the conceptual model of CHIS use beyond the study hospitals to other level 1 and level 2 hospitals in South Africa.

Keywords:

Hospital information system, South Africa, HIS evaluation, HIS success.

Introduction

Studies of factors associated with the success and/or failure of computerised health information systems have focussed on the factors themselves, and the relative weighting of the factors, rather than on the relationships between factors ([1] and [2] for example). In this study, factors associated with success; user assessment of success; and the relationships between factors associated with the success of computerised hospital information systems (CHISs) were examined.

In previous phases of this study, a conceptual model of CHIS use was developed based on case studies in four South African hospitals, as reported in [3] and [4]. A survey of CHIS use was conducted in level 1 and level 2 hospitals in two South African provinces, in order to test this conceptual model of CHIS use. The model is shown in Figure 1.

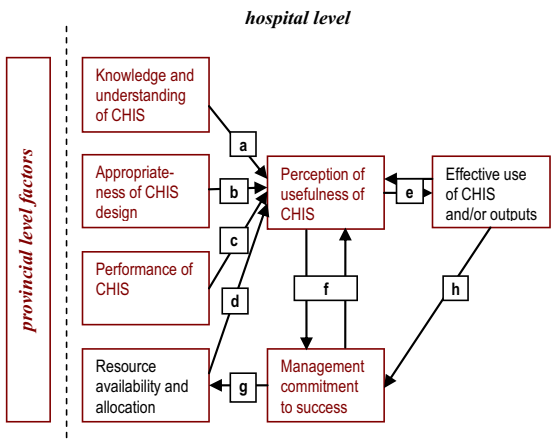

Figure 1- Conceptual model of CHIS use, identifying relationships between model factors for analysis

Methods

A survey of CHIS use was conducted in level 1 and level 2 hospitals in two provinces in South Africa. The objectives of the survey were

- To review the factors of the conceptual model of CHIS use;
- To further investigate relationships between factors of the conceptual model of CHIS use;
- To identify differences between groups of hospitals using the same CHIS in respect of factors associated with CHIS success or lack of success;

- To provide further data for identifying factors which could help to explain CHIS success or lack of success.

Two sets of questionnaires were used: hospital questionnaires were designed to obtain information about the CHIS implementation for the hospital as a whole, and user questionnaires were designed to obtain the opinions of individual users. Questions in the questionnaires were designed to reflect various aspects of the conceptual model. Extensive provision was made in the questionnaires for user comments. Quantitative data took the form of weighting on a 5-point scale (strongly disagree, disagree, neutral, agree, strongly agree) or presence or absence of a factor (yes, no, neutral). Provision was made for recording 'no response' to questions.

Data were collected from a wide range of CHIS users, including heads of hospitals, information officers, case managers, and supervisors of end users. Interviews were conducted in person or telephonically by arrangement, and the questionnaires completed by the interviewer; or questionnaires were self-completed by the respondents.

Results

Overview of the CHIS implementations

Data were obtained from 70 respondents at 30 hospitals in the two study provinces. The CHIS implementations in the study hospitals supported patient administration and billing, and included provision for recording limited clinical data. The study hospitals in Province 1 were using one of two CHISs (SystemA or SystemB) and all the study hospitals in Province 2 were using SystemC.

Data analysis approach

A major aim of the survey was to build on the results from the case studies, in order to further refine the conceptual model of CHIS use as a framework for analysing CHIS success. The analysis of the survey results was aimed at investigating the validity of the conceptual model in the survey hospitals (i.e. in additional level 2 hospitals in Province 1; in level 1 hospitals in Province 1; and in level 2 and level 1 hospitals in Province 2), and assessing whether changes in the model would be required (based on the survey results).

In general, data analysis was done by treating all respondents using the same CHIS as a single group, in order to work with a reasonable sample size (maximum 33 respondents for SystemA, 15 for SystemB and 24 for SystemC). Hospital data were combined in such a way as to reflect the overall view of the data from a hospital perspective.

Due to the limited sample size in relation to the number of variables being considered, it was not possible to use analytical statistical techniques for data analysis. Therefore, a descriptive statistical approach was followed to describe the results related to the factors in the extended conceptual model of CHIS use; and to compare and discuss the relationships between model factors as reflected in the survey results.

Conceptual model factors associated with CHIS success: User responses

Some of the survey questions were designed to obtain the respondents' opinions about the association between the **hospital-level** factors in the conceptual model and CHIS success; and between these conceptual model factors and lack of CHIS success. The factors associated with lack of CHIS success were conceptualised as being the opposite of those associated with success (i.e., lack of knowledge and understanding, inappropriate design, poor performance, etc.). A summary of user responses to questions related to the factors in the extended conceptual model of CHIS use, from users in Provinces 1 and 2, is given in Table 1.

Respondents appeared to find difficulty dealing with these questions relating to factors associated with success and lack of success, and particular difficulty with factors associated with lack of success. On average, there were 32% nil or neutral user responses to the questions related to CHIS success (see Table 1) and 42% nil or neutral response to questions related to **lack of** CHIS success. Possible explanations for the difficulties experienced with these questions include the phrasing of the questions, and a lack of general knowledge and experience of CHISs among some of the survey respondents, although conclusive evidence was not obtainable.

Table 1 - Rating values for factors associated with CHIS success – all users all hospitals

Conceptual Model Factor	Total users	Users no response/ neutral	-ve user response	+ve user response	% +ve user response
knowledge	72	23	1	48	98%
design	72	23	3	46	94%
performance	72	23		49	100%
resources	72	22	5	45	90%
usefulness	72	23		49	100%
commitment	72	24	3	45	94%
use effectively	72	23		49	100%
Average		**32%**		**68%**	**97%**

Taking into account the limitations in this data set, those respondents who did express opinions about the association between the (hospital-level) conceptual model factors and CHIS success in their environments agreed that there was an association between the conceptual model factors and CHIS success: Overall, approximately 97% of the respondents to these questions agreed that the factors in the extended conceptual model of CHIS use are associated with CHIS success. A few respondents indicated that these factors are not associated with CHIS success. These negative responses could be interpreted as meaning that, in the respondents' environments, these factors were not associated with CHIS success due to their absence or weakness (limited resources, or limited management commitment, for example). On average, 65% of the respondents strongly agreed or agreed that **lack of** each of the factors of the

conceptual model could be associated with lack of CHIS success in the hospitals in which they were working. Therefore, the available data do support the inclusion of the hospital-level factors in the conceptual model of CHIS use developed in this study as being factors associated with CHIS success. The converse, i.e. that lack of these factors is associated with lack of CHIS success, is less strongly supported by the data.

Although the number of respondents for which data are available is limited (average 47 respondents about factors associated with CHIS success and average 42 respondents about factors associated with lack of CHIS success), this is also true of other studies examining the factors associated with CHIS success or failure, such as those in [1], [2] and [5]. Future studies which include more respondents would enable stronger conclusions to be drawn.

Conceptual model factors and user perception of CHIS success

The variable 'successful?' reflects the responses of users to the statement 'Overall, in terms of my job, the CHIS is a success'. The rating values of this variable therefore provide the most direct reflection from the survey of the respondents' overall opinions of the CHIS which they were using.

One of the assumptions in this study (also supported by results from the literature) is that effective CHIS use is related to CHIS success. Therefore, if the conceptual model is valid, the rating values (and other measures) of the factors of the conceptual model of CHIS use, should be consistent with user perceptions of CHIS success in their working environments. The analysis of cross correlations between the variable reflecting CHIS success ('successful?'), and the variables reflecting factors of the extended conceptual model of CHIS use, was therefore aimed at exploring these relationships, based on the available numeric data from the study survey.

At hospital level, there were statistically significant correlations between 'successful?' and the variables linked to the conceptual model factors 'quality of data' (sub-factor of 'knowledge and understanding of CHIS'); 'performance of CHIS'; 'perception of usefulness of CHIS'; and 'effective use of CHIS and/or outputs'; respectively for some categories of users. At user level, there were statistically significant correlations between 'successful?' and the variables representing each of the model factors, for some categories of users.

Apart from counter-intuitive results for SystemB users, the results of the cross correlations at user level between 'successful?', and the variables representing the following model factors supported the corresponding relationships in the extended conceptual model of CHIS use: 'knowledge and understanding of CHIS'; 'appropriateness of CHIS design'; 'perception of usefulness of CHIS'; and 'management commitment to CHIS success'. The correlations between 'successful' and 'effective use of CHIS and/or outputs' were counter-intuitive or weak, in contrast to the strong correlations between these variables at hospital level. As for the hospital-level analyses, the results at user level did not support a relationship between 'successful?' and the variable representing the factor 'resource availability and allocation' in the conceptual model.

The hypotheses that the factors of the conceptual model are associated with CHIS success are thus largely supported by these cross correlations.

CHIS success: variables associated with factors of the extended conceptual model of CHIS use

Following the argument that the factors in the conceptual model are associated with CHIS success, the percentage of positive rating values for the variables representing these factors provides an indication of level of success. Therefore, the rating values were analysed, mainly at user level, for each of the variables used to reflect the hospital-level factors of the conceptual model. For the variable which reflects the resource allocation for ICD-10 coding from patient records, rating values were analysed at hospital level. A summary of the percentage positive rating values for the variables used to represent hospital-level factors in the extended conceptual model of CHIS use is presented in Table 2.

Table 2 - Summary of % positive responses for measures of conceptual model factors

Conceptual model factor	SystemA Prov 1	SystemB Prov 1	SystemC Prov 2
Knowledge and understanding of CHIS - training	92%	85%	65%
Knowledge and understanding of CHIS – quality of data	68%	46%	47%
Appropriateness of CHIS design	84%	69%	33%
Performance of CHIS	100%	68%	41%
Availability and allocation of resources (per hospital)	***38%***	***20%***	***71%***
Perception of usefulness of CHIS	89%	60%	64%
Management commitment to CHIS success	93%	80%	42%
Effective use of CHIS and/or outputs	75%	43%	33%
Respondents' perceptions of CHIS success	***95%***	***100%***	***37%***

For the purposes of comparison, the 'percentage of positive responses' was calculated for each variable, for each category of users. The 'positive responses' reflect all responses which reflect a positive response in terms of CHIS use. The percentage of positive responses was calculated using the total number of responses to the question as the denominator (i.e., excluding the number of 'no response's (rating value = 9)).

Apart from the data for 'availability and allocation of resources', these data for percentage positive rating values show that the survey respondents regarded SystemA as being more successful than either SystemB or SystemC, and that the two Province 1 implementations (SystemA and SystemB) were viewed as being more successful than the SystemC implementations in Province 2. This pattern is repeated in respondents'

perceptions of CHIS success, as reflected in the user responses to the question 'Overall, in terms of my job, the CHIS is a success', as shown in Table 2. All but one of the respondents among the SystemA users, and all the SystemB users, who responded to this question agreed or strongly agreed that the CHIS was a success in their jobs, while only 37% of SystemC user respondents shared this opinion.

Statistical analysis: relationships in the conceptual model

Eight relationships between factors in the extended conceptual model of CHIS use were analysed, reflecting the relationships between factors in the extended conceptual model of CHIS use, as shown in Figure 1.

The relationships between the characteristics of users and the CHIS and perception of usefulness of the CHIS (relationships (a) to (c)) were generally not strongly supported by the results of the cross correlations. However, the data from cross tabulations between the rating values of these variables did support these relationships.

Positive, but not statistically significant, cross correlations were shown between 'all patients' (reflecting resource availability for ICD-10 coding) and 'management commitment to CHIS success' (relationship (g)). A weak cross correlation was demonstrated between 'all patients' and 'perception of usefulness of CHIS' (relationship (d)).

Strong, but not necessarily statistically significant, relationships were demonstrated for most groups of respondents for the measures for the relationships involving 'management commitment to CHIS success', 'effective use of CHIS and/or outputs' and 'perception of usefulness of CHIS' (relationships (e), (f) and (h)). Where cross correlations were counterintuitive, cross tabulations did reflect positive relationships between these variables, as expected in terms of the conceptual model. The measures used for these conceptual model factors at hospital level all related to the respondents' perceptions of hospital management attitudes to and use of the CHIS at a hospital. The cross correlations between these variables were generally stronger than those for other conceptual model relationships, reflecting support for the relationships in the model. In a future study, more detailed comparisons between the answers to these questions by different groups of respondents could provide interesting insights into differences in perception of the CHIS between groups of hospital personnel.

Discussion

The aim of this survey was to test and refine the extended conceptual model of CHIS use developed following the case study phase of the study. The data from the survey were analysed from two perspectives: testing of hypotheses related to the relationships between the factors in the extended conceptual model of CHIS use, and CHIS success; and testing of hypotheses related to the relationships among factors in the conceptual model. The presentation and analysis of results in the previous Sections focussed largely on the results of analysis of the numeric data from the survey. In this Section, some of the available numeric and non-numeric data from the survey are discussed in combination.

Relationships among factors in the extended conceptual model of CHIS use

Results of analyses of data related to factors, and relationships between factors, in the extended conceptual model of CHIS use have been presented. Relationships between 'perception of usefulness of the CHIS' and other factors of the conceptual model; and data related to 'resource availability and allocation' are discussed further in this Section.

Perception of usefulness of CHIS

This factor of the extended conceptual model of CHIS use is linked to all other hospital-level factors in the model, reflecting the strong influence of perceptions on users' attitudes to CHISs. As discussed previously, there were few statistically significant cross correlations between the variable used to represent 'perception of usefulness of CHIS' and measures of other factors in the conceptual model.

Respondents were also asked a series of questions about the CHIS which they were using. The responses to these questions were coded in terms of factors of the conceptual model, yielding a set of approximately 300 coded comments from all the users who responded to these questions.

The coded comments linked to positive perceptions of usefulness of the CHIS related mainly to the model factors 'appropriateness of CHIS design' (approximately 50% of coded comments); 'knowledge and understanding of the CHIS'; 'CHIS performance'; and CHIS outputs (a sub-factor of 'effective use of CHIS and/or outputs'), and confirmed relationships between these factors and 'perception of usefulness'. For the coded comments linked to negative perceptions of usefulness of the CHIS (fewer than 100 coded comments), the majority of comments were related to 'CHIS performance' and 'appropriateness of CHIS design', thus supporting a relationship between poor CHIS performance and/or design, and a perception that the CHIS is not useful.

Combining all available data related to 'perception of usefulness of CHIS', it can be claimed that the relationships between this factor and factors related to the CHIS implementation ('knowledge and understanding of the CHIS' by users; 'CHIS performance' and 'appropriateness of CHIS design'), **are** supported by the available data from the survey.

Resource availability and allocation

Statistical analyses for the relationship between 'resource availability and allocation', and 'perception of usefulness'; and between 'resource availability and allocation' and 'management commitment to CHIS success' resulted in weak or counter-intuitive cross correlations, although the cross tabulations between these measures were generally positive. The comparison of the rating values for 'resource availability and allocation' for the different CHISs indicated that the system which performed most poorly in terms of most other measures (SystemC) had 71% positive ratings, compared with an average of 33% positive ratings for the Province 1 CHISs (Sys-

temA and SystemB). These statistical analyses therefore were considered in combination with other data related to the conceptual model factor 'resource availability and allocation'.

An important component of the conceptual model factor 'resource availability and allocation' is the availability of the required human resources to support the CHIS implementation at hospital level. The personnel arrangements for information management at hospital level in the two study provinces were rather different: The organogram for posts related to the CHIS at Province 1 hospitals makes provision for Information Officers at each hospital, and a case management function (full- or part time), which includes responsibility for ICD-10 coding for fee-paying patients. For Province 2 hospitals, the organogram includes an information management function at management level, as well as software and hardware support staff. Respondents reported that clinical and/or senior ward administrative staff were responsible for ICD-10 coding. There were no case managers at any of the study hospitals.

Although there were major differences in the organograms in the two provinces, the arrangements for system support appeared to be similar: during office hours, queries were referred to the information officer, a superuser in the section (for example, admissions or fees) or to external personnel responsible for application software or hardware support. After hours, calls were logged at call centres in both provinces, although in some cases, application software support staff were contacted directly. As was found at the case study hospitals, limited CHIS support available at hospital level and from external personnel was not highlighted by most users as a major problem.

Conclusion

Results of this study have shown that the factors of the conceptual model of CHIS use are associated with CHIS success, and that the relationships between factors of the model could be demonstrated.

This study makes a significant contribution to the literature on HIS success and failure on several counts:

- there have been few reported surveys to obtain data on HIS success and failure – data were obtained from approximately 70 users at 30 hospitals, across two provinces, each using one of three CHISs;
- this study was conducted in level 1 and level 2 hospitals using commercially-supplied CHISs, and in environments of limited resources for CHIS support;
- data were obtained from the perspective of CHIS users and hospital managers, rather than from HIS experts as in other reported studies.

Issues to be addressed in future studies include:

- Further refinement of proxy measures for conceptual model factors;
- Obtaining larger and more representative samples of different categories of users, to enable comparison of data from different perspectives;
- Combining data obtained from a CHIS user and user support perspective with data obtained from CHIS experts in the study environment;
- Comparisons between data obtained from public sector level 1 and level 2 hospitals in South Africa with data obtained from similar hospitals in other settings.

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The Evolution and Uptake of a Drug Information System: the Case of a Small Canadian Province

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Abstract

In 2008 the province of PEI, Canada implemented a province-wide, web-based drug information system for the purpose of improving patient safety. An evaluation study using grounded theory examined the human and workflow impact. Results indicated a need for great attention to the details of change management during implementation, including: ensuring application quality of all informational and technical elements, just-in-time training and technical support, on-site preparation for changed workflow processes, and collaboration among all stakeholders throughout.

Keywords:

Drug information systems, Cost-benefit analysis, Community pharmacy services, Clinical pharmacy information systems, Drug utilization review

Introduction

Prince Edward Island (PEI), the smallest province in Canada, implemented a system in 2008 for sharing information among pharmacies on prescribing and pharmaceutical dispensing. Implementation of DIS in PEI pharmacies began in March 2008. Following 10 years of planning and preparation in PEI and a ground-swell of national attention to the general process, PEI set a provincial government body in place to create a digital system and network; passed legislation to require compliance; and watched the results unfold. Principles of change management and adoption were actively planned into the process as part of an investment program initiative of Canada Health Infoway [1].

Our study was conducted as a cost-benefit analysis of implementation. The aspects noted in this report are those where we reviewed the results to determine the possible influencing factors around change management that would create differences in efficiency and effectiveness of workflow processes in pharmacies between those which had implemented; those in the process of implementing; and those which had already implemented and become relatively proficient.

Research Objectives

This research initiative was conducted by two members of the faculty of Dalhousie University, at the request of the National e-Pharmacy Task Force. The overall objective was to examine costs and benefits of the Drug Information System (DIS) as it was being implemented so that comparisons could be made among those locations which had already implemented, those that were in the process of implementing and those that had not yet implemented. It encompassed a number of specific objectives. The objective of this paper is to look at the outcomes of the implementation process for three of the objectives of the study and how those can be related to change management processes and uptake of innovations (adoption) that were applied to the implementation process. The three objectives that will be used relate to examining the impact of implementation of the DIS in a) workflow changes; b) acceptance of the DIS by stakeholders, especially practicing pharmacists; and c) observed or recorded patient safety issues including patient education, flags, adverse events and documentation processes [2].

Methods

This study used qualitative methods to gather data for the change management side of the study. Evaluation of costing and the programming was also conducted but is not part of this report. We conducted a review of the history of development and application of the DIS in this province as told by persons directly involved in the process. We observed workflow in 30 of the 43 community pharmacies in the province for at least 1 hour. In each of the pharmacies we prepared sketches of the dispensing area layout and equipment with the physical movement patterns and workflow noted. Following observations, we interviewed community pharmacists (in all instances), pharmacy technicians (in some instances) and with pharmacy managers and/or owners (in a few instances). We held focus groups with pharmacists and managers together. Input from all these sources was then text analyzed and sorted into major themes.

The qualitative research method applied to the objectives of the study was based on grounded theory,[4] or theory generated from the ground up. It explores the social processes of how people interact, take action, and engage in response to a particular phenomenon. In this research, the phenomenon is implementing the DIS in the community pharmacies in a relatively small province that functioned as an excellent living

laboratory. As part of using a grounded theory approach, the researcher guided interviews and focus groups with a series of open questions that were designed to allow the participant to guide the contents of the interview/focus group from that point on. Extensive notes were taken during each interview and focus group, noting direct quotes using the participants' own words. These were shared with the interviewee to ensure that the words and the tone were reflected accurately. Each focus group and interview was preceded by an introduction to the scope and purpose of the research.

The model provided a basis for measurement of factors such as system quality, information quality, service quality, and user satisfaction, which have an impact on benefits realization.

Results

Based on interviews using 30 semi-structured interviews with observations and 2 focus groups, the following common or important themes were brought out by participants:

Table 1-Themes reported by participants

Themes	Frequency of mention in interviews and focus groups
There was near universal commitment by participants to the objectives of DIS: - reduction of medication errors - reduction of drug abuse through double doctoring or poly-pharmacying - prevention of adverse events due to adverse drug interactions	32 or 100%
The province was starting to realize benefits from the DIS	26/32 or 81%
There was a desire for access to the full patient profile and participation by others in the health care system (hospitals, clinics, physicians' offices)	26/32 or 81%
The system generated multiple unimportant alerts that caused concern: - that they may be missing an important alert in the midst of the many unimportant - that it takes precious time to "manage" each unimportant alert, that would better be spent on other things during peak busy times	24/32 or 75%
A perceived lack of collaboration among software providers	
Insufficient preparation for implementation	21/32 or 66%
Need for better clinical information support on drug utilization review (DUR) alerts	5/32 or 16%
Allergy notation related to drug use is too rigid and standards-bound to be useful.	5/32 or 16%
System down-time is a major issue.	27/32 or 84%

The History of the Project around Change Management

Based on several interviews we were able to determine the history of the project. This showed that there was a 10 year period of planning for implementation, with the original ideas for the concept coming from the PEI Pharmacists Association. Between the Association, the government planners, the software developers and the national e-health body there was collaboration on a well-developed change management plan. This included participatory planning by members of the above groups, and support from change management consultants at several levels.

Using Kotter's model of organization development through change management [3], there was an emphasis on such aspects as creating a powerful coalition, that convinced all that change was necessary to the point where legislation was passed to require the change to take place.

There was careful planning around the details of the drug information system software to ensure that all safety issues were adequately addressed. There was a concerted effort to bring all vendors of software that served the individual pharmacies to the table. There was one pharmacy in an urban setting that was designated as a pilot site where the drug information system software was tested and refined.

Commitment to the Change

The findings of the study showed that there was universal commitment on the part of all participants in the process to the objectives of DIS and that the implementation of the system was starting to realize benefits outlined in the objectives, such as improved patient safety in preventing potential drug interactions or duplicate therapies; and recognizing and preventing customers from getting the same prescription filled at multiple pharmacies, as well as preventing customers from using prescriptions for the same medication from multiple doctors. At the point of our study, only community pharmacies were universally expected to be on the Drug Information System, and to share prescribing information across all pharmacies. One major finding was that participants expressed a desire that all stakeholders be on the system, including hospitals, emergency departments, outpatient clinics and all physicians in private practice: that greater benefits could be achieved if that were the case.

Nature of the System for the Purpose

The nature of the system was such that, to be most effective, information on prescriptions for each customer had to be on the system in order to be shared with all other pharmacies. The decision was made to start with no history, so that only new prescriptions were entered on the system. This meant that the usefulness of working with information from the full scope of other pharmacies across the province was not evident in the early days, and that the "costs" in terms of irritation with learning new processes in the middle of a busy work process, was not compensated for, yet, by the "benefits" of being able to see a fuller prescription history for each customer.

From a technology and software programming perspective: observations showed, and participants noted, that there were

multiple unimportant "alerts" (indications of potential patient safety hazards) that were too sensitive. For example, early renewal of a prescription resulted in an alert for "duplicate therapy", or an address that had a different version of a person's name was alerted as an error that had to be corrected before continuing.

Another aspect of the system was that the provincial DIS provided information that was fed into and integrated into the existing pharmacy software that already managed their dispensing processes. For some stores, this made the transition relatively easy, as the learning curve was focused on the information and processes related to the DIS that supplemented their pharmacy software system. In these stores, there might have been some irritation with the multiple alerts, but the transition to using a shared information base was relatively easy and required marginal new learning.

It was discovered that some of these individual pharmacy systems were incompatible with the provincial DIS, so that several groups of stores were required to implement entirely new pharmacy software systems, some of which had lesser functionality than what they had originally. This meant not only a steep learning curve as a totally new software system had to be learned, but also irritation with loss of functions that staff had become accustomed to. This also meant that these pharmacies had to re-enter data about prescribing history in their own stores, which meant a large investment of data entry time. These things had not been planned for in the original change management plan, as it was expected that individual pharmacy software vendors would manage that part of the transition. The researchers heard from participants that there was strong dissatisfaction with the introduction process as a result. This included a perception of insufficient collaboration among the following key stakeholders prior to implementation: the vendor community, the government representatives who were responsible for planning and implementing the DIS, and the DIS system software developer.

Preparation at the Individual Pharmacy Level

One area of importance to participants was a perception of insufficient preparation with the individual pharmacies for introduction of the system in the individual stores. Participants noted lack of on-site training. They noted, and we observed, that pharmacies were very busy places and that there was little time available for training with on-the-job kinds of tools. Since this tool was integral to the primary function of the pharmacy – to dispense medications according to valid prescriptions – and once the system was installed its usefulness was dependent on everyone using it immediately, there was no period of time during which a pharmacist or pharmacy technician could take time away from dispensing medications to learn the new system, because it was the only way available to dispense medications once it was installed. There was no opportunity for parallel systems.

Of the three dispensary software vendors used in the province, we observed only one that sent a training team to work with the dispensary staff to introduce the new system, to enter any background data that was needed, to train staff and to work with them in using the system during the changeover. However, we observed that several of the chains organized for another, we observed that several of the chains organized for an active help desk person from the parent organization, other than the DIS software system team, to be available for sorting out issues. Many participants expressed appreciation for these functions.

Training

There was also a perception of lack of training. In preparation for implementation, the implementation planning group held a teleconference introduction and training session for all pharmacists, that all were required to attend (there was 97% participation). This made it possible for all participating pharmacists to get an introduction to the new processes as well as information on how to resolve issues. The perception of lack of information was thus more likely due to the nature and timing of the teleconference. For many participants, it would have occurred several months prior to implementation, thus any learning from the call would have been lost. For others who may not have been auditory learners, they did not have reinforcing information in other formats to support retention of their learning. As a learning tool, it was likely sadly insufficient to meet the needs. It might have been better to have an on-line support function with help for learning particular processes when the participant actually started to learn how to use the system.

Help and Support

Many noted a lack of information on how to resolve issues and of consistent help desk support from either the provincial DIS provider or from the pharmacy's software provider in the early days. It was not always clear which help function was needed, and participants noted instances where each help desk would suggest that the other would be the better one to call for support.

Discussion

We could find no clearly accepted framework internationally for evaluating the comparative effectiveness of change management processes for eHealth projects [5]. The major model for benefit evaluation in use for Canadian e-health projects through Canada Health Infoway includes user satisfaction and ease of use as a central component of its framework [6]. For purposes of examining the change management process, this study accepts the premise that, for professional healthcare providers (pharmacists and pharmacist/managers), user satisfaction gives an indication of the quality of the system as well as the quality of the implementation process, since their professional interest is in information quality and outcomes for their patients.

Those who have examined the value of an integrated drug information system after its implementation have shown that there is value for prescribing clinicians in having access to a complete drug profile in combination with a clinical decision support system that allows for indications of interactions with other medications in the profile, with health condition or with allergies, and indications of appropriateness of quantities and other factors [7]. A study from an inpatient facility in Taipei [8] that looked at nurses' use of an integrated drug information

system found that it helped to reduce medication errors to a certain extent, except for errors in time of administration. One could speculate that a change management approach that included examining the workflow and perspectives of the nurses might have made a difference to that factor.

Conclusions

There were many valuable lessons to be learned about how to do effective change management around complex system changes to be derived from this study. The principal one appears to be that the process of introduction to users must be as carefully planned in all its details, and prepared for, as the shape of the technology itself. In addition, it seems that the preparations for change must also be focused on each individual workplace or store, since there was significant variation among the ability of each workplace to adopt the changes, and in the perceptions of the store personnel about its effectiveness. Differences included the kind of technology currently in use in the store, and the level of technical expertise of the users. It is the people who are affected most by the change, namely the system users at the interaction point with customers, who are most important. Preparation for the details of the change, support for on-the-spot training, support for technical issues and opportunities to learn in a time and place where the customer will not be affected, are all important aspects that came out in this study.

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Social Networking in the National Health Service in England: A Quantitative Analysis of the Online Identities of 152 Primary Care Trusts

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Abstract

Increasing numbers of the public are becoming digitally connected. In particular, younger "born digital" generations now use the World Wide Web as their primary source of information alongside conventional media such as television and print. Little is known as to whether health organisations are using new media channels such as Facebook and Twitter to engage with the public and patients. This quantitative analysis investigates the online identities of Primary Care Trusts (PCTs) in the NHS in England to inspect their usage of social utilities. Results showed that a total of 61 organisations (40.13%) use at least one utility with the most popular being Twitter (n=30) and Bebo the least (n=1). However, organisations appear to be failing to take advantage of the interactive nature of social utilities instead using them as unidirectional information "push" channels. The ways in which health organisations could use social utilities for engagement is underexplored and so we must look to other research disciplines for best practice and evidence.

Keywords:

Consumer health informatics, Internet, Organisation-patient relations

Introduction

Five billion minutes are spent on Facebook worldwide per day [1]. In the UK alone, Facebook user numbers account for approximately one quarter (18,711,160) of the population [2]. Collectively Bebo, Facebook, Twitter and YouTube are used by millions of people worldwide to communicate with friends and family, to share and consume information. This is known as online social networking. In healthcare, there could be several use cases for utilising these systems such as facilitating virtual clinician-clinician, clinician-patient and patient-patient interaction. From an organisational perspective, they can be used for internal communication, but also outreach into the community which is the focus of this study. The aim of this research is to quantify whether health organisations in the NHS in England are using these "social utilities" to engage with patients and the public so further research can be conducted into how and whether digital communications is an appropriate communications channel for health organisations.

Primary Care Trusts (PCTs) manage health services such as family doctors, community nursing and dentists, commission secondary care services and account for approximately 80% of the total NHS budget [3]. There are currently 152 PCTs in the NHS in England. Theoretically, they are best positioned to understand the needs of their local communities and work with authorities and other agencies that provide health and social care to ensure the community's needs are met. PCTs are developing "world class" commissioning competencies [4] with the aim of achieving the most cost effective greatest healthcare gain and reducing health care inequalities. One of these competencies is to engage with patients and the public a role now enshrined in the NHS Constitution [5] giving them the right to be involved in the planning, development and feedback of services directly or indirectly affecting their care. Digital communications could form part of this ongoing engagement strategy. We report the outcomes of a quantitative analysis of the online identities of 152 PCTs in the NHS in England.

Methods

To determine whether PCTs in the NHS in England are using digital communications as a means of public engagement, a quantitative analysis of all 152 organisations' digital identities was conducted. Organisation names were extracted from the NHS Connecting for Health Organisation Data Service which provides a downloadable Comma-Separated Value (CSV) or Microsoft Excel (XLS) snapshot of data including national identifiers and local addresses. These names were cross-referenced within the Bebo, Facebook, Twitter and YouTube social utilities to assess whether the organisation was represented. If an organisational presence was found it was investigated using metrics defined for each social utility. A preliminary search was conducted to identify that these four social utilities were being used by the NHS organisations and ruled out other social utilities such as MySpace as no accounts were found. In the future it is possible that other social utilities will be adopted and current metrics will need to be created to include them.

Founded in January 2005, Bebo ("Blog early, blog often") is a social networking site similar to Facebook. It allows users to share video, photos and groups as well as providing blog and whiteboard commenting functionalities to communicate and

share with friends. Bebo profiles list the number of times somebody visits a profile and also public information that has been permitted to be shared including the number of friends a user has. As suitable metrics the number of videos, photos, groups, blog posts, whiteboard entries, comments, number of friends, profiles views and links back to Facebook, Twitter and YouTube were recorded.

Founded in February 2004, Facebook is the largest and most-used social utility in the world today [6]. While complex, Facebook gives users full control over their use of core applications such as Photos, Groups and Video. The context analysis was split into three Facebook entities:

- Facebook Profiles are reserved for individuals and are not generally accessible to the public due to privacy restrictions. For this study they were excluded as there was no way of verifying whether they are owned by the official organisation.
- Facebook Groups can be created by anybody and are generally used for petitions, tributes and general conversation. Closed or "secret" groups are available which require an explicit invite as public ones can be subject to exploitation by malicious users.
- Facebook Pages are reserved for organisations and other business entities rather than them creating an individual account which is against Facebook Terms of Use. Facebook Pages are like Groups but are more flexible in terms of functionality and control.

All entities were queried using the internal Facebook search engine although Profiles were excluded from the quantitative analysis. As suitable metrics the number of members (fans), discussion topics and posts, notes (only on Pages), wall posts (only on Groups), photos, links, videos, events and links back to Bebo, Twitter and YouTube were recorded. Only "official" Groups were analysed which were filtered by discounting ones which did not display a legitimate .nhs.uk e-mail address. This is not a perfect solution but an adequate indicator of veracity.

Founded in 2006, Twitter is an open social networking and micro-blogging service that enables its users to send and read messages known as tweets. Like a cocktail party, users amass in groups and talk openly whilst listening in to surrounding conversations and contribute if they hear something interesting. On Twitter users "follow" others so that their tweets appear in their tweet-stream (the conversation) and can also be "followed" by other users so that they appear in somebody else's tweet-stream. As suitable metrics the number of tweets, following, followers, date joined and links back to Bebo, Facebook and YouTube were recorded.

Founded in February 2005 YouTube is a video-sharing site owned by Google, Inc. YouTube allows users to share, upload and comment on videos worldwide through playlists and user accounts known as "channels". Many YouTube videos are made public and are easily accessible which has both positive effects on mass viral distribution and reducing barriers to entry for video clip and movie producers but also brings negative effects such as comment abuse and illegal uploading of copyrighted materials. As suitable metrics the number of channel subscriptions, videos, channel views, date joined and links back to Bebo, Facebook and Twitter were recorded.

Data was collected on the 29th July, 2009, using a tripartite search strategy: via four generic Google search queries e.g. *NHS OR PCT OR "Primary Care Trust" site:bebo.com* replacing *bebo.com* with *facebook.com*, *twitter.com* and *youtube.com* to identify presences across the WWW; an internal Facebook search for *NHS OR PCT or "Primary Care Trust"* to identify Facebook Groups and Facebook Pages; and, PCT-specific Google searches e.g. *bebo OR twitter OR facebook OR youtube site:doncasterpct.nhs.uk* for all 152 organisations to identify any missed presences from the previous searches. Each presence was investigated and quantitative data recorded for each metric. Due to the human element of inquiry and the need to assess veracity this process was not computer-automated. Results were stored in Microsoft Access and exported to Microsoft Excel for analysis. Each result was then marked with the date it was collected to allow for future longitudinal research.

Results

Figure 1 shows the total number of online accounts (Bebo, Facebook, Twitter and YouTube) created by PCTs in the NHS in England. In two instances, two PCTs had two Facebook Pages which were both included in the data analysis. The results show that Twitter is the most widely adopted platform (n=30) although this represents only 19.74% of total organisations, and the least adopted platform is Bebo (n=1). While Figure 1 gives an indication of quantity it does not give any indication of qualitative engagement by the public and patients.

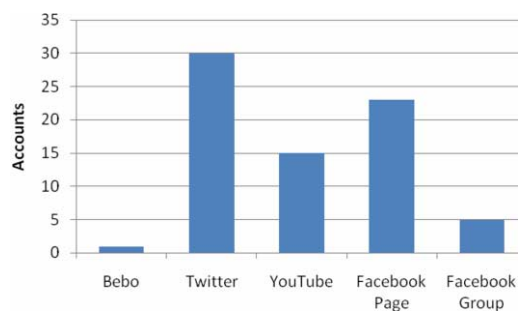

Figure 1 – Total Number of Accounts (n=73)

The total number of accounts represented 61 organisations (40.13%) out of all PCTs. Out of these organisations 42 (68.85%) utilised a single social utility, 16 (26.23%) used two, and three (4.92%) used three utilities. From the collection of official PCT web sites only three linked to their Facebook Group or Facebook Page, 12 to their Twitter accounts and four to their YouTube account. These statistics suggest that no clear, unified strategy has been enforced to link all identities or to align with organisational and communication strategies

which could lead to a richer, more streamlined experience for patients and the public.

Bebo

Only one organisation was utilizing the Bebo social utility. This organisation utilised all parts of the platform – photos, blog posts, videos, groups, comments and whiteboard – and had 136 friends and 76 profile views. Due to the low uptake of Bebo it is questionable whether it is a suitable utility for public engagement. Further investigation is required to elicit why the organisation decided upon Bebo and what prior market research led them to adopt the platform.

Facebook

Table 1 shows the frequencies of metrics across five Facebook Groups and 23 Facebook Pages which account for distinct 28 organisations. In one instance two organisations were amalgamated as they were using the same Facebook Page. Two organisations had two Facebook Pages which were both included separately. The results show many organisations failed to engage at all, with zero metrics accounting for 61.11% of outcomes. While discussions were used in 13 (44.83%) cases, in only five (38.46%) was a reply to the original post made. In only three cases did the organisation reference their presence on another social utility – all were Twitter.

Table 1 – Facebook Engagement (n=28)

Metric	0	1	2-10	11-20	21+
Discussion Topics	17	6	5	0	0
Discussion Posts	17	4	7	0	0
Events	19	5	4	0	0
Members (Fans)	3	2	9	3	11
Links	15	3	7	1	2
Photos	19	2	5	0	2
Notes	14	2	6	1	0
Videos	21	4	3	0	0
Wall Posts	2	1	2	0	0

To better understand engagement strategies, means were calculated to determine how often these strategies were employed across each organisation. Organisations provided more links (m=4.000, SD=9.623) than any other strategy, but also posted notes (m=2.217, SD=3.884), photos (m=1.786, SD=6.711) and discussion posts (m=1.107, SD=1.892). For discussions it is important to note that of the 11 organisations that used them, only 5 (45.45%) had a reply to an original post. The mean number of members (fans) was 35 (SD=58.421) with support varying from a high of 277 to a low of zero.

Twitter and YouTube

Figure 2 shows the cumulative number of organisations on Twitter and YouTube since June, 2007. In one instance two organisations were represented via a single Twitter account and so only one instance is reported. Since the beginning of January 2009, which was when Twitter began being mentioned in mainstream media, there has been a sharp increase in the number of Twitter accounts opened, and a marked plateau of account openings on YouTube. Further longitudinal research will need to be conducted to identify whether this trend will continue to be satisfied or whether it will plateau like YouTube in the future.

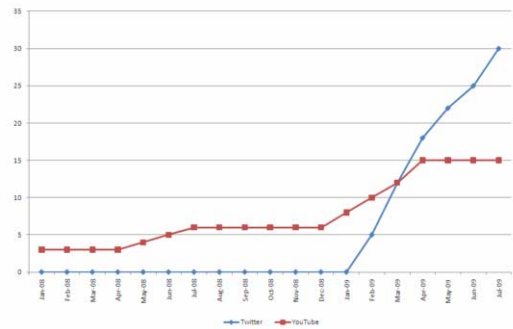

Figure 2 –Accounts Opened on Twitter (n=30) and YouTube (n=15) Since June, 2007

Figure 3 shows a bubble chart of the relationships between subscriptions, videos and channel views (indicated by the bubble size) of all 15 YouTube accounts.

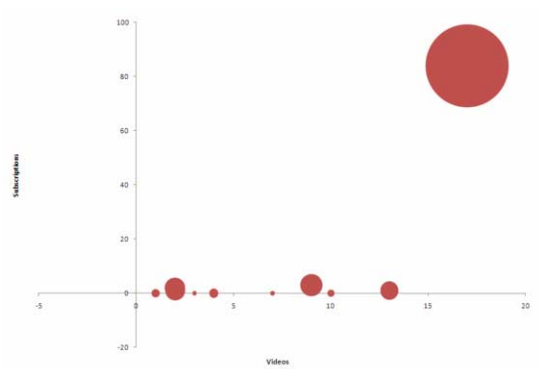

Figure 3 –YouTube Engagement (n=15)

The correlation between metrics is positive with subscriptions to channel views being the strongest (0.9982) followed by videos to channel views (0.6857) and videos to subscriptions (0.6764). This suggests it is more about the quality of videos to gain channel subscriptions than posting multiple videos that are not engaging. The large value in the top-right of the chart was due to a controversial video related to teen pregnancy which generated lots of media attention and thus increased views of the video before it was removed.

Discussion

By analysing the amount of content of online identities of PCTs in the NHS in England this study found that organisations using social utilities were in the minority. The tentative use of technologies parallels earlier studies on how public relations practitioners viewed the WWW and its impact on relationship building. Hill and White [7] found even though the value of the WWW for helping improve an organisation's competitiveness and image was recognised, they were sceptical about its ability to advance. Practitioners highlighted that they "could not articulate or demonstrate with research that they were currently achieving [these] benefits" and that often their sites "did not reflect positively on the organisation". Even though this research pre-dated utilities such as Facebook and Twitter there is still a reluctance to adopt online identities.

This research fits within the broader context of consumer health informatics (CHI) which is defined as "the branch of medical informatics that analyses consumers' needs for information; studies and implements methods of making information accessible to consumers; and models and integrates consumers' preferences into medical information systems" [8]. CHI focuses on prevention, self-care, patient empowerment and "consumer-as-partner" models of care rather than traditional, industrial-age, paternalistic, educational or Internet-age models of the consumer-professional relationship [9]. A subset of CHI, Medicine 2.0, describes an eHealth development which defines the broad adoption of Web 2.0 technologies and approaches to social networking, participation, apomediation, openness and collaboration within and between numerous stakeholders of health and social care [10]. This paper describes one element of a much broader picture and focuses on the interaction between healthcare organisations and the public using social networking. As an increasing number of "born digital" generations are entering the world of work their expectations of openness, transparency, access and privacy vary greatly from their predecessors. It could be hypothesised that these Generation Y (and beyond) workers could be the change agents required in healthcare technology utilisation [11] such as their ubiquitous use of the social utilities in their personal lives.

Our results indicated that organisations are failing to take advantage of the interactive nature of social utilities instead using them as unidirectional information "push" channels for news and links and providing a contact e-mail address instead of embracing components such as tweets and wall posts. It is unknown whether this is a strategic decision or one related to lack of operational knowledge as few guides exist for organisations on how to use these sites. Official Twitter [12] and Government [13] templates are emerging to fill this gap but what is not known is how they apply to health organisations and whether they need to be adapted to suit stakeholder groups. In health there is often a reluctance to engage with open systems for fear of reprimand or breaches of confidentiality. The fact that the Government appears to be endorsing the systems may be at odds with other controls within the service. Further research is needed into how these documents can be disseminated, used and evaluated across organisations.

The ways in which health organisations could use social utilities is underexplored and so we must look to other research disciplines for evidence. An analysis of non-profit organisations' use of Facebook for stakeholder engagement [14] suggested it could be used for message dissemination such as posting links to external news items about the organisation such as press releases or its campaigns and causes; posting photographs, video or audio files from the organisation and its supporters; and using discussion boards to post announcements and answer questions [15]. A calendar of events or listing volunteer opportunities was encouraged to bolster offline communications. Putting the influence research of Watts and Dodds [16] into practice who concluded that "large cascades of influence are driven not by influentials but by a critical mass of easily influence individuals" would suggest that by increasing the number of communications channels used you will increase the serendipity of these random information cascades. However, this was noted as being outside of the scope of the research paper. Would creating a Facebook Event or using targeting social advertising recruit more people to patient engagement focus groups?

Outside of academe there are two public projects that show that this is not just topical in the UK. Ed Bennett, a Hospital Web Manager from the United States has compiled a "Hospital Social Network List" of 351 organisations using Blogs, Facebook, Twitter and YouTube which is updated on a regular basis [17] and complementary to this, Lucien Engelen has begun compiling a "European Hospitals List" [18]. Preliminary results show that a staggering 253 (72.08%) of American hospitals have a Twitter account and approximately 50% have Facebook and YouTube accounts. Is this purely down to the competitive nature of care in the United States? Or is it something more complex?

Maintaining a digital identity will not in itself increase awareness or engagement as links between any two people do not imply an interaction between them as was shown by an analysis of a sample of Twitter users [19]. With an appropriate strategy, leadership, policy and guidance there is no reason why more health organisations cannot sensibly embrace new technologies rather than their adoption being linked to one or two keen enthusiasts who use them for personal use. What this research contributes is that organisations are using online identities, whether rightly or wrongly, and from those that do not digitally engage we can investigate whether this is an informed decision or ignorance.

A limitation of the data collection process was assuring veracity of digital identities. Veracity was assessed by the presence of an official NHS contact e-mail address or list of administrators that belonged to the organisation. Where appropriate, identities that appeared unofficial due to spurious e-mail addresses or objectionable content were removed and the organisations were contacted regarding the offending and potentially damaging presence. In all cases, there was no perfect and scalable way to address trust issues but this reflects the un-monitored nature of the World Wide Web (WWW). Further research involving organisational stakeholders is needed to address this issue. What is still not known is the effectiveness of engagement on social utilities such as Facebook and Twitter as little health-focused research has been

published to address this. Social utilities may have been adopted purely to "ride the wave" rather than forming any part of a much wider organisational communications strategy. Whether or not this is true was not the rationale behind this research, but to state that this is happening whether authorised or not.

Conclusion

The quantitative analysis has proved that the adoption of technologies such as Bebo, Facebook, Twitter and YouTube in PCTs in the NHS in England is underway. We identified that Twitter was the most popular and fastest-growing social utility although this was closely followed by Facebook and YouTube. In all cases there was no apparent strategy to integrate all information channels although this may not have been made available to the public. Further research is needed to qualify this hypothesis and to gain feedback from those organisations that are both using and not using these technologies. We must explore each social utility in detail to identify why they are being used, evaluate how effective they are and what values organisations perceive they have so that others can see the benefits or drawbacks of digital engagement. Longitudinal studies could offer insights into how organisational strategies change over time and case studies should be conducted both in the UK and other countries as a means of sharing successes and failures of engagement efforts.

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Standardizing Implementation of a Surgical Information System in Danish Hospitals – A Comparative Study

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Abstract

Implementation of IT-systems in modern healthcare organizations is associated with large, complex, and expensive projects. Purchase of the system is costly, but resources used to implement the organizational changes that follow, can be extensive. In an attempt to reduce costs, and at the same time to provide a thorough basis for local implementation, Corporate IT in The Capital Region of Denmark developed a standardized system-specific implementation concept for use by the hospitals´ local implementations of a Surgical Information system. The system has been implemented in five hospitals within the Capital Region. Through document analysis and interviews with the local project managers, we investigated the use and effectiveness of the standardized implementation concept across five hospitals involved. The study shows that total resource requirements and duration of projects are difficult to compare due to different constructions of the project organizations. We conclude that the implementation concept supports local IT-implementations, but parts of the concept are difficult to translate into practice, while other parts are directly operational.

Keywords:

Standardization, Implementation, Surgical information system, Organizational innovation, Change management

Introduction

Implementing new IT-systems is an activity which modern healthcare organizations have to manage alongside day-to-day operational tasks. These implementation projects are often large, complex and expensive, since they include not only costs related to the purchase of the IT-system, but also resources concerning the associated organizational changes that are required. A detailed plan that is driven by both capacity for change and context of change [1] is required, which includes change management, training, workflow analysis, and configuration of the IT-system [2].

One way to control IT implementation costs in large organizations is to standardize the implementation process. However, such a top-down approach can be problematic when viewed from a sociotechnical perspective, which argues that the specificities of the local work practices are essential and need to be taken into account for the setup and use of a new information system [3]. In an attempt to standardize the implementation processes and thereby reduce costs, while simultaneously facilitating the local adoption of the IT system, Corporate IT in the Capital Region of Denmark developed a Standardized System-Specific Implementation Concept (SSSIC) for use in the local implementation of a Surgical Information system in the Region´s thirteen hospitals. Development of the SSSIC is based on recommendations from selected literature on implementation [4], which divides implementation into five key activities: communication, workflow analysis, project organization, education, and configuration.

The Capital Region of Denmark has 36,000 employees and is responsible for providing healthcare to the region's 1.6 million inhabitants. Corporate IT is responsible for IT acquisition, maintenance and operations. The local hospitals and their IT-organizations are responsible for implementing new IT systems in the hospital wards. The typical lifecycle of IT-projects in the Capital Region is as follows: Corporate IT is responsible for the acquisition of the system; this phase of the project includes two pilot projects that involve the clinical utilization of the system in two different hospital wards. The aim of the pilot projects is to validate the suitability of the system in real-life work situations, as well as to estimate change requirements and training needs. An impact evaluation of the system is also performed in the pilot projects.

After completion of the two pilot projects, the project manager from Corporate IT and the local project manager in the pilot hospital produce a report that documents experiences gained during conducting the pilot projects. This documentation forms the basis of the SSSIC, which consists of guidelines and templates for use in the different implementation activities such as project organization, workflow analysis, education, configuration and communication. During a collaborative workshop, the SSSIC is presented to the local project managers from the hospitals which are due to implement the system. An overview of the SSSIC is presented in Figure 1 below.

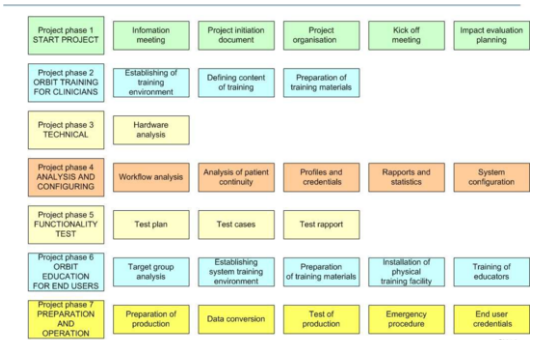

Figure 1- Overview of the Standardized System-Specific Implementation Concept

The first SSSIC was produced in relation to the ORBIT pilot project (OpeRation planning By Intelligent Technology). The purpose of providing the standardized implementation concept to the hospitals is primarily to simplify the implementation process and reduce time consumption for each of the hospitals and thereby reduce cost. Furthermore, the objective is to provide a point of departure for the local implementation projects, identify better practices, and to prevent repetition of mistakes that occur during the pilot projects.

ORBIT is a standardized surgical information system used for planning and documentation of surgical procedures in surgical departments. In addition, ORBIT is based on templates that are configurable by each surgical ward [5]. The system helps to secure effective use of resources needed for each surgical procedure e.g. the operating theatres and manning [6]. The clinicians' real-time documentation provides a constantly updated view of planned, on-going, and completed surgeries. Furthermore, ORBIT provides a graphical overview of the surgical schedule, which is available from multiple locations in each department and allows the ward staff to follow the actual status of ongoing surgeries.

By the end of 2009, ORBIT will be implemented by nine out of thirteen hospitals within the Capital Region and used by 16.000 clinicians. At the time of our study, the system had been implemented in a total of five hospitals. This paper investigates the implementation of ORBIT across these five hospitals with focus on the use and effectiveness of the SSSIC. The structure of the paper is as follows. First, we introduce the methods utilized for data collection and analysis. Second, we present the results of our study. Third, we discuss the findings in relation to the overall aim of the study, and finally, we conclude on the use and effectiveness of the SSSIC.

Materials and Methods

In order to assess the ways in which the SSSIC supports implementation, we conducted a study in early spring 2009, including local projects and their respective project managers in the five hospitals. This comparative study is a simple approach used to extract quantitative and qualitative data concerning the implementation activities [7]. Through document review, we identified and compared similarities and differences related to time utilization and costs in each of the respective projects. Furthermore, we aimed to elaborate on areas of special interest, importance, and unforeseen discoveries. The study focuses on the elements contained in the SSSIC and on the general use of implementation activities. To understand the scale of each project, we extracted quantitative data from local project documentation from each implementation activity in order to objectively compare time and resource consumption in detail.

On the basis of the listed activities in the projects documentation, we developed a semi-structured interview guide to provide direction with regards to the interviews with the project managers of the local implementation projects. Each semi-structured interview guide was further refined with the quantitative data from the document review [8]. The project managers received the interview guide a week prior to the interview in order to validate the questions and to prepare them regarding the issues we wished to discuss. Furthermore, we interviewed the project manager from the Corporate IT pilot project and the Coordinating System Administrator (CSA) who is also employed by Corporate IT.

The aim of the interviews was to validate and elaborate on the information extracted in the document review according to the actual performed implementation activities and use of resources. The interviews enabled us to identify and elaborate on issues unique to the specific hospital and project activities that were carried out differently than stated in the project documentation. We transcribed all interviews, and for analysis we thematized the data according to the elements in the SSSIC, condensed, and construed meaning.

Results

The results from our study are structured according to the listed implementation activities in the SSSIC with focus on similarities and differences between the hospitals. However, the data extracted from the quantitative analysis proved impracticable to compare, due to profound differences in the organization of the local projects and variation in the recording of documentation.

Across the five hospitals, we found great variation in how the local projects were *organized*. This influenced not only the manner in which cost of resources utilized and project duration were documented, but it also affected the duration of the project. In order to optimize new work processes in ORBIT, one hospital decided to introduce Lean as a parallel project with shared resources. Another hospital shared the Executive Group and the administrative tasks with two other projects. In two hospitals, ORBIT was introduced to all of its surgical wards as one, single, all encompassing implementation project. The other three hospitals conducted the project as a sequence of smaller sub-projects with each of the individual surgical ward following one other consecutively. Influenced by the manner in which the local projects were organized, the duration of implementation varied from 32 to 85 weeks across the five hospitals. Ensuring sufficient resource allocation for the im-

plementation project as proposed in the SSSIC, proved a significant challenge for two of the local implementation project managers. The project manager of the pilot project and the CSA acknowledged this challenge, and expressed frustration due to lack of authority regarding the resource availability.

All five project managers emphasized the importance of *communication*; that communication to managerial level, as well as to general staff, is important for consolidating the project in the organization. However, only three of five hospitals had an actual written communication strategy in their project plans, and none of these were in accordance with the guidelines provided by the SSSIC. None of these three hospitals kept to their plans regarding communication to end-users and surrounding context. Furthermore, communication activities were down scaled as soon as concrete operational activities pressed the project. In all five hospitals, the clinical managers were responsible for distributing information about implementation to hospital staff, and in two of the hospitals, the project managers followed-up on this task. The project manager of the pilot projects found it challenging to stress the importance of communication enough in the SSSIC.

The third element we compared was *workflow analysis*, which is used as basis for configuration of ORBIT. An external specialist consultant developed the method proposed in the SSSIC for analyzing workflows. Three of the five hospitals used the consultant to analyze the workflows in their wards. One project manager was critical to the fact that the workflow analysis was confined to only one of the initial phases of the project. She argued that the analysis should be iterative, as it is her experience that project members gain valuable knowledge throughout the entire project. Another project manager was not aware of the importance of introducing the participants to ORBIT before the workflow analysis. As a consequence, several dilemmas surfaced as it became clear that the outlined new workflows were not aligned with the possibilities provided in ORBIT. The project manager in the fifth hospital did not use the recommended method, but chose to observe and interview ward staff as basis for the workflow analysis. Although four of five projects used the method suggested in the SSSIC, local resources in only one of the projects performed the task. The project manager in the pilot project stressed that the method presented in the implementation concept is merely a guideline, including templates, which can be altered or substituted according to local needs.

The fourth element in our analysis is *education.* Training in ORBIT is twofold; a thorough training of the clinicians who partake in the implementation project in order to equip them to configure the system to the needs of the department. And end-user training for ward staff, adapted to the system tasks specific for each profession. An external consultant, who for the most part also produced the training material during the pilot project, performed the training for the project participants in system configuration. In addition, one of the hospitals used the same consultant to facilitate the training of end-users. The training of the staff in the other four hospitals was conducted either by the IT-department or the clinical project members in the ward. The training material produced in the pilot projects and published in the SSSIC had been adapted and used in all five hospitals. In addition, one hospital produced a small educational video as a supplement to the SSSIC.

Configuration is the fifth element of our analysis. System configuration is a comprehensive activity in the implementation of ORBIT. The system must be configured according to the outcome of the workflow analysis (e.g. set up to support the local work practices in each individual ward). First, a test version of the system is installed to run tests according to workflow. Then, the configuration is repeated in the production version of the system including any necessary changes. Optimally clinicians perform this work as it involves items of clinical documentation. Due to pressure in maintaining schedule in the ward, the project manager in one hospital configured the system despite project contracts with clinicians. Consequently, the hospital decided that the future configuration was to be performed by IT-staff. The clinicians configured the system in the other four hospitals, with the support of the project manager.

None of the five project managers used the SSSIC to its full extent, although the training material was widely used. Four of the project managers possessed vast knowledge of the content of the material and the scale of implementation in ORBIT, so they merely used the material as reference and to some extent substituted some of the proposed standardized methods with others. When implementation at the fifth hospital was started, the material had not yet been distributed, but to accommodate this, the pilot project manager from Corporate IT assisted in drafting the project plans for the hospital and accessing the undistributed material. The local project manager with no prior experience in implementing ORBIT, kept close to guidelines, methods and templates recommended by Corporate IT, and did not exhibit the same autonomy as the project managers with prior hands-on experience.

All five project managers found the material useful, but all expressed that a complex implementation project, such as ORBIT, cannot fully rely on written material as distributed in the SSSIC. They shared the opinion that greater use could be made of the coordinating system administrator (CSA) in supporting the local projects at the outset as well as being the carrier of experience between the hospitals. However, they believed that a distributed pack of materials would be adequate for less complex projects.

The Corporate IT project manager involved in the pilot projects, as well as the CSA agreed on this point of view. They strongly suggested involving the CSA as early as possible in the pilot projects, preferably in the test phase in order to gain a thorough knowledge of the system, which (s)he will be administrating. Thus, for projects as complex as ORBIT, they suggested a taskforce to be formed in order to collect and share experience between the hospitals, and to provide assistance in the early stages of the local projects. One of the experiences obtained over time is that the local project managers request implementation concepts for new projects to a greater extent. On these grounds the project manager in the pilot expressed a wish for a much stronger collaborative effort between the hospitals in the production and maintenance of the individual parts of the SSSIC. For example, when a local project substi-

tutes a method with another, elaborates, changes or extends material, they should publish guidelines, templates, and results for use in the other hospitals.

Discussion

The present study examined the use of a Standardized System-Specific Implementation Concept (SSSIC) for use in implementation of a complex IT-system in five Danish hospitals. Due to variation in the organizational construction of the five local projects, the study rendered it impossible to extract comparable objective values for *use of resources* and *project duration* and thereby costs. As a consequence, we omitted the planned comparison of costs and duration of implementation. Furthermore, the study shows that compliance and utilization of guidelines and templates provided by the concept varied across the five hospitals and was primarily related to the local project managers' prior knowledge of the pilot projects. This suggests that both thorough knowledge of the local context and understanding of the technology which are to be introduced, are critical skills for the project manager. This is supported by Lorenzi and Riley who found, that failure to succeed in implementation can be outlined in four major categories: technical shortcomings, project management shortcomings, organizational issues, and the continuing information explosion [2].

Communication is essential to change management, especially managers taking responsibility for change. The clinical management was responsible for end-user communication activities in all five implementation projects. However, the study showed that the concrete tasks in the project and the daily clinical practice often lead to a downgrading of planned communication activities. The organization requires a change owner who constantly demands the implementation of the change [2], and failure to do so, poses a great risk for resistance to the project. For all of the local projects, the IT departments inhabited the role of change owner, performed by the local project manager. For all of the five projects, the local project managers communicated on a regular basis with the Executive Group and clinical managers, but delegated the task of end-user communication to the clinical management. For three of the hospitals, this left the change owner out of touch with the actual level of information provided to the end-users. In two hospitals where the project managers followed up on communication, they were able to instigate further activities for change management.

Most of the local project managers were unable to conduct *workflow analysis* based on the guidelines and template provided in the SSSIC, and three out of five hospitals hired a consultant to perform this task. Workflow analysis is an essential activity when implementing IT systems in clinical wards, but the form and content of the analysis vary widely and depend on the participants and the purpose of the IT system; i.e. Business Process Reengineering (BPR) [9], Use Cases [10], or Computer Supported Cooperative Work (CSCW) [11] is often used. The challenges with workflow analysis are many; including the users' expectations of the IT system being tailored to their workflows and not vice versa. Such a desire can be problematic when implementing standard systems like ORBIT. In addition, it is questionable to what extent it is possible to model clinical workflows, characterized by numerous interruptions and complex decision making [12]. However, for ORBIT projects, workflow analysis is performed in order to enable clinicians to configure the system to best fit local practices. Thus, the need to hire an external consultant to perform the analysis, suggests that the local project managers were not confident in performing the task even with the method presented. The complexity of the method, the managers lack of prior experience of performing a workflow analysis, and for one of the project managers; lack of understanding of how in fact, the result should be brought into effect, are all possible reasons the project managers did not perform the workflow analysis independently supported by the method presented in the SSSIC material.

Thorough *education* of the clinical project members roots the project in the ward; it also transfers the responsibility for system maintenance from the IT-staff to the ward staff, which has the local knowledge needed for configuration and thereby to render a successful implementation possible [13]. The training material and tools included in the SSSIC were used extensively, suggesting that this part of the concept is easier to reuse across the organization. The core functionality of the system is the same and the local project managers can, with few resources, customize the training material to local practice. Nevertheless, one hospital supplemented the existing teaching methods with an educational video. This finding suggests the need for a broader range of training methods to accommodate the different needs for IT training among clinicians.

As ORBIT requires *configuration* according to local practices, it is essential for the quality of the future workflows and surgical documentation that the clinicians configure the system. For all five hospitals, contracts for devoting clinical resources to the projects were agreed upon. However, as the organization failed to substitute resources, the pressure of surgical schedules pressed the projects, as clinicians' commitment is primarily to their clinical work. Characteristic for all the hospitals is that the IT department holds ownership of the project through configuration and system maintenance. The advantages of ownership by clinicians are that it roots ownership of the system and system knowledge on location as argued by Pries-Heje et al. who state that ownership held by the ward secures the clinicians' commitment to the project and subsequent use of the system [14].

The SSSIC proved useful as a reference for methods and plans for implementing the specific system, and four out of five project managers exhibited great independence as how to put it into use based on their prior knowledge of the methods and the system. Only in the case of training material did the project managers kept very close to material and guidelines from the SSSIC, which also proves to be a most time consuming activity. However, as one hospital chose to produce a supplementing educational video, it is worth considering a broader selection of educational material for future projects.

The SSSIC for ORBIT was the first of its sort in the Capital Region of Denmark, and for this particular project, the local system implementation projects proved to be unable to rely on

written material alone. The complexity of the system implementation is one reason, but also differences in organizational constructions according to local culture played a role. However, as the local project managers presently request SSSIC for new projects, we reason that although a standardization of the implementation processes did not occur, the study showed that standardization of the implementation documents, methods and guidelines, establishes a framework of best practice from which the local projects draw valuable information and material. Furthermore, an earlier and deeper involvement of the CSA would be a valuable carrier of knowledge across the hospitals.

Conclusion

The standardized system-specific implementation concept (SSSIC) has not led to the standardization of the implementation process but contributes to the efficiency in the project through references to methods, and especially through the reuse of training materials. The SSSIC must be designed according to the complexity of the system implementation and the experience of the project managers. However, at the same time, it must be possible for the project managers to customize the content to accommodate local practices. The study exposed the varied ways in which the different local projects planned and performed the implementation of ORBIT. This influenced the possibility of comparing project duration and expenses.

For implementation projects as complex as ORBIT, the project managers request the CSA to play a larger role from an early stage of the project, in order to share and distribute experience between the hospitals.

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Interoperability prototype between hospitals and general practitioners in Switzerland

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Abstract

Interoperability in data exchange has the potential to improve the care processes and decrease costs of the health care system. Many countries have related eHealth initiatives in preparation or already implemented. In this area, Switzerland has yet to catch up. Its health system is fragmented, because of the federated nature of cantons. It is thus more difficult to coordinate efforts between the existing healthcare actors. In the Medicoordination project a pragmatic approach was selected: integrating several partners in healthcare on a regional scale in French speaking Switzerland. In parallel with the Swiss eHealth strategy, currently being elaborated by the Swiss confederation, particularly medium-sized hospitals and general practitioners were targeted in Medicoordination to implement concrete scenarios of information exchange between hospitals and general practitioners with a high added value. In this paper we focus our attention on a prototype implementation of one chosen scenario: the discharge summary. Although simple in concept, exchanging release letters shows small, hidden difficulties due to the multi-partner nature of the project. The added value of such a prototype is potentially high and it is now important to show that interoperability can work in practice.

Keywords:

Hospital information Systems, Medical informatics, Medical records, Interoperability.

Introduction

The advent of fully electronic patient records has strongly altered data management and processes in hospitals [1]. The availability of all data in digital format allows for an easy communication and clinicians can access the records at the same time as data can be duplicated easily. The exchange of health data in digital format also has other advantages because data loss can be prevented (for example compared to the case of images transported on film) and it can lead to the availability of essential and more complete data on patients avoiding mistreatments [2,3]. Double examinations can be avoided if the examination results can be communicated quickly.

To tackle the high potential of the domain of medical interoperability but also respond to potential risks of data abuse, strategies for the interoperability exist in many countries [4,5] and also on a European level [6]. The Swiss Confederation has also started an eHealth strategy creating a clear outline for the next ten years of managing health data at various scales, and including participants from a large number of interest groups. This effort has lead to several concrete propositions for potential standards regarding data exchange and particularly an identification of partners in the system. For a highly federated country such as Switzerland a strongly distributed structure is foreseen, storing the data at the place where they were produced, and then allowing selected access.

Although many standards already exist in the domain, not all of them offer an optimal scenario and the choice needs to be made well as the consequences are important. HL7 CDA (Health Level 7, Clinical Document Architecture) offers formats for exchanging several types of documents and CEN 13606 (European Committee for Standardization) also offers a general framework for data exchange. Coding standards exist for many domains including ICD (International Code of Diseases) for diseases, SNOMED CT (Systemized Nomenclature in Medicine Clinical Terms, [7]) as a very large-scale terminology, LOINC (Logical Observation Identifiers Names and Codes) for laboratory and clinical results, and many others.

Political processes usually advance slowly as it is a sensitive domain and wrong steps can lead to negative feedback, particularly for politicians interested in the voter's opinions. On the other hand a clear need is currently visible to have all health data of a patient in a single place. Large companies such as Microsoft[1] and Google[2] have also realized this and allow for a creation of personal health profiles. In the US many hospitals also offer such personal health records or allow for an export of the data to one of the commercial solutions [8]. This creates a risk that the commercial players might misuse the data they manage. On the other hand, patients have an interest to have a complete personal health profile.

The Medicoordination[3] project described in this paper tries to complement the Swiss eHealth strategy by collaborating mainly with regional medium-sized hospitals and smaller partners in the health system, where data exchange has not been an as important subject as in large University hospitals that often already exchange health data with external actors [9]. By communicating with several actors in the health system, a few scenarios for health data exchange could be identified, where a simple implementation brings a clear added value for all part-

[1] http://www.healthvault.com/
[2] http://www.google.com/health/
[3] http://www.medicoordination.ch/

ners. This allows for testing the infrastructures in parallel to the creation of the eHealth strategy also for smaller actors in the health system to gain experience with these tools and potential problem. This project has currently limited its scope to the French-speaking part of Switzerland.

This paper presents the prototype implementation of an interoperable healthcare infrastructure. The MediCoordination Healthcare Infrastructure (MHI) is based on the recommendations of the Swiss Confederation [5] and is intended to make accessing and sharing important medical data between small-to-medium medical actors more efficient and easier. The objective of the project is to promote electronic healthcare data exchange Switzerland, through:

- the adoption of technologies recommended by the Swiss Confederation, especially Integrating the Health Enterprise[4] (IHE);
- an informative survey, representing the interoperability requirements of the Swiss medical industry;
- a prototype emphasizing the benefits of interoperability in the context of electronic data exchange.

The goal of the prototype is to communicate a release letter from a hospital to a general practitioner (GP) identified by its EAN[5] (European Article Number) number in an automated way, and integrating the letter directly into the GP health record without manual intervention. The prototype is fully implemented and deployed. Its design, implementation and tests are presented in this paper.

Methods

The Medicoordination project includes two distinct phases. During the first phase interviews were performed with several actors in the Swiss health sector (limited to the French-speaking part of Switzerland), from small to medium and large hospitals, medical associations, insurance companies, producers of laboratory and imaging data, producers of software for GPs and hospitals. The selection was made after creating an exhaustive list of actors, and then choosing to have all sectors included. The second phase has started in early 2009 and concerns the choice and concrete implementation of one use case. The first phase is described in [10] and a few results are added for completeness. Personal interviews with 18 chosen partners were performed with the goal to have a qualitative evaluation of the needs of each partner concerning medical interoperability at the largest sense. The questions were taken as a basis for a longer qualitative discussion during the interviews. Interviews took around 120 minutes per partner and were moderated by several persons from the project (two persons per interview). The project partners developed questions together:

- Which electronic patient record is used and what exactly is digital?
- Which standards and terminologies are used, or even entire data models (such as HL7 RIM)?
- What is your attitude towards interoperability and data exchange? What is the potential and risks?
- Which scenarios would help you concretely in exchanging data (2-3 examples) with external actors?

Use cases chosen for a first reference implementation

Scenarios were defined in [10]. From discussions, 3 use cases were specified: (1) quick electronic release note, (2) electronic release letter, and (3) operation protocol. After discussion, it was clear that a prototype for exchanging release letters would provide the highest added value for GPs.

We defined the first specifications of the scenario with an architecture using a document server, as illustrated in Figure 2. The release letter (RL) is a short text summarizing the patient stay in a hospital. The medical doctor in the hospital (MD) directly writes it in free text (semi-structured) in the information system when the patient leaves the hospital. Currently, RLs are sometimes handed to the patient on paper, but most often sent by fax or mail, often several days after the patient leaves the hospital. The goal of RLs is informing the treating GP about the diagnosis, possible interventions, medications, as well as controls to perform.

The flow of events in the proposed use case can be summarized as follows:

1. The MD in the hospital creates a new release note;
2. The recipient of the document is chosen;
3. The document is generated partly with the data from the patient record;
4. The document is filled with diagnosis information;
5. The document is encrypted (encryption system has not yet been chosen);
6. The document is sent to the document server;
7. The server notifies the GP that a new document is available (GP requests the document on the next patient visit);
8. The GP connects to the server and creates a secure channel;
9. The GP downloads the document into its application using a secure channel;
10. The document is decrypted;
11. The GP checks the document and confirms its validity and correctness, then logs out.

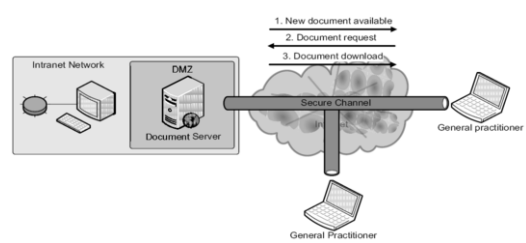

Figure 1 - The scenario of a document server inside each hospital and an exchange with external partners through a secure channel.

The MD is responsible for composing and sending the RL that will be archived in a MediCoordination repository hosted by the hospital (data is stored where it is produced).

[4] http://www.ihe.net/
[5] http://www.gs1.ch/

In this context, the MediCoordination prototype does not replace, but rather complements the traditional RL communication practices (mail, fax). Paper RLs are still sent to the GP alongside their electronic version for comparison.

Requirements for the reference implementation

Three main requirements for the prototype were sketched out from the results of the survey and from partners' expectations:

- it has to provide a measurable speed gain (orders of magnitude) compared to old practice (post mail, fax);
- it must not disturb the normal practice of the GP (transparent for the user);
- it has to provide interoperability with solutions already installed in medical offices (no IT changes or updates).

We collaborated with several GPs in the elaboration of a set of requirements for metadata and document formats. This process made clear that release letters are currently preferably produced in the Portable Document Format (PDF) format before printing them. For each produced document, we chose to generate metadata as XML documents including identifiers for the sending and receiving clinicians as well as for the patient.

Results

This section details the architecture of the prototype and the results we obtained with the current implementation.

Architecture

The prototype's architecture consists of a registry/repository and two clients, one for submitting documents (MD) and one for receiving them (GP). An XDS-based (Cross-Enterprise Document Sharing) server was used for both the repository and the registry. The IHE XDS Integration Profile describes an infrastructure based on standards (ebXML), for managing the information exchange of sensitive medical data between medical enterprises. A more recent version of the XDS profile (XDS.b), replacing the old one (renamed as XDS.a) was released. It supports SOAP 1.2.

The MHI prototype does not implement notifications. GPs have to manually query the registry. Once a document is downloaded it is archived and disappears from the server.

The MHI architecture in Figure 2 shows the interactions between actors. Corresponding IHE transactions are shown as link lables. The MD writes the discharge summaries for the patient and forwards it to the server along with predefined metadata. The client application of the GP then communicates with the server registry to query and retrieve the available documents. Client-server communications are channeled through a Web service endpoint in the bridge.

Server-side implementation

The server infrastructure (blue rectangle) is subdivided into two layers: an XDS.b implementation and a bridge. Bottom Layer : XDS.b

The backend server in charge of the XDS transactions consists of a Microsoft XDS.b Reference Implementation service. The registry and repository are both implemented as Windows Communication Foundation (WCF)/.NET services using standard Web communication protocols. Simple Object Access Protocol (SOAP) 1.2 is used for messaging, Message Transmission Optimization Mechanism (MTOM) for message attachments and WS-Addressing[6] for message delivery.

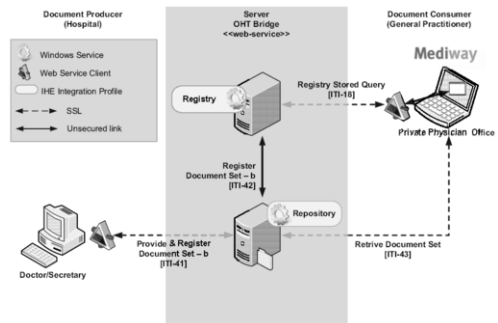

Figure 2 - Global view of the prototype with IHE IT Profile Transactions.

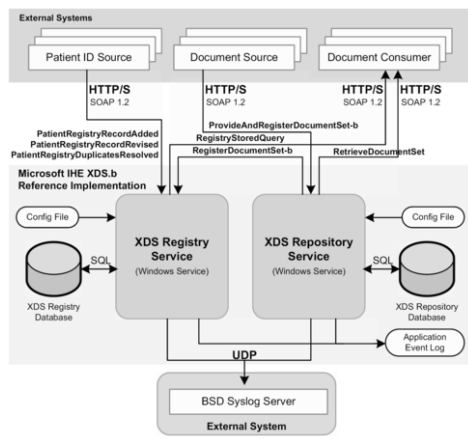

Figure 3 - Microsoft XDS.b reference implementation, including protocols and components.

The architecture illustrated in
Figure *3* shows Microsoft's XDS.b implementation. The prototype described here uses bidirectional (certificates in each side) SSL (Secure Socket Layer) encrypted communication channels between layers. The certificates are self-signed (for testing purposes).

Top Layer: OHT Bridge

iheprofiles is a subproject of Open Health Tools[7] (OHT), formerly known as Open Health Framework (OHF). It aims at facilitating the integration of IHE profiles into healthcare projects and consists of a plug-in oriented architecture. As shown in Figure 4, profile implementations are interfaced by

[6] http://www.w3.org/Submission/ws-addressing/
[7] https://iheprofiles.projects.openhealthtools.org/

plug-ins. A Web service end-point (OHT Bridge) then exposes functionality behind a unified interface.

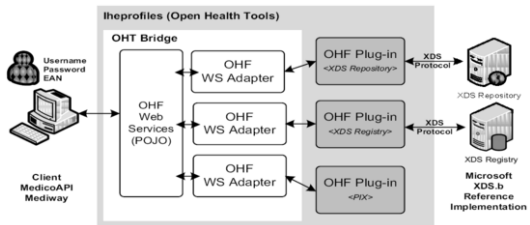

Figure 4 – iheprofiles integration in MHI

The bridge consists of many Web services encapsulated in an AXIS 2.0 container running on top of a Tomcat 6 server. Communications with the XDS.b server use SOAP 1.2 and SSL with self-signed certificates (SSC). Communication with the clients uses SOAP 1.1, SSL with SSC and token-based authentication (UsernameToken[8] from WS-Services).

The prototype uses a complementary access-control mechanism. Indeed, GPs and MDs have to provide an additional EAN-13 number in order to submit or retrieve documents. This additional credential is used to filter out documents that are not intended for the requested recipient. The EAN is kept in a database (currently a text file) along with the credentials.

Client-side implementation

The document source produces documents and the document consumer retrieves them. The prototype provides thus implementations for two types of clients.

Client-side implementation ─ Document Producer

A Java tool, CheckAppFolder, polls the state of the folder at regular intervals. When new documents are available they are forwarded to the bridge for registration and storage by the MedicoManager component, as illustrated in Figure 5.

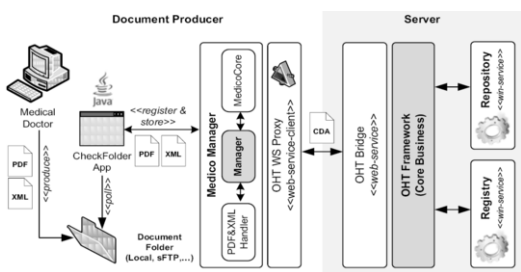

Figure 5 - Document Producer to Server integration

Documents found in the folder are base64-encoded and embedded in a HL7 CDA file by the MedicoManager component. This behavior follows from the fact that it is the only supported format by the bridge. Accompanying metadata files (in XML) are used to complete the associated CDA files before they are sent to the XDS server, and are mapped to XDS Registry.

Client-side implementation ─ Document Consumer

The consumer client is implemented in a modified version of existing well-disseminated software. Mediway[9] is an application for managing Electronic Health Records (EHR) of GPs. The modification was brought in the form of a .NET module, the OHT Connector, connecting seamlessly with the existing software. It is responsible for the communication with the repository and the registry (through the bridge).

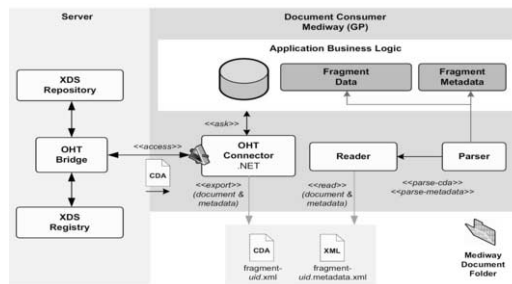

Figure 6 – Document Consumer to Server integration

The GP side prototype is shown in

Figure *6*. The system first reads the list of release notes targeting the GP from the registry. All documents are then downloaded from the repository and placed in a temporary folder chosen by the Mediway user.

The OHT Connector also produces accompanying metadata files. All documents are transferred in the original CDA format and require decoding prior to extracting information and then storing it in Mediway.

Timing and results

Two servers were used for testing the prototype. The first, H-Fr was installed in a state server farm for a hospital in Fribourg. The second, named RSV was installed on a physical machine in a hospital in Sion (Valais). Both servers have running instances of Microsoft XDS.b Reference Implementation[10] and ihetools[11], which are described previously in this paper. The first system runs a copy of Windows Server 2003 R2 on an Intel Xeon CPU @ 3.2 GHz with 1GB of memory. The second machine runs Windows XP Pro SP3 on top of a Pentium 4 CPU @ 3GHz with 1 GB of RAM.

All communication tests were performed on both servers using four different GP accounts and a reasonable amount of files for each situation. We measured timings and transfer rates with a T1 connection on a consumer PC. Obtained results are expected to prove the stability of the system for an arbitrary number of files, and confirm the clear advantage of an electronic system compared to the traditional paper release letters.

[8] http://docs.oasis-open.org/wss/2004/01/oasis-200401-wss-username-token-profile-1.0.pdf

[9] http://www.logival.ch/

[10] http://www.codeplex.com/ihe/

[11] https://iheprofiles.projects.openhealthtools.org/

For each server, we made a batch of measurements concerning the transfer time (TT) and the transfer rate (TR). The first measure indicates the elapsed time (in seconds) between the start and end of the download. The second measure measures the effective speed (kbps) of the download. For each measure we computed the max, min and average values. Data consisted of PDFs embedded in CDAs. Each file is about 4KB in length.

Table 1 - Timings and rates for H-Fr server

Statistic	UserA	UserB	UserC	UserD
Files	49	86	50	97
Total TT [ms]	6.45	10.66	6.37	11.79
Max TT [ms]	550.79	490.71	540.78	480.69
Min TT [ms]	100.14	100.14	100.14	100.14
Avg. TT [ms]	131.82	124.13	127.58	121.72
Max TR [kbps]	324.61	324.69	325.23	325.16
Min TR [kbps]	59.02	66.26	60.23	67.74
Avg. TR [kbps]	267.49	271.74	274.06	276.49

Table 2 - Timings and rates for the RSV server

Statistic	UserA	UserB	UserC	UserD
Files	23	23	18	26
Total TT [ms]	2.72	3.94	2.52	3.13
Max TT [ms]	200.29	480.69	480.69	180.26
Min TT [ms]	100.16	110.16	110.16	100.14
Avg. TT [ms]	118.81	171.55	140.20	120.56
Max TR [kbps]	295.10	295.10	295.67	324.77
Min TR [kbps]	162.31	67.64	67.74	180.60
Avg. TR [kbps]	278.05	231.47	278.94	274.49

File transfers were 100% successful (all files were transferred). Furthermore, results exhibited linearity (average values and total transfer time) as the number of files increases, which is representative of a stable system.

Discussion

In the context of interoperability, it is important that the information flow is quick and the GP is informed about the status of his/her patients as soon as they leave the hospital. A similar process can then be created for the admission of a patient, the full release letter, and other simple document types.

Traditionally, GPs used to query hospitals for the release letters and wait until they were sent or faxed. Upon reception, a RL had to be stored in the corresponding patient record. This process has inherent costs. The time elapsed between the query and the reception/storage counts in minutes. Our prototype reduced the process time to the millisecond range, which represents an important gain. Time lost for administrative tasks, is thus reduced.

Furthermore, with the integration of a module in Mediway, GPs accustomed to it did not have to change their habits and no additional expensive IT solutions were required.

Thus, results confirm our vision and prove that the solution is feasible. We managed to bring interoperability to actors that were until now isolated from the national eHealth strategy and relied on rather slow communication means. The experience is positive and our solution proved to have an added value.

Acknowledgements

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Experience Implementing Electronic Health Records in Three East African Countries

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Abstract

Introduction: Efficient use of health care resources in low-income countries by providers and local and national managers requires timely access to patient data. Objective: To implement electronic health records (EHRs) in HIV clinics in Kenya, Tanzania, and Uganda. Results: We initially developed and implemented an EHR in Kenya through a mature academic partnership. The EHR was then implemented in six HIV clinics in Tanzania and Uganda in collaboration with their National AIDS Control Programmes. All implementations were successful, but the system's use and sustainability varied depending on who controlled clinic funding. Conclusions: Successful EHR use and sustainability were enhanced by local control of funds, academic partnerships (mainly by leveraging research funds), and in-country technology support.

Keywords:

Computerized medical record systems, Developing countries, Africa South of the Sahara[*]

Introduction

Health care is an information business – most of what clinicians do is collect data (e.g. by history and physical exam), record data (in the patient chart), process data (choose treatments), and transmit information (via orders and letters). Information is necessary to provide and manage health care at all levels, from individual patients to health care systems to national Ministries of Health (MOH). The efficiency, effectiveness, accountability, and quality of health care at each of these levels depends on having accurate, timely data. In developed countries, electronic health records (EHRs) are becoming a necessary component of health care. For example, the U.K. and Sweden have national EHRs, and the U.S. has committed to wide use of EHRs by 2014 [1].

Developing countries trying to squeeze the most care from their limited health care resources have similar needs for timely health information. Yet being on the far side of the "digital divide" results in low-income countries having insufficient information to effectively manage their health systems. Since 2004, the U.S. Agency for International Development (USAID) committed more than $60 billion for HIV/AIDS care in developing countries. With more and growing HIV treatment programs, EHRs are becoming a necessity for managing and monitoring patients and health care systems while providing funders with data on the care provided and outcomes achieved. In this article, we describe our experience implementing OpenMRS [2], an open-source EHR, in three East African countries: Kenya, Tanzania, and Uganda. We evaluated each site and describe factors that led to successful implementation and sustainability of OpenMRS.

Implementing an Electronic Health Record System in Western Kenya

In 2001, Indiana and Moi Universities teamed with Moi

[*] The Tanzania-Uganda OpenMRS Consortium included National AIDS Control Programme of Tanzania (Dr. Geoffrey Somi), Morogoro Regional Hospital (Dr. Rita Lyamunya, Mayanga Mbaula), Ocean Road Cancer Institute (Dr. Hussein Mtiro, Willy Willifest), Tumbi Special Hospital (Japhal Mwamufupa, Joseph Myalla), Masaka Regional Referral Hospital (Drs. Penina Iutung, Kenya Mugisha, John Ssali, Michael Ssonko), Mbale Regional Referral Hospital (Dr. Peter Masaba, Helen Okwii), Mbarara Regional Referral Hospital (Dr. Mwebesa Bwana, Nneka Emenonyu), and the World Health Organization (WHO) (Dr. Mark Spohr, Christopher Bailey).
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Teaching and Referral Hospital (MTRH) to form AMPATH (the Academic Model Providing Access to Healthcare) and opened HIV clinics at both MTRH and nearby rural health centres. Anticipating their data needs, AMPATH and developers from the Regenstrief Institute developed an EHR to capture data from clinical encounters and provide AMPATH with data for both clinical care, monitoring and evaluation, and quality improvement. Initially, the AMPATH Medical Record System (AMRS) was a series of MS-Access® spreadsheets linked by patient identifiers and visit dates [3]. Following USAID funding in 2004, AMPATH grew to more than 15,000 patients who made 50,000 visits by mid-2005, overwhelming MS-Access®. Using the Regenstrief model [4], in 2006 we reconfigured the AMRS as a Java web application atop a series of MySQL databases. Through 2009, the AMRS supports HIV/AIDS, primary care, and specialty clinics 23 sites (rural health centres, district hospitals and Moi Teaching and Referral Hospital) contains 60 million observations from 2 million visits to 23 AMPATH rural and urban clinics by almost 150,000 enrolled patients, more than 110,000 of whom have HIV/AIDS. Figure 1 below shows the cumulative patients and visits in the AMRS from 2001 through 2009.

For each adult and pediatric visit, AMPATH's nurses and clinical officers complete paper encounter forms that were developed by AMPATH clinicians and managers to capture data for day-to-day patient care. Because clinicians' have the greatest need for detailed patient information, a system that captures sufficient data to serve clinicians' needs also serves the needs of local health system managers, national health programs, and international funding agencies [5]. Moreover, the same processes that capture clinical care can also capture data for non-clinical support programs. AMPATH provides care for HIV/AIDS and other conditions and collects clinical and non-clinical data as shown in Table 1. The AMRS currently employs 48 Kenyan data entry technicians, 10 data managers, 3 programmers, 3 information technicians, 2 biostatisticians, and 1 program manager.

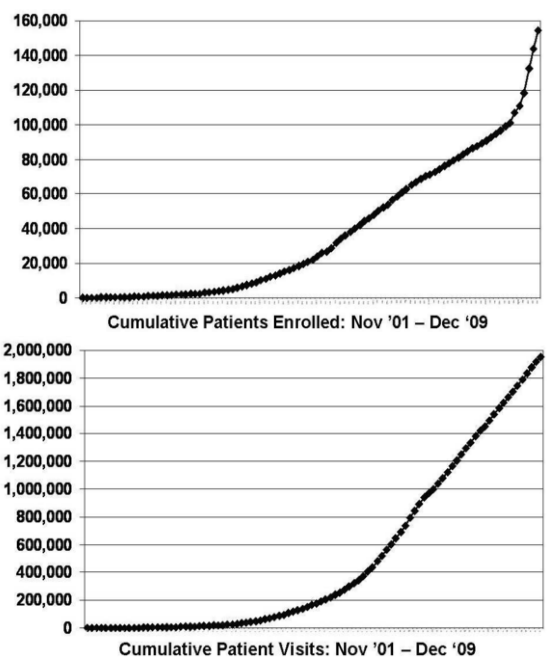

Figure 1- Cumulative patients enrolled and visit records

Table 1- AMPATH's electronic data collection

Clinics	Support Programs
HIV/AIDS – adults	Mother-baby register
HIV/AIDS – children	Social worker assessments
Primary care – adults	Outreach – patient follow-up
Primary care – children	Drug adherence assessments
Antenatal and postnatal	Nutrition assessments
Cardiovascular disease	Food supplement distribution
Pulmonary disease/tuberculosis	Microfinance program
Diabetes	Clinic pharmacies
Oncology	Clinical laboratories

Although all AMPATH care is delivered in Kenyan MOH facilities and mainly by MOH personnel, funding from USAID and other program-specific sources flows through Indiana University, Moi University, and MTRH. Investments by local AMPATH leaders in the AMRS to capture, manage, and analyze clinical data are recouped via enhanced provider and system productivity. Besides antiretroviral drugs (which are provided by USAID), care delivered by AMPATH cost only $175/patient/year in 2007 [6] and is now less than $100/patient/year in 2009.

In addition to the local monitoring and evaluation and routine and *ad hoc* reports required by funding agencies and the MOH, the AMRS also provides data to a robust multidisciplinary research program: researchers from Moi University and more than a dozen North American universities currently have more than 30 ongoing studies in East Africa, supported by >$40 million in grants from various U.S. federal granting agencies and foundations. Since 2006, Kenyan and North American AMPATH investigators have published >70 articles in peer-reviewed journals describing AMPATH care.

In early 2005, developers from Regenstrief and Partners in Health transformed the AMRS into OpenMRS [2,7] – a free, open-source EHR [8] and a community of developers who are creating a generalizable EHR to support health care delivery systems in developing countries [9]. To date, OpenMRS has been implemented in 25 countries, mostly low income, and supports HIV and a variety of other care programs.

The Rockefeller Foundation and the World Health Organization (WHO) observed that by having timely electronic data, AMPATH was able to deliver high-quality, evidence-based care. They then funded OpenMRS developers to test its usefulness to HIV/AIDS programs in other developing countries, specifically Tanzania and Uganda.

Implementing OpenMRS in Tanzania

In late 2005, leaders of the National AIDS Control Programme (NACP) of Tanzania expressed interest in participating in this OpenMRS demonstration. At the time, the NACP had implemented a paper-based HIV/AIDS registry that collected a core set of data on enrollment and at each visit, including vital signs, lab data, and treatments. The NACP had an electronic database for this registry, but few of these forms had been entered into the database or analyzed. Subsequently, there was scant information to support program management and strategic planning.

NACP leaders selected three sites OpenMRS for that varied in size, location, and experience with electronic data: Morogoro Regional Hospital (a large referral hospital, located 3 hours west of Dar es Salaam, that had prior experience with an electronic national hospital data system), Tumbi Special Hospital (a district hospital located on the outskirts of Dar es Salaam), and Ocean Road Cancer Institute (the site of care for AIDS-related malignancies) located near the NACP offices in Dar es Salaam). Neither of the latter two sites had any experience with electronic records of any kind.

In April of 2006, clinicians and data managers from each site and the Director of Epidemiology for the NACP met with OpenMRS developers in the AMPATH Centre in Eldoret, Kenya to learn about OpenMRS and develop adult and pediatric HIV/AIDS encounter forms. These forms included data required by the NACP plus additional information the clinicians thought would be useful for ongoing care. For guidance they used the AMRS encounter forms and a minimum dataset for HIV/AIDS care developed in 2004 at a WHO-sponsored meeting in Nairobi [5]. Also included in this 2006 meeting in Eldoret were computing and communication technology (IT) consultants from the University of Dar es Salaam who were contracted to program encounter forms and reports into OpenMRS and install and support it at each site. The United Nations Development Program provided computers and network hardware for all Tanzanian OpenMRS sites. The NACP supported data entry and management, aided by an epidemiologic research grant to Indiana University.

Because of high printing costs the desire for consistency with past data collection efforts, NACP leaders decided to forego the encounter forms developed by the Tanzanian clinicians and instead use their existing HIV registry forms. The computing consultants created a Patient Summary Report containing identifying data, diagnoses (HIV-related and others), drug allergies, HIV-relevant lab test results, and HIV/AIDS treatment data. This report was printed for clinicians before each patient visit to each demonstration clinic.

OpenMRS was first implemented at Morogoro in January of 2008 (Table 2). By the demonstration project's end in December of 2008, OpenMRS had been successfully deployed at all 3 sites, more than 11,000 patients had been enrolled, and OpenMRS had captured data from more than 58,000 visits. Patient Summary Reports were printed for most visits.

Reception of OpenMRS was generally positive. The university computing consultant independently maintained the system and generated reports for the NACP. Because OpenMRS was used to provide a database for the NACP's HIV/AIDS registry, implementing OpenMRS resulted in no fundamental changes in local clinic workflow and data management. However, by June of 2009 Morogoro had ceased to use OpenMRS.

Table 2- Implementation of OpenMRS in Tanzania with patients enrolled and visits stored through 31 December 2008

Tanzanian Site	Date EHR Initiated	Patients Enrolled	Visit Records
Morogoro	January 2008	5,204	23,436
Ocean Road	March 2008	621	3,707
Tumbi	July 2008	5,220	31,088
All Sites		**11,045**	**58,231**

Morogoro ceased its use of OpenMRS because its computer system failed and the consultant's contract ended. Subsequently, support was reestablished, and Morogoro is back using OpenMRS as a vehicle for capturing HIV registry data. Clinicians at Tumbi and Ocean Road Cancer Institute have continued to use their local versions of OpenMRS for all patients, sending electronic data to the NACP rather than paper HIV-register forms. Both Tumbi and the Ocean Road Cancer Institute continue to use the Patient Summaries.

Implementing OpenMRS in Uganda

The NACP and MOH in Uganda also participated in the demonstration project, choosing three sites differing in size, location, and university affiliation: Mbarara Regional Hospital (5 hours SW of Kampala, affiliated with the Mbarara University of Science and Technology), Masaka Regional Hospital (2.5 hours SW of Kampala), and Mbale Regional Hospital (4 hours NE of Kampala). HIV clinicians from these hospitals attended the April 2006 meeting in Kenya. Mbarara already had an MS-Access database (for data copied from patients' clinic notes) to support collaborative research with the University of California, San Francisco (UCSF). We contracted with a computing consultant at Makerere University in Kampala to install and maintain OpenMRS at all three Ugandan sites.

Each Ugandan site developed local encounter forms that captured data required by the Ugandan NACP and data that local clinicians needed to manage HIV-infected patients. The computing consultant installed OpenMRS at each site and programmed it to capture data from encounter forms and produce Patient Summary Reports and required reports to the NACP and MOH. Neither the Ugandan NACP nor the MOH required patient- or visit-level data from its HIV/AIDS clinics and as a result provided no support for OpenMRS. Research grants to UCSF and Indiana University paid for OpenMRS computer hardware, programming, and data entry.

Mbarara was first to initiate OpenMRS in January of 2007 (Table 3), employing seven Ugandan data entry technicians, a data manager, and one technologist, all with prior experience with their electronic chart abstracting database.

Table 3- Implementation of OpenMRS in Uganda with patients enrolled and visits stored through 31 December 2008.

Ugandan Site	Date EHR Initiated	Patients Enrolled	Visit Records
Mbarara	January 2007	9,854	12,869
Mbale	November 2007	1,601	,493
Masaka	January 2008	9,714	1,811
All Sites		**21,169**	**147,173**

Mbale had fewer HIV/AIDS patients and required one data entry clerk and one data manager. Masaka had three data entry technicians and one data manager. By the end of 2008, 21,169 Ugandan patients had been enrolled in OpenMRS at the Ugandan demonstration sites, with more than 145,000 visit records stored. Almost half of the patients and three-quarters of the visits were at Mbarara.

Care processes differed at the three Ugandan sites, and hence OpenMRS' effects on workflow varied. We assessed the effects of OpenMRS on workflow via a formal time-motion study [10]. At Mbarara, with experience with EHRs, patient visits after OpenMRS were slightly shorter (186 minutes pre-OpenMRS vs. 198 pre-OpenMRS, ($p<0.05$), with significantly less time spent waiting (88 minutes vs. 122 minutes) and more time spent with pharmacists (12 vs. 2 minutes) and non-clinical staff (61 vs. 42 minutes). There was no impact on provider time spent in various activities. At Masaka, which had no EHR experience, total visit time when up post-OpenMRS (102 vs. 77 minutes), all of which was due to increased waiting time (88 minutes increasing to 51 minutes). Yet there was a significant drop in time spent with pharmacy (1 vs. 3 minutes) and non-clinical staff (5 vs. 11 minutes). There was a statistically significant reduction in percent of the day clinicians (physicians, clinical officers, nurse practitioners) spent in patient care (43% of the workday pre-OpenMRS vs. 60%) and more time spent in administration (23% vs. 14%). At Mbale, a small clinic working out of two rooms, there were no significant changes in practice patterns.

Because only the Ugandan sites had fully implemented OpenMRS, we sent questionnaire Ugandan OpenMRS users (and not Tanzanian users) to assess their satisfaction with various aspects of the system. Respondents included clinicians, clinical support staff, and medical record clerks. As shown in Figure 2 below, users were highly satisfied with OpenMRS, finding it to be reliable and useful for performing their duties.

Currently, OpenMRS use continues at all three Ugandan sites. But Masaka has had problems paying for printing encounter forms, and data managers at all sites are being paid with research funds from Indiana University as part of an NIH-funded global HIV/AIDS epidemiology network [11]. Research grant funds from UCSF support OpenMRS data entry clerks and data managers at Mbarara.

Discussion

OpenMRS was initially, developed, implemented, and successfully supported rapidly expanding care in AMPATH clinics in western Kenya, aided by a long-standing partnership between Moi University, MTRH, Indiana University, and especially the Regenstrief Institute, one of the world's oldest and most active academic medical informatics institutions. Three decades of experience allowed Regenstrief investigators to replicate their data model into a new software platform (MySQL) that is able to support what is likely the largest clinical informatics enterprise in sub-Saharan Africa.

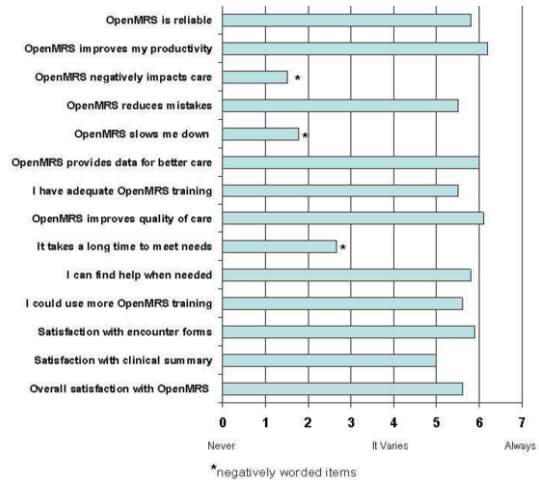

Figure 2- Results of OpenMRS user survey in Uganda

In Tanzania and Uganda, OpenMRS was successfully installed and used at all six sites. The most substantial and effective use was at Mbarara in Uganda, likely for several reasons: (1) Mbarara had previous experience managing electronic medical records via a small MS-Access research database. Thus they had both information technology in place and existing trained data entry clerks and data managers who could support the IT infrastructure, data entry, management, and reporting with minimum instruction. The local data manager was highly capable in programming as well as data management. Hence, problems with OpenMRS got solved quickly, usually by local staff able to work either alone or with help from Makerere University, Indiana University. (2) Mbarara University had a strong existing partnership with a sister university in the U.S. (UCSF). This led them to be friendly towards innovations and actually depend on data for both clinical care and research, even before OpenMRS was implemented. (3) Mbarara's clinicians and investigators had an incentive to perfect data collection to support future research. (4) And finally, a new clinic building was built just prior to implementing OpenMRS which was configured to accommodate OpenMRS' information technology infrastructure. Mbarara is a good example where a multi-disciplinary, multi-sector partnership was leveraged to enhance the implementation and rapid rise in use of an EHR. Such partnerships may be key to success in implementing health information technology in low-income countries.

Three factors influenced OpenMRS use in all three East African countries: local budgetary control, academic partnerships, and in-country IT support. AMPATH's local fiscal control and

global budgeting allowed it to pay for OpenMRS because it could recoup the cost through enhanced efficiency of care [12]. Pulling charts for scheduled patients facilitated patient flow while recording clinic data on a single form via tick boxes, numbers, and coded text (e.g., diagnoses). AMPATH could anticipate its personnel needs and avoid drug and lab stockouts. If control of local health care budgets resides in national MOHs, a local health care provider organization cannot pay for an EHR by increasing efficiency of care and lowering local personnel costs unless there is a national plan for installing and maintaining health information technology. Even then, EHRs will still need to be customized to serve local needs while serving the data needs of the government's national health care management and strategic planning.

EHRs that support local care can also provide sorely needed support for investigators and care programs in low-income countries. Research grants between North American and East African investigators helped implement and sustain OpenMRS in AMPATH [12] and all three Ugandan sites. Long-term sustainability and optimal use of EHRs to improve health care in developing countries, both locally and nationally, could therefore be enhanced by collaboration among academic, public, and private stakeholders [13,14]. Moreover, the resulting research could help identify strategies for more efficient and effective health care in low-income countries while supporting careers of local academic investigators.

Expertise in information and computing technologies, especially health informatics, is scarce in many low-income countries. Due to lack of medical informatics training in Kenya, the Regenstrief Institute trained all of AMPATH's local IT support staff and data managers. University IT consultants from the University of Dar es Salam supported OpenMRS in Tanzania while consultants from Makerere University in Kampala supported OpenMRS implementation in Uganda. These consultants participated in the OpenMRS collaboration and were thus backed by the global OpenMRS developer community which helped train them at annual OpenMRS Implementer Conferences and through online consultations. Such global developer communities can thus be a free and effective source of support for computing organizations that can then provide support to multiple EHR users in developing countries.

In conclusion, we successfully implemented a sophisticated EHR in HIV clinics in three East African countries. The locus of funding and oversight dictated the range of data captured, whom the EHR served, and how data were used to monitor, evaluate, and improve care. Local control of funds, academic partnerships, and enhanced local technical support bolstered developing countries' ability to implement and sustain EHRs to help low-income countries deliver, monitor, manage, and improve health care.

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eHealth in Thailand: The current status

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Abstract

The World Health Organization (WHO) defines eHealth as the use of information and communication technologies (ICT) for health. Thailand is one of the leading countries in emerging and developing economy that the use of ICT applications is pervasive including eHealth. However, the status of eHealth in Thailand hasn't been assessed. Employing the WHO Global Observatory for eHealth development model and its instrument, this study describes the uptake of eHealth foundations and the extent of eHealth applications and services implemented in the country. A group of the nation 18 eHealth experts met and evaluated country eHealth status and provided recommendations. The results show that the development of the country's eHealth foundations is inadequate and need to be the priority for national eHealth development.

Keywords: eHealth, Thailand, Evaluation study

Introduction

The World Health Organization (WHO) identifies fully functional health information system as one of the six important building blocks of high performance health system[1]. To understand a country's health information system, it is essential to understand the extent of information and telecommunication technology (ICT) use in her health system, because, in the world today, information systems and ICT are closely related and amalgamated to be an almost inseparable entity. WHO broadly defines eHealth as the use of ICT for health. eHealth has the potential to address inequities in health systems and services in countries. Its applications span across a wide range of areas such as the use of ICT to: 1) store, process and transmit patient information 2) manage the diverse clinical, administrative and financial information generated in health services facilities 3) improve quality of patient care and patient safety 4) provide mechanisms for diagnostics and treatment between health professionals separated by distance 4) build capacity by offering health sciences training and continuing education courses online to students and health professionals 5) offer innovative approaches for health care using rapid growing mobile devices 6) make highly complex biomedical research achievable[2]. Thailand is one of the countries that have achieved an elevated level of access to and use of ICTs and ICT skills (rank at the upper group countries by ICT Development Index -IDI)[3]. However, the status of eHealth hasn't been evaluated in Thailand. This study was conducted in the collaboration between Thailand's Ministry of Public Health and the WHO Thailand to analyze Thailand's eHealth current situation and identify the country's eHealth development gaps. The project aims not only to help Thailand assess her current status on practices, policies, standards, and the implementation of eHealth but also to contribute to the Global Observatory for eHealth second survey[4]. Moreover, the gaps identified from the survey will help health policy-makers at the ministerial level to plan for improving the nation's eHealth.

Methods

This study employed the WHO Global Observatory for eHealth's (GOe) development model and its second survey instrument. The GOe's questionnaire was designed to identify and analyze trends in 1) the uptake of eHealth foundations and 2) the extent of eHealth applications and services implemented. The questionnaire consisted of close end questions and open end questions asking participants to describe eHealth activities and projects in the country, including comments which participants considered relevant to the survey. We identified and invited 18 experts from both public and private sectors to participate in the survey. They are experts in health systems, health information systems, and ICT from Ministry of Public Health, public and private hospitals, National Health Security Office (the office of country's universal insurance scheme), National Statistics Office, Ministry of Information and Communication Technology (MICT), International Telecommunication Union (ITU), National Electronics and Computer Technology Center (NECTEC), medical schools, universities, health informatics professional association and health information non-government organizations (NGOs). These experts are working on various aspects of eHealth activities in the country. All experts accepted the invitation. The questionnaires were sent to the experts three weeks before a full-day discussion and consensus meeting. We asked them to study the questionnaire and be prepared for the discussion to get the country's consensus on eHealth. The

consensus and experts' recommendations are compiled to represent current Thailand eHealth.

Results

eHealth foundations

Since 2000, Thailand has a national ICT policy/strategy framework (IT 2010 framework) and two five years national ICT master plans[5][6]. The framework and plan has been implemented since 2002.The national ICT framework laid out e-strategy for eGovernment, eEducation, eCommerce, eSociety, eIndustry but not eHealth. As the results, the country has no national eHealth governing body that provides leadership and direction. Although there is no national eHealth policy/strategy, many eHealth applications and services has been developed, piloted and implemented. Major funding of the projects comes from public sector, the government. A few eHealth projects have been supported by public-private partnerships and health information NGOs. Even though, there are few public-private partnerships, the partnership between the Thai Medical Informatics Association (TMI), MOPH, public universities and NECTEC to organize annual health information and health information technology conference has been carried on almost two decades.[Table 1]

For eHealth capacity building, the human resources skills and knowledge, ICT skill and knowledge training courses have been offered for students of health sciences in more than 75% of tertiary educational institutes in Thailand (public and private). There are also institutions/organizations, such as MOPH and universities offer continuing education in ICT for health as part of the ongoing training of health and allied health professionals. Nevertheless, the short term training courses and degree training courses in biomedical/health informatics has not been instituted.

Although Thailand has enacted a legislation to ensure privacy of personally identifiable data of individuals irrespective of whether it is in analog or digital format, the country doesn't have a specific legislation to protect privacy of individuals' health-related data held in digitized format. The country doesn't have legislation which provides for the sharing of health-related data between health care staffs through an Electronic Medical Records/ Electronic Health Records (EMR/EHR) at all level of health care services. It means that there is no legislation about the data sharing 1) within the same health care entity and its associated network of care providers, 2) with different health care entities 3) with health care entities in other countries. Moreover, the country has no 1) legislation which grants the right of access by individuals of their health-related data when held in an EMR/EHR 2) legislation which allows individuals to demand the deletion of personal data and/or health-related data from their EMR/EHR 3) legislation which allows for the transmission and sharing of research data containing personal and health-related data between research entities in different countries and 4) legislation about the legal right to specify which health-related data from their EMR/EHR can be shared with health provider(s) of their choice. Regarding online pharmacies in Thailand, there is no legislation that either allows or prohibits internet pharmacy operations and no mechanism that regulates, accredits or certifies internet pharmacy sites. Furthermore, the legislation that allows or prohibits internet pharmacy sales purchased online from other countries hasn't been enacted in the country. In short, Thailand doesn't have laws to keep up with the rapid changing online pharmacy business. In terms of children protection from online risk, Thai government has sponsored websites or official initiatives to provide appropriate information and education about internet safety and literacy. These efforts aimed to protect general population and children, in particular. However, there is no safety tools and security technologies required by law for schools, libraries and other public places with internet facilities used by children.

Table 1-Summary of eHealth uptake in Thailand

eHealth Development	Uptake
I. Foundation Policies & Strategies	
1. National eGovernment policy & strategy	√ ICT2010
2. National eHealth policy & strategy	X
3. National eHealth governance body	X
3. Funding	+ Public, No Private
4. Public & Private partnership	+
5.Infrastructure	++
II. Enabling Policies & Strategies	
1. Health information security & privacy laws	X
2. Actions on Multilingualism & Multiculturalism	X
3. Capacity building	++
3.1. IT courses for health science students	+++
3.2. IT courses for health professional	+
4. National health IT standards (Interoperability)	+
4.1.Core data set standards	12 & 18 files standards
4.2.Semantic standards	ICD 10 TM, ICD 9 CM
4.3.Syntactic standards	X
4.4.Security and privacy standards	X
III. eHealth Applications	
1. mHealth	++, mostly pilot
2. Telemedicine	+, pilot
3. eLearning in health sciences	+
4. EHR/EMR (Health Information Exchange)	++
4.1 For administration, claims	+++
4.2 For clinical care	+

Note: √ = Adopted, X = No uptake, + =0-25% uptake, ++ = 26-50% uptake, +++ = 51-75% uptake, ++++ = 76-100% uptake, ICT 2010 = Thailand ICT development frame work 2000-2010, ICD 10 TM = International Classification of Disease version 10 Thai Modification, ICD 9 CM = ICD9 Clinical Modification procedure codes.

Regarding Multilingualism and multiculturalism in eHealth, the country has no national policy or strategy that promotes the production of electronic health information in a manner that is multiculturally sensitive. Although at the three southern most provinces of Thailand there is a large number of Thai Muslims. Their dialect, religion and culture are differences from the traditions and language of the majority Thais. The experts agree that this issue should not be ignored and identified this issue as one of the national eHealth priorities.

At the national level, ICD10-TM (International Classification of Diseases version 10-Thai Modification) and ICD9-CM (Clinical Modification) are used for coding diagnosis and health service intervention respectively. Thailand has developed and implemented citizen identification number for more than two decades by the Ministry of Interior. Every Thai citizen has a unique identification number, known as "13 digits number". It is also used as patient identifier. There are two national health minimal data set standards which are developed for administrative purpose. They are 1) standard data sets for health insurance, known as the "12-file data set", and 2) standards data set for health center, known as the "18-file data set".[7] They are used mainly for health insurance payment and healthcare activities reports. National drug code, national health provider identifier, medical device coding standards, survey metadata standards, indicators standards are at various stages of development. HL7 messaging and LOINC standards (Logical Observational Identifiers Names and Codes - a laboratory coding standards) are implemented in a few large hospitals. They are not the national standards. DICOM (Digital Imaging and Communication in Medicine), a standard for handling, storing, printing, and transmitting information in medical imaging, is used in many health facilities in the country usually where PACS (Picture Archiving and Communication Systems) are implemented. However, it is not instituted as a national standard.

eHealth applications and services

The mix of paper and computerized patient information (individual data and aggregated data) are being used in healthcare services. In public sector, almost all of hospitals (1,001 hospitals) and health centers/primary care units (10,068 PCUs) have implemented various degrees of capabilities of EMR/EHR. If we categorize individual patient information into administrative data (used for reimbursement, administration and reports) and clinical data (for patient care e.g. laboratory data, pharmacy data, providers' notes), these two data type are not equally developed in Thailand. Administrative data are computerized and can be transmitted and exchanged electronically in nearly all health facilities in Thailand. The clinical data are collected in both paper and computerized format but the capability to exchange electronically is very limited.[Table 1]

Thailand doesn't have a national telemedicine policy or strategy and also a national agency for the development and promotion of telemedicine and its applications. Furthermore, there is no scientific institution involved in the development of telemedicine solutions in the country. In the past decade there were many telemedicine projects and activities. Many of them were short term demonstration projects which were the works between international agencies and Thai's universities or big private hospitals [8-10]. There was only one national telemedicine project implemented by the MOPH during 1998-2003, called MOPH's telemedicine network.[11] This big project aimed to deliver medical care to people in remote rural areas where there were the shortage of doctors and other professionals. However, the project was not very successful and was abandoned in 2003. There were many factors contributing to the ending of the project, for instance, no national body to continuously provide national telemedicine policy and strategy, the lack of requisite IT skills among health professionals, the country's economic crisis, the rapid changes in technology, and the rapid social and political changes taking place in Thailand. Currently, there are private teleradiology services which provide services largely for big private hospitals in big cities. Several public telemedicine pilot projects are being piloted such as the teledermatology consultations which run by Institute of Dermatology, MOPH.

mHealth is an emerging term for medical and public health practice supported by mobile devices, such as mobile phones, patient monitoring devices, Personal Digital Assistants (PDAs), and other wireless devices. mHealth applications include the use of mobile devices in collecting community and clinical health data, delivery of healthcare information to practitioners, researchers, and patients, real-time monitoring of patient vital signs, and direct provision of care. In Thailand, several mHealth initiatives are being piloted and implemented. The cross-border Mekong Basin Disease Surveillance System is an example of a piloted mHealth project which uses mobile devices for diseases surveillance and management of emergency and disaster situations. The project uses GeoChat SMS groups communication software developed by InSTEDD to report communicable diseases and emergency occurred in community in Mukdahan province (Thailand) and Suvanakhet (Laos). The public health personnel working in the sub-district level use SMS format to report cases in order to improve timeliness of report and warning for potential disease outbreak and disaster.[12]

In Thailand, eLearning program has been used to teach health sciences students and the development of continuous health professional training programs in many institutes. At the national level, the use of eLearning to teach health sciences students was estimated at medium level (more than 25% and less than 50% of institutes and/or courses). But the level of use for professional development programs in the ongoing training of health professionals was estimated at low level (less than 25%). Thailand Cyber University Project [13], operates by the Commission of Higher Education, Ministry of Education, provides supports to the eLearning programs development for students and non-students to teaching institutes in the country

including health sciences teaching institutes. A number of health sciences eLearning courses are available at its website.

Discussion and conclusions

Among developing countries, evidences show that Thailand is one of the leading countries that the use of ICT applications is pervasive including eHealth [3, 14]. However, our study reveals that the country is lag behind in laying down the eHealth foundations. The WHO GOe identifies three layers of eHealth development.[2] [Figure 1] The first layer, the foundation policies and strategy, forms the basis of country eHealth development. This includes the creation of an appropriate governing body—a multi-stakeholder, national-level, eHealth authority to provide leadership and direction, the development or adoption of eHealth policy to define the vision and action required, the development of a funding framework to support the vision, and mechanisms to develop ICT infrastructure for the provision of eHealth services. Although Thailand has national e-strategy for various sectors, but the vision and strategy for eHealth haven't been laid out. This may be both the cause and result of not having national eHealth governing body.

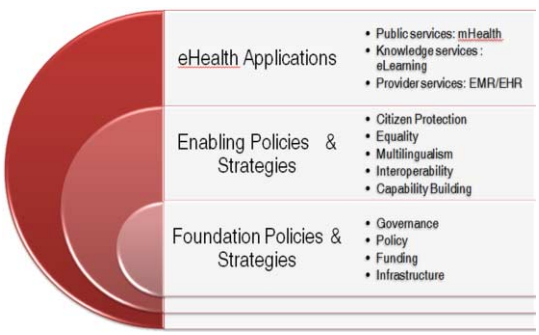

Figure 1-The Global Observatory for eHealth Development model (modified)

The second layer of eHealth development model, consists of enabling actions, which broadly act as a bridge between foundation policies and strategies and the planned outcome of providing eHealth services for all. The functions of enabling actions are to protect the citizen, promote access and equity, and to act on the need for multilingualism and multiculturalism in cyberspace. They include eHealth interoperability policies and strategies to ensure that systems can communicate with each other. Finally, they include a component to build the ICT capacity of health professionals and students. Consider components in this layer, Thailand doesn't take action on multilingualism and inadequately takes actions on citizen protection, eHealth capacity building and interoperability of systems.

The third layer, eHealth applications such as EMR/EHR, mHealth, telemedicine, are being implemented in Thailand, but these services are fragmented and scattered. It is known that, the success of these applications is largely dependent on the actions leading up to them, that is, services in this layer will be more effective if the actions in the first two layers have been executed well. Solid foundational layers lead to more effective eHealth systems and services. Unfortunately, Thailand is inadequately taking actions on developing these two layers.

The country's eHealth experts recommended that the country should put the development of eHealth foundations the priority. The identified foundational gaps should be closed to enable the development of sustainable and effective eHealth systems and services. The recommendations are 1) Thailand should create a multi-stakeholder, national-level, eHealth governing authority to provide leadership and direction, the development or adoption of eHealth policy to define the vision and action required 2) the country new national ICT framework, ICT 2020, should incorporate eHealth strategy into the framework along with eGovernment, eEducation, eIndustry,eSociety and eCommerce 3) legislations related to health information security, privacy and confidentiality should be enacted to protect people 4) national health information standards need to be developed to enable eHealth services interoperability and health information exchange and 5) systematic mechanism for capacity building of people who design, implement, operate and use of the eHealth systems has to be planned and implemented

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Diffusion and use of Electronic Health Record Systems in Norway

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Abstract

This paper sums up some of the findings from a national survey on the diffusion and use of Electronic Health Record (EHR) systems in the Norwegian health sector. The survey shows that almost all hospitals and GPs use their EHR systems on a daily basis, while the municipalities are lagging behind, All three view costs and missing functionality as the most important challenges. The GPs are very concerned with the complexity of the daily operation of the systems, while the hospitals are mostly concerned with costs of daily operations, maintenance and further development of the systems. Better integration with support systems is requested. User involvement and ownership seem to have contributed to the development and diffusion of the most successful EHR systems. National diffusion processes require good planning and are time consuming. It has taken 15 years from the first EHR systems were introduced until 90% of the actors used the systems. This has to be taken into account in national strategy processes in the health sector.

Keywords:
Electronic health record, Shared care, Survey, Benefits, Diffusion, Strategy

Introduction

The Norwegian Directorate of Health did a strategic study on EHR strategies in the Norwegian Health Sector 2005. The study pinpointed the need of "a better decision base for further development of EHR systems". More documentation on the diffusion of existing EHR systems and also their usage and potential benefits in comparison to paper based systems was requested.

An increasing focus on shared care that involves health workers from different organizations, leads to more transfer of a patient's health information across organizational boarders. This extensive information exchange will also imply new requirements and challenges regarding further development of the EHR systems that are used by the collaborating actors.

So far, data about clinicians' use of EHR systems in Norway have only been gathered and analyzed in relation to hospitals by Lærum et al [1], Ellingsen and Monteiro [2] or at a local level by Christensen [3]. Examples of documentation regarding EHR diffusion in other countries are Castro's report on leadership in Health IT [4], Protti and Nilsson's comparison of IT in general practice in ten countries [5] and Nøhr's analysis of development, implementation and diffusion of EHR systems in Denmark [6, 7] and Gans et. al [8]. In order to get a better overview of the Norwegian status, the Directorate of Health initiated the EHR Monitor project. The project will monitor the implementation and use of EHR systems each year. Data will be retrieved by surveys. This paper sums up some of the findings from the first survey, and also sees some of the findings in relation to existing research related to diffusion of EHR systems.

Method

The questionnaire

The purpose of the first survey in 2008 was to collect quantitative data as a basis for further study based on a set of indicators. Examples of indicators are the number of hospitals, GPs or nursing homes that use EHR systems and the number of actors that plan to implement such systems within a fixed number of years. The researchers have found it necessary to use both open questions where the user can answer quite freely, and questions that require quantitative input.

Four different types of questionnaires were developed, one per type of actor in the survey: GPs, municipal health stations, nursing homes and hospitals. The questionnaires were developed through workshops, expert feedback and pilot testing.

It was assumed that the informants had little time available for paperwork, and it was thus decided to use questionnaires that could be filled out with limited use of time. The questionnaires were also intended for reuse in order to provide comparable data over a period of two or more years. It was decided that the number of questions should be held within the limit of 4 pages. It was assumed that several reminders would be required to get the forms returned or until a negative answer to the request would be given. The GPs received compensation

comparable to a patient consultation as a compensation for loss of income.

Selection of informants: The survey was directed towards GPs, municipal care and hospitals. 180 municipalities were selected based on size and geography in such a way that they could be regarded as representative for the national average. 150 GP practices were included. 130 of these were selected based on a random pick among the selected municipalities. In addition 5 practices from each of the four largest cities were included. The questionnaire was sent to all the hospitals.

The response rate was: 43% from the municipalities, 62% from the GPs and 83% from the hospitals. The number of forms returned from the GPs and hospital were quite high, but a better response from the municipalities had been appreciated. The fairly low response from the municipalities might be due to the fact that a more general survey on ICT use had been sent to the municipalities not long before the her Monitor survey.

Results

The most visible indicators for dissemination of EHR systems in the health sector are the share of actors that use these systems. This is illustrated in figure 1. The survey shows an almost full coverage among GPs and hospitals. It has been 20 years since the first EHR installation in a hospital until full dissemination. The same process started earlier among the GPs, and their adoption curve was even steeper. The use of EHR systems in municipal care (nursing homes and maternal and child health centers) is more limited, but seems to follow the same trend. The smaller municipalities are slower to introduce new ICT-solution than the larger ones.

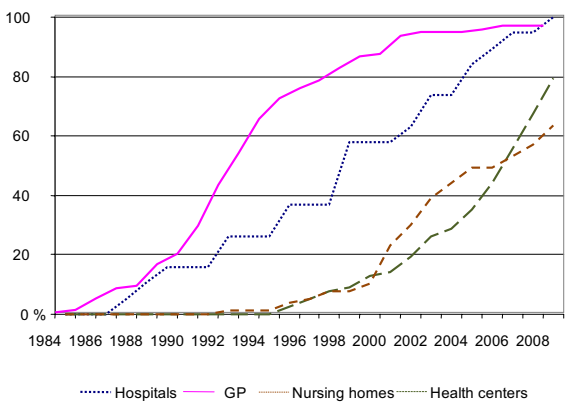

Figure 1- Planned or fulfilled implementations of EHR systems

The GPs do not keep paper records any more, but only 25% of the hospitals have a completely paper free record. Some of these hospitals scan selected parts of the record that have been preexisting in paper form when the patient is admitted. 65% of the hospitals use the electronic record as the main source for medical information. There are also regional differences in the use of paper free EHR. 75% of the hospitals in Mid-Norway do only use the EHR, while 70% of the hospitals in South-Eastern Norway still use the paper record as the main archieve.

83% of the municipalities reported to use some kind of EHR system. EHR systems are used in nursing homes (82%), home-care services (56%), school health services (39%), community habilitation services (34%) and maternal and child health centers (65%). The smaller municipalities with less than 2500 inhabitants are the slowest ones when it comes to adopting new systems. This can be related to relatively high cost for both buying new systems and daily operating cost for the systems.

6% of the municipalities were using PDAs with access to the patients' EHR in the home care services. Another 12% reported that they were about to implement PDA systems the following year.

The informants in the survey were also asked what they saw as the main challenges in relation to future EHR use.

Table 1- The hospitals reported challenges regarding further diffusion and development of EHR systems

	All answers	Most important	Sec. most important
High costs	80 %	44 %	15 %
Missing functionality	50 %	13 %	15 %
Complexity in daily operation and maintenance	28 %	3 %	3 %
Resistance against change among users	10 %	5 %	-
Missing standards	35 %	8 %	9 %
User education	40 %	5 %	3 %
Missing integration	63 %	5 %	30 %
Realization of benefits	53 %	8 %	9 %
New government requirements	20 %	3 %	0 %
Vendors that do not deliver as promised	55 %	5 %	12 %

Both groups saw rising costs and missing functionality as the most important challenges. The GPs were particularly concerned with the complexity of the daily operation of the systems. Integration between the main EHR system and other clinical and administrative systems at the hospital is also a great concern. Improved functionality is highly requested by all actors. Further, it has proven to be difficult for the hospitals to realize the expected gains and benefits from the new systems, and vendors do often not deliver their new version on time.

The hospitals were less satisfied with their vendors than the municipalities and the GPs.

Table 2 - The GPs reported challenges regarding further diffusion and development of EHR systems

	All answers	Most important	Sec. most important
High costs	54 %	34 %	7 %
Missing functionality	36 %	9 %	13 %
Complexity in daily operation and maintenance	52 %	13 %	22 %
Resistance against change among users	8 %	-	3 %
Missing standards	29 %	4 %	10 %
User education	18 %	3 %	4 %
Missing integration	44 %	11 %	16 %
Realization of benefits	28 %	3 %	4 %
New government requirements	15 %	3 %	4 %
Vendors that do not deliver as promised	27 %	10 %	4 %

The hospitals were also asked about their possibilities for electronic message exchange. It is important to emphasize that it is a gap between possibilities for use and actual use of electronic message exchange. This is both due to the fact that not all collaborating actors have EHR systems that can communicate, and that not all organizations are ready to use the collaboration possibilities. 59% of the hospitals have systems that can receive electronic referrals, 100% can send electronic discharge summaries, and 91% can send laboratory reports.

24% of the General Practices send electronic referrals, but more than 50% of these referrals are sent with paper referrals in parallel. More that 90% of the discharge summaries and laboratory reports are received electronically by the GPs, but paper is also sent in parallel with 55% of the discharge summaries and 45% of the laboratory reports.

Discussion

The diffusion curves of the Norwegian EHR systems all seem to follow the same s-shape. The starting point differs (Figure 1), but the norm is that it takes at least 15 years from the first systems are introduced until 90% of the actors use the system. In an evaluation of ten European projects [9] it was shown that the factors that influenced the diffusion time most, were dependencies to existing software and infrastructures. A break/even point for costs and benefits would in most projects be reached after five years. This is a challenge when it comes to realization of ICT strategies because the planning horizon is too short. Our finding are in line with Bower's suggested adoption rate for EHR [10], where he compares diffusion of EHR with diffusion of ICT systems in other industries.

Diffusion of EHR systems among General Practitioners

The first EHR systems for Norwegian GPs were in use as early as in the late 1970ties. This was the PROMED-system [11]. Another system was installed in Balsfjord in 1980 [12]. The development of the Balsfjord system was financed by research grants and government funding. The system did only have a limited number of users in Northern Norway. The GPs outside the Balsfjord-project did not get any subsidies or incentives from the government when the new EHR systems were introduced. They had to buy the systems themselves, but found the new systems so useful that they were worth the investment. Later EHR systems in general practice have all been developed without any subsidies or incentives.

The first systems were based on use of the operating system MS-DOS. The market leader during the first decade was Infodoc [13]. When new systems that used MS-Windows were introduced, many of the users did not only change version of their system, but also vendor. This process is illustrated in the figure below. This shift took place in the period 1999-2001.

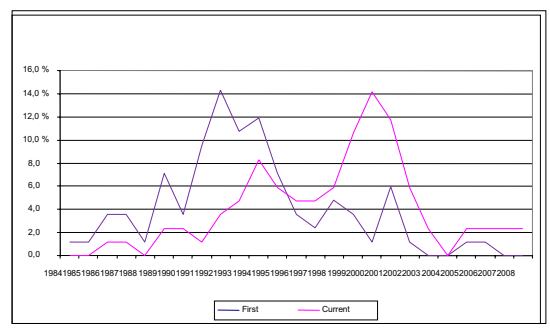

Figure 2 – GPs' purchase of EHR systems

An international survey in 2007 [14] showed that 98% of the GPs in Finland, Denmark, Norway, United Kingdom, the Netherlands and Estonia use ICT-systems to support their daily work processes. An American survey [15] from medical group practices in the USA showed that adoption of EHR systems progressed slowly, at least in smaller practices, although a number of group practices planned to implement an EHR within the next two years. The process of choosing and implementing an EHR system appeared to be more complex than first expected.

Tom Christensen [3] has in his doctoral thesis analyzed how GPs use EHR systems and how they can be developed further in order to better support the GP's work processes. The GPs reported that they generally believe that using the computer saves time, and observations showed that they used even less time than reported in front of the computer. On the other hand they also tell that the introduction of EHR has transferred

workload from the secretary to the GP. They are generally satisfied with their system, but need better decision support and support for communication with other systems even if possibilities for message exchange have been made available in most of the systems. They also reported that it had become more difficult to get the overview of the patients' earlier health-history. The clinician-patient relationship is of great concern GPs, but they denied that the use of an EHR system drew the attention away from the patient.

Diffusion of EHR systems in Norwegian hospitals

The diffusion of EHR systems in hospitals has been much slower than in primary care. Ellingsen and Monteiro [2] stated that establishing EPRs in hospitals, especially the larger ones, has been notoriously difficult. The increase in organizational, institutional, political and technological complexity was seriously underestimated during the first years. Before the introduction of EHR systems in hospitals, patient administrative systems had been available in hospitals for a decade.

The benefits have not been equally visible when it comes to health record systems that can support the clinicians' daily work-processes [3], [15]. The clinicians in hospital often move over long distances during their workday and uses EHR systems only a few minutes at a time. It has been shown that information resources must be easily available in the clinicians' workspace in order to be used [16] In the EHR Monitor survey 80-90% of the hospitals agree that there are big potential quantitative and qualitative benefits related to the introduction of EHR systems, but only 20-30% agree that these benefits already have been achieved. It is common that it takes some time from the ICT-systems first are introduced until the benefits can be achieved. It is however surprising that the survey showed that less than 50% of the hospitals had a plan for realization of benefits related to the introduction of new systems.

In comparison to the development of EHR systems for the GPs, the government has provided significantly more funding for the development of hospital's EHR systems. Still the diffusion time has been much longer. This is probably due to the complexity of hospital organizations, and the large amount of work required for integration with many different information systems at the hospitals. Another difference is that the GPs have been planning, ordering and using the new systems themselves. They have not bothered to invest in systems that could not provide them with obvious benefits neither in terms of reduced cost nor as support for their daily work processes. On the hospital side, most of the procurement processes have been managed by the administration. The health workers have often been involved in the requirement specification processes, but their possibilities to grasp how these specifications would influence on their work processes have often been limited, simply because many of these systems are very complex.

Three major EHR systems are in use in Norwegian hospitals today, of which one is on the way out of the market. One vendor has a significantly larger market share than the others. This system originated from a small Norwegian hospital and the first version was developed in close collaboration with the users at the hospital. This contributed to the making of a system that to a high degree supported the health worker's daily work processes. From being a system that should support a limited number of users, the system is now in use at many, both large and small, hospitals. This can be a challenge when it comes to user involvement in the design process and flexibility to satisfy diverse requirements. The study showed that 67% of the users of this system were dissatisfied with the functionally of systems with the largest market share versus 33% of the users of one of the other systems that have been used by the same hospitals for a long period of time.

The company has now started to use agile software development. Agile software development refers to a group of software development methodologies based on interactive development, where requirements and solutions evolve through collaboration between self-organizing cross-functional teams. Agile methods are also used by at least one of the vendors of EHR systems in primary care.

EHR systems in municipal care

The first EHR systems were introduced to municipal care as late as in 1995. The municipalities have the responsibility for a diverse set of ICT-services in order to serve schools, technical offices, administration and health care. Benefits related to introduction of ICT-services in other sectors than health care may have been more obvious, and may have led to a reduced focus on the EHR systems.

The diffusion curve for EHR systems in nursing homes and at health stations now seems to follow the same pattern as for the hospitals and GPs.

The municipalities seem to be very optimistic regarding future benefits of mobile solutions, but research [17] also indicates that at least in the introduction phase, the nurses will spend significantly more time using electronic mobile solutions than paper.

Conclusion

Costs, both related to purchase and maintenance are important for all actors. Expectations of possible future qualitative and quantitative benefits of the systems seem to be high, but cost/benefit analyses are to a large extent lacking.

User involvement and ownership are important for the success or failure of EHR systems. The GPs have been closely involved in the design of EHR systems from the beginning. The most successful EHR system for hospitals did also originate from a hospital setting. This is likely to have contributed to the making of a system that worked well in a real life hospital setting.

The installed base of EHR systems is growing, and this is also a challenge when functionality is lacking and new extensions and functions need to be added to the existing system. EHR systems are not static, and even if many of the modules will remain stable over time, new and innovative modules needs to be developed. New health reforms and technology changes will also put pressure on vendors for further development of the systems. More extended user involvement, use of agile

system development methods and reusable components may make this process easier in the future. The large existing installed base of software, however, can also be a challenge potentially limiting for rapid development.

A diffusion process of systems that shall be used on a national basis requires good planning and is time consuming. This has to be taken into account in national strategy processes for the health sector.

The EHR Monitor survey gives an indication of how many actors in municipal care that use today's EHR systems, but not necessarily of how they use them. Further work is needed in order to get a better understanding of how the systems are used as support for daily work processes.

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eHealth Vision towards Cooperative Patient Care – Domain Fields and Architectural Challenges of Regional Health Care Networks

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Abstract

Numerous eHealth projects and efforts to establish inter-organizational communication and to build up regional health care networks could be observed in the last ten years. Nevertheless the success of such efforts is profoundly different. The aim of this paper is to introduce the lately started regional initiative eHealth.Braunschweig compounding of the major health care players (hospitals, physician offices, nursing services and nursing homes) in the region of Braunschweig, participants from research institutions and industry. We propose in this paper the main goals of the regional initiative eHealth.Braunschweig, its constitution and major approaches. Based on respective literature and our former projects as well as experiences in this field we discuss our vision of a patient-oriented cooperative health care by depicting regional distinctions, identifying the major domain fields in this context and discussing the architectural challenges for the regional health care network eHealth.Braunschweig. In our view this work can be considered as a systematical approach to the establishment of regional health care networks with lasting and sustainable effects on patient-centered health care in a region.

Keywords:

Regional health care networks, Collaborative care, Integrated health care systems, Interdisciplinary communication

Introduction

Medical collaboration and cooperation is considered as an essential need to achieve high-quality and patient oriented health care beyond sectoral boundaries of primary care, secondary care, outpatient care, rehabilitation or home care [1]. Also the application of information and communication technologies in health care systems and the establishment of regional health networks have a positive effect on the data exchange and access, effectiveness of patient care, and communication and coordination within a region [2], [3], [4] and [5].

Although computer based information and communication technologies have been used in health care facilities for several years and electronic medical records within health care institutions are already common and well appreciated, the communication of discharge letters and findings between different institutions is still mainly paper based [6].

Compared to other European countries the German health care system has a poor cost-benefit ratio which causes in connection with the impact of the demographic change and other related problems great further challenges [7]. The present situation is marked by over-, under- or inappropriate supply of health care services as well as the low patient centered orientation of care [8]. Despite general consensus about the importance of coordinated cross-sectoral cooperation in health care networks during increasing cost pressure and rising quality expectations, the required services are not yet area-wide implemented [6].

Due to the demographic change, there is a growing number of older citizens entail a growing number of chronic diseases and polymorbidity [8]. To allow adequate treatment for these kinds of complex diseases a lot of health care providers need to adjust with each other over a long period of time.

Various national and international eHealth projects have been started, with the aim to advance communication between providers in health care networks via information and communication technology (ICT). For example the European Union's project PICNIC (ProfessIonals and Citizens Network for Integrated Care) aim is to define the architecture for mainly flexible IT support delivered by exchangeable components [9],

[10]. An example for a national project is the health care region HealthCapital Berlin-Brandenburg [11]. In general the cooperation compounding of different care providers aims to extend beyond areas of activity, traditional boundaries of different specific disciplines and conventional structures. Furthermore the degree and speed of innovation will be specified by this cooperation [6]. The results of the broad mass of eHealth projects admittedly vary in quality and sustainability. Reasons could be the heterogeneity of the ICT landscape in the German health care system, missing business models to continue established networks, little user compliance as well as slow rethinking among the providers.

Against this background the project eHealth.Braunschweig was started in April 2009. The vision of all members, composed of care providers as well as representatives from science and economy, is the establishment of an interoperating, ICT supported, patient-centered health care network spanning all health care sectors in the region of Braunschweig and the surrounding neighborhood. The main idea of the project is: „Move the information not the patient".

By having a look at the following research questions the project should be effectively realized into practice and the results should have a lasting effect:

Q1: What regional distinctions does Braunschweig offer concerning the establishment of a local health care network supported by information technology?

Q2: What are the domain fields which have to be addressed for the development of a regional health care network and how can these domain fields be supported by modern information and communication technology?

Q3: What architectural challenges do regional health care networks face regarding defined requirements and addressed domain fields?

Materials and Methods

Our investigation is based on our previous work and experiences in the field of transinstitutional sensor-enhanced health information systems [5, 12-14] and integrated health care networks [15-18]. With regard to the respective literature we summarize the regional distinctions and the domain fields of our lately started regional network project eHealth.Braunschweig and then give an overview of architectural considerations for an inter-organizational information and communication platform which is part of the transinstitutional regional health information system. Finally we discuss the relevance of the project for the region and conclude with an outlook on future steps.

Results

Regional Distinctions

The need and effects of electronic communication in health care systems have been approved in many publications [2, 3, 6]. Through the use of information and communication technology (ICT) along the health care supply chain interruptions as well as delays in the workflow and media cracks could be reduced [19]. For instance by the use of electronic and online available discharge letters instead of paper-based discharge letters, which are often missing or incomplete. In this way the percentage rate of re-hospitalization could be reduced which also means a raise in quality of care while saving costs [6]. Based on the former demonstrated problems and future challenges for the German health care system different requirements for the establishment of a regional health care network supported by information technology were initially identified for the eHelath.Braunschweig project. While developing a regional IT- infrastructure for health care networks a wide variety of partly quickly changing economical, political, technical conditions have to be considered [20]. Most important for a well operating and accepted health care network are the specific user requirements and goals. First of all care providers and other shareholders concerned were compiled into collaboration within the eHalth.Braunschweig initiative. The most important participants on care givers side are the Medical Center Braunschweig, which represents the biggest care provider in the region, the German Red Cross (DRK) with representatives of nursing homes and mobile nursing services as well as the Association of Statutory Health Insurance Physicians Lower Saxony with several general practitioners and medical specialists. Further cooperation partners are the City Council of Braunschweig and the Public Health Department, different local house-building companies, the Council of Elderly People, several business companies and research institutions such as the Peter L. Reichertz Institute for Medical Informatics.

By realizing the ideas of eHealth.Braunschweig numerous advantages for participants are expected. In future care providers will benefit from the availability of relevant patient information spanning the entire network in the right place at the right time for the right person. Through the intensive cooperation with care providers new possibilities and innovations can be identified by the local business enterprise sector early. From this follows a head start for the local businesses which eventually results in competitive advantages for the region of Braunschweig. Because of great economic importance of the health care sector these advantages are leading to a multiplication at all levels of the chain in health care as well as public health or economy.

By identifying the requirements of the cooperation partners during several workshops the requirements for the establishment of a health care network were elaborated. The main problems identified by the care providers are e.g. an insufficient communication flow between different institutions in the region as well as poor coordination of care giving organizations along the health care supply chain. Based on these problems the major domain fields to establish a regional health care network will be specified next.

Domain Fields

Based on the project goals and previously described regional distinctions and requirements we identified our fields of activity which have to be addressed in order to achieve the

intention of the regional health care network eHealth.Braunschweig. The main goal of eHealth.Braunschweig is to establish seamless and patient centered health care in the region. This means vertical integration (across different health care sectors) and horizontal integration (across different specialization fields, indications and diseases) of health care processes and at the same time consideration of the patient in the main focus of every process. Therefore ways of information flow should be established and tightened in order to enable a continuous and barrier-free transmission of patient related information between different care givers. Taking into account organizational, functional, workflow-related, technical and financial aspects, we identified in our project different domain fields which depict in our opinion essential parts of inter-organizational communication and collaboration in a regional health care network. Identified domain fields will be described in the following section as main work packages which have already been started in the last month.

The first step towards inter-organizational communication is the establishment of a *consistent inter-organizational information standard* for the information exchange between different care givers (e.g. hospital (H), general practitioner (GP), medical specialist (MS), nursing home (NH) or mobile nursing service (NS)). Despite numerous efforts in the last decade, there is still no agreement in daily practice on a reasonable base data set or information set, which should be transferred e.g. from a general practitioner to the hospital along with hospital admission and back from the hospital to the following care provider after discharge. An information standard at this point should be determined bidirectional at least for the term of hospital admission (from GP/MS/NH/NS to the hospital) and discharge (from hospital to GP/MS/NH/NS). The base information set which should be made available electronically to different care givers, will contribute, in our view, to an effective and purposeful information flow especially at critical time points e.g. before weekend and should also help to reduce time-consuming telephone requests.

The next domain field describes the process-related definition of the *admission and discharge management* as a core part of transinstitutional health care management. Hospital admission and discharge are highly multifactorial activities in which different care giver professional groups inside and outside of the hospital as well as patient relatives are involved. Therefore a lot of problems e.g. delays or lack of information emerge at this point. At the same time as the base information set is specified in an inter-organizational information standard, the processes which are affected by this information should be aligned regarding a barrier-free information flow. This means that the target process definition should facilitate the availability of information and an easy access to it. Similar to the first step relevant processes need to be analyzed and target processes specified in a bidirectional way between care givers in primary and secondary care as well as nursing care and home care for elderly people.

The following domain field arising from the first two fields is the *workflow support* for transinstitutional medical, organizational and administrative processes within a regional health care network. The entire interaction regarding one treatment case at different points of care (e.g. GP, hospital or home care) including medical, organizational and administrative tasks requires workflow monitoring and control mechanisms. Adequate trigger mechanisms within inter-organizational information and communication processes which e.g. initiate the submission of patient data to a document portal after discharge or inform a GP about the discharge of his patient and the availability of documents could support the transinstitutional collaboration and workflows.

In order to support the inter-organizational collaboration tasks and workflows (described above) in a regional health care network via IT, the development and implementation of a *transinstitutional information and communication platform* depicts the next major domain field in the course of the project. Essential functionality of the platform will consist of services which interconnect the backend application systems of care giving network participants (GP or hospital) in order to extract and represent the required information of a patient problem-oriented and purposefully. Ideally system and data integration should be the main goal for the future which can only be achieved by standardization and semantic interoperability of the affected application systems. The next lower level of integration could be given by an architectural model involving web applications or web services which are interacting with each other and the backend applications. The information and communication platform should furthermore provide a role-based and secure access to the information through a web application, if there are no backend applications e.g. for patients, their relatives or also the mobile nursing services.

A fundamental part during the constitution of and operation within health care networks, which often fails into oblivion and does not get enough attention, is the domain field of *network management* and development of *sustainable business and financing models* for regional health care networks and for the continuing operation of the network after the termination of an eHealth project. Network management in a regional health care network comprises different management tasks – information management, patient and network participant administration, strategy definition, monitoring and control as well as controlling and reporting tasks. A major part of information management is the alignment of strategic goals of organizations and the corresponding information system architecture taking into account the specific characterization of health care networks e.g. non-hierarchical governance forms or collective vs. individual interests of network members [15]. In general health care networks can be characterized by means of the DIOGEN classification system along the five axes: network structure, network management system, medical care system, transinstitutional information system architecture and network phase [18].

A further substantial domain field of eHealth.Braunschweig, which differentiates this project from many others, is *intelligent home environment for elderly people* and the integration of sensor-enhanced health information systems into

regional health care networks, their health care processes and information system architectures [21]. Several apartments for elderly people owned by local house-building companies in Braunschweig are going to be prepared as age appropriate apartments for older people and additionally equipped with sensor-enhanced information technology (e.g. accelerometer, motion sensor, bathroom scale, ergometer etc.). The integrated technology helps to develop and provide new health care services (e.g. home monitoring) for older persons in order to support self-sufficient and self-determined life. The collected data should be preprocessed and supplied to the care givers in the regional health care network who are involved into treatment context of the patient or the older person [13], [21]. Other domain fields such as telehealth (e.g. video conferences or consultations), selective information providing concerning personal health and well-being (e.g. for elderly people), common multidisciplinary education and training portals for health care professionals are reasonable and could be integrated into the context of our eHealth project in future.

Architectural Challenges

Regional health information systems comprise health care environments in a certain region, e.g. including hospitals, offices of general practitioners, pharmacies, rehabilitation centers, or organizations for home care as defined in [22]. These information systems are characterized by mainly paper-based communication between the particular institutions even if there may be well established and successful used computer-based ICT infrastructure within one institution. The willingness to share information with other institutions usually depends on historically grown relationships and trustfulness between health care institutions as well as on availability of appropriate applications and their integration with the workflows of several institutions. Haux identified in [22] five current problems of regional health information systems which are the problem of obtaining referential integrity, information logistics problem, terminology problem, stability problem and information management problem. The regional health care networks which are part of the regional health information system are facing these problems when trying to introduce an inter-organizational information infrastructure to support the collaboration within the network.

The architectural challenges for the establishment of an inter-organizational information and communication platform within a regional health care network are still integration and interoperability between heterogeneous applications in different institutions, patient identification beyond institutional borders, workflow support between institutions and workflow adaptation of inter-organizational processes within institutions in order to support collaboration [23], [24]. Compliance with new inter-organizational workflows and processes should be supported and thus could be increased by adequate trigger mechanisms e.g. reminders. Integration of home telematics platforms and sensor-enhanced data with health information systems and applications of health care providers is a major challenge in the context of regional medical and social networks. More services of telemonitoring, telehealth or personal health records will be available in future to the patients and elderly people and thereby more data could be collected and preprocessed by the patient. Therefore the institution *patients' home environment* should be also considered as an important institution within the regional health care network [22]. These architectural considerations should certainly be made with regard to data safety and security which are basic requirements in a distributed information and communication infrastructure dealing with sensible patient data.

Discussion

The importance of inter-organizational collaboration and positive effects of information processing in regional health care networks have often been pointed out and partly found realization in regional projects of integrated care networks. Nevertheless the core problems of integration and interoperability as well as workflow support are still existent and there is a lack of introduction of new solutions into daily health care practice. In our regional health care network eHealth.Braunschweig we aim to work on the described domain fields in cooperation with network members from all organizations in order to identify substantial relevant and significant collaboration tasks, to develop applications to support these tasks and to evolve sustainable and lasting information system architectures which will be embedded into the regional health information system and infrastructure. Our goal is to establish inter-organizational health care processes which support and help the care givers in their daily work, to facilitate easier information exchange and reduce the time spent on data searching and request.

Conclusion

We identified the regional distinctions and requirements for regional health care networks and because of that depicted in our opinion the most important domain fields which should be dealt with in a regional eHealth project. The domain fields were identified as follows: consistent inter-organizational information standard, admission and discharge management, workflow support, transinstitutional information and communication platform, network management, development of sustainable business and financing models and intelligent home environments for elderly people. We also highlighted architectural challenges for the establishment of an inter-organizational information and communication platform within a regional health care network regarding the addressed domain fields. Our future work will concentrate on process analysis, inter-organizational process definition and information standards as well as design and development of a prototype system which can be deployed in the health care network and evaluated by network members.

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A countrywide clinical informatics project in Uruguay

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Abstract

FEMI is a federation of 23 private not-for-profit health care organizations across Uruguay. It covers approximately 700 thousand people (20 percent of the Uruguayan population) and owns a tertiary center in Montevideo. Pressure from ongoing national changes in health funding and regulation have pushed FEMI to develop a project, in order to improve efficiency in health care through the use of information and communications technologies. In particular, a federal electronic health record and a strategic management system are pursued. This project is supported by the Inter American Development Bank. The project has four lines of action: Specification, construction and implementation of the systems; Alignment through the use of standards; Cultural change through training and prototype systems; and Infrastructure. Short term results include a federal balanced scorecard, federal identification and authorization services, a terminology service, telemedicine applications and massive training of interdisciplinary teams at the local level. The importance of collaboration at the regional level and the advantages of having a multi-institutional commitment are stressed.

Keywords:

Uruguay, South America, Information systems, Computerized medical record systems, Inservice training

Introduction

Uruguay is a small country located in the southern cone of South America, with 3.4 million people, half of them living in Montevideo. Its health indicators (e.g., life expectancy of 76.6 years, infant mortality rate of 11.9 deaths / thousand) are close to those of developed economies. The health care system is comprised of public and private not-for-profit organizations. The latter cover approximately 60% of the population and are HMO-type organizations, providing both insurance and health care. There is an on-going health care reform, designed to increase coverage and improve management of the first level of health care.

FEMI (www.femi.com.uy) is a federation of 23 private not-for-profit organizations across Uruguay. It covers approximately 700 thousand people, owns a tertiary referral center in Montevideo, over 30 hospitals with 1500 beds and 100 outpatient clinics across the country, and 2800 physicians work there. Three-quarters of its budget comes from the National Health Fund, administered by the Social Security.

Pressure from ongoing national changes in health funding and regulation have pushed FEMI to develop a project, in order to improve efficiency in health care through the use of information and communications technologies (ICT). This project is supported by the Inter American Development Bank through the MIF Fund, and by the Secretary of Health. It aims at the exchange and analysis of administrative and particularly clinical information at a federal level, taking into account the different levels of information system development of each individual institution of FEMI. The project was officially launched in March 2008 and has a four-year duration.

A previous publication [1] has shown the massive training strategy across the country during 2008, in agreement with a more general conception for developing countries [2]. In this paper, a description of the main lines of action and short-term results, and an update of the training efforts are shown.

The project

The project needed to consider the different levels of information system development across the Federation, as shown in the survey performed across it: While all of the institutions have the administrative systems necessary for the day-to-day operations, and the majority have some kind of departmental clinical system in place, most of them don't have comprehensive electronic health records. There currently are about 2500 PCs and 100 servers across the Federation.

Furthermore, each Institution within the Federation was free to choose the information technology vendors, so there are a variety of systems in place, although two vendors cover half of the institutions. The project also intended to provide federal functionalities while accepting autonomy, and legacy administrative and departmental systems of each institution. A general diagram of the proposed system architecture is shown in Figure 1. The main lines of action in order to achieve the above results are shown in Figure 2.

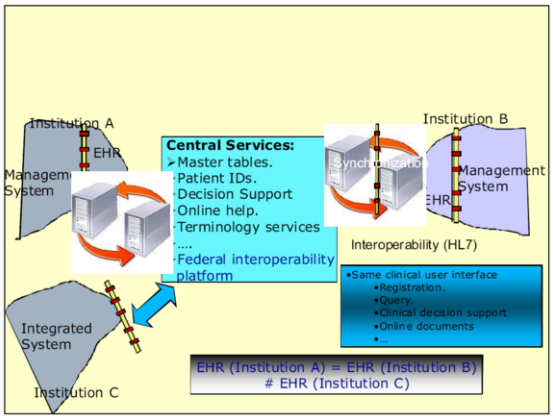

Figure 1- Model of the federal electronic health record.

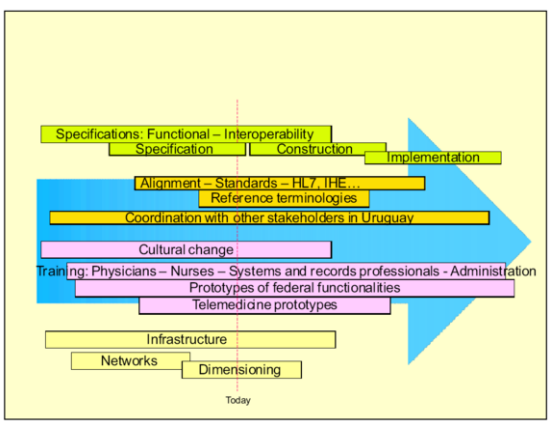

Figure 2- Main lines of action at the FEMI Project.

The first line of action, *Specifications*, includes the Specification itself, Construction and Implementation of the Federal Electronic Health Record (EHR). The EHR will be implemented in the Emergency rooms and later in the outpatient settings in five pilot institutions during a first phase, and in the rest of the institutions in a second phase. Most other components involve all of the FEMI institutions from the beginning. This line of action also includes the design and construction of a balanced scorecard (a strategic performance management tool).

The second line of action, *Alignment*, includes the 1) use of standards for information exchange and representation (for example: messaging standards, standard terminologies, federal identification services), and 2) coordination with other stakeholders in Uruguay (Secretary of Health, Social Security, HL7 Uruguay, other health care organizations).

The third line of action, *Cultural Change*, includes 1) Training, 2) Prototypes of federal functionalities, such as the Federal Authorization Services, and 3) Telemedicine, where Telemedicine applications are used as a rather quick way to bring health care professionals into the use of information technology and into the Project.

The fourth line of action, *Infrastructure*, includes Computer and Videoconferencing Hardware, Software and Networks.

Results

In this section, the short term goals and achievements already realized or expected before March 2010 are discussed, in the context of the overall project.

There is a crossover among the lines of action. For example, the federal identification service is related to *Cultural Change* and to *Alignment* and is a requirement for the federal electronic record explained in line 1; and the telemedicine applications needed the Intranet – *Infrastructure* - to be updated.

Specification, Construction and Implementation

Regarding this line of action, a **federal balanced scorecard** will be implemented before the end of 2009, after having finished the selection process of the consulting firm. Each institution will have available their indicators from the National Indicators System SINADI and other clinical performance data, compared historically to themselves and to the rest of FEMI Institutions.

Regarding the specifications of the **Federal Electronic Health Record System**, KPMG Consulting firm has just finished the Specification, and next steps (construction/adaptation and implementation) are to begin.

In parallel, there is a **process redesign in clinical areas** where the electronic health record will be implemented (particularly Emergency room and ambulatory settings), with the help of Hospital Italiano de Buenos Aires.

Alignment

In this chapter, the advancements in identification and terminology services are shown. There also is a national consensus to use HL7 CDA as a messaging standard. These and other topics are being discussed in periodic meetings with the other main stakeholders in Uruguay (Secretary of Health, Social Security, HL7 Uruguay, and other health care organizations), since the alignment includes organizations external to FEMI.

Identification services

The provision of identification services in order to identify a person unequivocally is a foundation for the federal record system and other federal applications, as disparate electronic systems need to link personal information across institutions with the lowest chance of error. This service also needs to take into account the legislation regarding personal data, which has

recently been passed and applies to every health care organization and to the federation as a whole.

In Uruguay, there is a national identity number that exists from birth. Nevertheless, a series of patient data needs to be taken into account to ensure that a proper match among existing records within the federation is being done, because no single patient identification number is considered to be sufficiently reliable or universal [3]. That is why the goal is to implement an identification service instead of trying to look for the best unique identification number [4].

This service cannot be successfully implemented unless the different processes involved in identifying patients are carefully reviewed. The main processes involved are: Registration, accreditation and audit. *Registration* is the process through which each Institution assigns a personal identifier and registers it along with his/her personal data, in order to be able to carry out a correct accreditation at a later moment. *Accreditation* is the process through which each person is verified to be the person who claims to be, and consists in taking the personal data given by a person and then compare them with the data registered in the previous process. These processes depend on the quality of the information registered in the organizational systems. For example, if the registration process has an error, the accreditation process will be affected. For this reason, there is an *auditing* process, where the registered data are verified for completion and accuracy. If all the information registered is verified, then the accreditation process could be performed in an optimal way. To help in the auditing process, the records could be marked in different states, such as: temporal, permanent or validated. The "temporal" state means that the record was not verified as complete or correct. The "permanent" state means that the record is complete but was not validated as correct. The "validated" state indicates that the record is complete and correct.

The process followed to obtain the identification service at FEMI was developed in several stages. First, there was a survey to understand what data were registered for FEMI patients and to detect problems in registration and also possible incompatibilities among different institutions which could lead to problems in the future, when attempting to share clinical information. The main problems detected were under-registration (to register less data than necessary for a correct identification), and the formats of some fields, such as date and codes for gender. This survey was carried out in 13 of the 23 institutions, and the rest of the institutions will be surveyed before the end of 2009. In a parallel work, there is coordination with the Social Security and the Public Health Services, to use similar identification data sets and algorithms.

The federal identification service is currently being implemented, with the goal of not only identifying persons, but also to offer related services, such as coverage for each patient, and geo-referenciation of patients' homes and workplaces, as well as physicians' offices.

The federal identification service is a key element to implement other federal services, such as sharing of clinical documents among institutions.

Terminology services

The use of natural language simplifies the registration requirements in the EHR for health care providers, but limits the reusability of the data, except for patient care. If, at the same time, specific fields are coded automatically from natural language strings, the best breed is achieved. This is one of the main reasons for using a Terminology Service. Through this service, a terminology is used as a reference (for example, SNOMED CT) and then it is related to the natural language used in the country or region. Classifications are used as output vocabularies (such as ICD-10, CPT, DRG) for reports and analysis [5].

To obtain this product, an adaptation of the medical terminology service developed at Hospital Italiano de Buenos Aires [6] was decided. This service uses international standards, and will take into consideration the needs of FEMI and other Uruguayan institutions. A match of over 80% is expected from Argentinean to Uruguayan natural medical language as a starting point for the service, considering the experience between Argentina and Chile [7].

The use of standards is a fundamental component of the Project. The Terminology Service will allow to represent clinical data mapped to different standard classifications, increase the analytical capabilities of data registered in FEMI systems, allow the exchange of information across institutions within and outside FEMI, and eventually implement decision support systems.

At this time, an agreement with Hospital Italiano de Buenos Aires has been reached, and the first trials are being made. A note should be made that current FEMI systems could use the Terminology Services, without the need to wait until the Federal Health Record is in place.

Cultural Change

Cultural change is a main line of action of the Project, as success largely depends on it. It involves hundreds of professionals at local governing boards and technical coordinating teams across 23 institutions, as well as eventually 2800 physicians and more than ten thousand health and administrative personnel. A more professional strategy is being finalized with the help of communication and organizational change specialists, but – in the meanwhile – the project coordinating team has devised several change management strategies, including training, implementation of system prototypes and telemedicine applications, described below.

Training

A great effort has been made to train local interdisciplinary units, as shown in [1]. An update of these results shows that:

- The 10 x 10 introductory online course on health information systems (approximately 150 hours of coursework), developed by AMIA and adapted for

the region, was taken by 72 professionals in its 2008 and 2009 editions.

- The face-to-face introductory course developed in conjunction with the Uruguayan Health Informatics Society SUIS was taken by 85 professionals in its 2008 and 2009 editions.
- The HL7 online course was taken by 40 informatics professionals in its 2008 edition.
- Sixty-seven nurses in coordination roles from across the country participated in the Nursing Informatics and Quality Conference in March 2009.

Now an end-user training strategy is being designed and implemented, considering the massive training needed and that the deployment times will differ across institutions. First, a *survey* to understand end-user basic and health-related informatics literacy has been designed and is being implemented in pilot institutions. Then, three levels of training will occur: 1) *Basic informatics training* for those who need it (which will rely on local organizations). 2) *Concepts about the Electronic Health Record*. This is intended as a change management tool for health care providers, designed to change attitudes and provide basic knowledge about the topic. The methodology is train-the-trainers, where the ones providing the actual training will be the local coordinating units, because they will then become the local experts for the end-users regarding the new system being implemented. The first courses on Concepts about the EHR will be at the beginning of 2010. 3) A more *skills- and processes-oriented training* just before the implementation of each module will be provided as needed, blending professionals from the consulting firm in charge of the EHR, the central unit and the local units.

Authorization service

A by-product of the federal identification service, which has been needed for a long time in FEMI, is the authorization service. This service will allow a patient from one FEMI institution to go to another institution and be authorized though a semi-automatic and documented process. It is a change management strategy at the management level, because a short term result is shown while waiting for longer term goals.

Telemedicine applications

At the other end of the spectrum, telemedicine applications are viewed as a way of integrating technology for the end user. A plan has been designed, including continuing health education, then tele-rounds and finally tele-consultations (without and with the EHR). The first continuing education events are being carried out. As an example, in September 2009, about 700 health care professionals in 20 sites participated in an educational event about type 2 diabetes, with the use of tele-confererencing technology. Small-group discussion was included in the methodology (78 small groups reported back), and the final plenary with the experts took into account the small group reports, integrated automatically via Google forms.

Infrastructure

FEMI has a national intranet that has been expanded to take into account the new requirements, including high quality live videoconferencing.

Discussion

There are some topics that come across the different lines of action of the project. One of them is the **added value of having a federal project**: 1) there are functionalities that involve the whole federation and not each one of the institutions (for example, the authorization service, and distance continuing health education events or tele-consultations); 2) there is an economy of scale in working together in a project (for example, in change management and training, or in having some services at the federal level, such as the terminology services); 3) it is possible to do things that otherwise would not be possible, such as negotiating with the other main stakeholders, having the advise of recognized international academic institutions, or having a centralized highly specialized coordinating unit.

The other topic is **international south-south collaboration**, particularly with Hospital Italiano de Buenos Aires, in distance health informatics training, terminology services, and consulting. But other organizations or experts from abroad have also helped in nursing informatics training (Brazil and Argentina), Telemedicine applications (Switzerland and Argentina), and HL7 (HL7 Argentina), as well as in the overall project strategy (Chile, Argentina and others).

Conclusion

This ambitious project intends to integrate 23 institutions across Uruguay, using the electronic health record and management tools. The first stages of change management and alignment have been successful, but there still is a long way to go in order to achieve the main results.

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EHR Implementation in South Africa: How do we get it right?

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Abstract

In an environment of expanding demand on the health care system to provide equitable, accessible and safe health care, usage of information communication technology is one of the strategies identified to fulfil such expectations. Electronic Health Record (EHR) is an important tool towards achieving better health care using such technology, although, across the world EHR implementation has experienced a high failure rate. Nevertheless South Africa has made a strategic decision to implement EHR system in the public health sector. An evaluation toolkit was developed, to measure the state of readiness of health institutions in South Africa in implementing EHR based on Kaplan and Norton's work on Balanced Score Card (BSC), and the subsequent variant model developed by Protti. A Critical Success Factor (CSF) scorecard to assess the state of readiness and a Balanced Score Card matrix to be used as a strategic framework was developed. These tools were validated using critiques by a panel of experts. The toolkit developed has the potential to assist the organization towards a better EHR implementation path.

Keywords:

BSC, Balanced Score Card, Evaluation, EHR Implementation, Critical Success Factors

Introduction

South Africa is a developing country consisting of vast rural areas. The South African Health Care System consists of public and private health sectors. The Public Health sector caters for 82% of the population, and accounts for 40% of health expenditure. The balance of the population (18%) is served by the private sector, which enjoys 60% of the health expenditure. The public sector is funded and provided for by the state through its National and Provincial Department of Health (DOH). Health services are free at the point of delivery in the primary health care facilities. The secondary and tertiary levels of health services are provided for a nominal payment, based on each individual's income. However, vulnerable populations such as children (under 18years), elderly (over 60 years), pregnant mothers, and patients suffering from conditions like Human Immunodeficiency Virus (HIV) infection, tuberculosis and epilepsy and so on, receive free health services, even at the secondary and tertiary levels.

The country is inundated with inequitable health service delivery between its rich and poor, as well as rural and urban populations. The use of technology is hoped to improve the quality of health services, as well as reduce the inequality between rural and urban health service delivery.

Although advanced Information Communication Technology is available in many urban healthcare institutions, most rural facilities do not even have computer technology. On the other hand, even though the telephone infrastructure is lacking in rural parts, mobile phone technology (e.g. 3G technologies) is widely used across the country.

The potential benefits of the EHR system (better, safer and equitable health care) are well known,[1-3] but more than 50% of the information systems either fail, or fail to be utilized to their full capacity.[4,5] Even among developed countries, the degree of adoption of EHR varies largely.[5] Lessons learned from the past caution us about the barriers and challenges facing EHR implementation projects in healthcare institutions.

Many models [5-9] have been presented by researchers for the successful implementation of information systems in healthcare sector. However, none of them is a readymade solution to the problem, as implementation is highly dependent on the context of the organization, with its technology, people and organisational issues. The degree of adoption of EHR is difficult to predict, as it has been shown that different organisations, and different units within one organisation, adopt some functionality of the EHR better. [10]

Healthcare organisations are complex due to the fact that various units, divisions, people, sectors and technology, all work together to reach an objective. In complex organisations, the poor performance of one area, affects the performance of the other areas, essentially giving rise to the snow ball effect. Therefore, complex healthcare organisations present huge people, and organisational, issues in the quest to change from paper to EHR. [11]

More and more emphasis is put on the need to address the people and organisational issues for achieving success. [12-17] The EHR should not be seen as a technological issue, but rather as a socio-technological one.[15] The emphasis is on the requirement for the technology to change to adapt people's work flow, and the people to adapt to a different way of work-

ing to adopt the technology. Success will be difficult without this 'fit'.

The aim of the project was to illustrate a way to maximize the chances of success in the envisaged National EHR implementation project in South Africa. The objective was to develop a toolkit to assess the state of readiness of health organisations in South Africa to implement EHR. In order to fulfil this objective, two instruments have been developed based on Kaplan and Norton's work on Balanced Score Card (BSC), and the subsequent variant model developed by Protti.; first, a critical success factor (CSF) scorecard, and the other, a strategic planning and management framework matrix.

Critical Success Factors Scorecard

Critical success factors (CSF) are defined as the limited number of areas in which satisfactory results will ensure successful competitive performance. [18] The CSF come from the areas of hardware, software and the people and organisational issues. In this paper the CSF used by Protti [19] for the assessment of the state of readiness to implement Information for Health in the National Health Service in the United Kingdom was identified as the baseline instrument. This baseline CSF list was modified for two reasons. Firstly, the structure of the health system of the United Kingdom is different from the South African health system, and secondly the experience from the past EHR implementation projects highlights the need for addressing the people and organisational issues among the CSF.

There are eleven CSF identified for the CSF scorecard. Each of these CSF is described below.

Clinical initiative linkage: Protti claims that explicit linkage of EHR project implementation to clinical services and clinical governance is important for success.[19[The IT strategy (EHR) should be part of the organisational strategy in order for it to be successful.[20] Only then can the organisational strategy influence the IT, which in turn can influence the organisation, as an isolated EHR project will be neither successful nor sustainable.

Clinician involvement: Involvement of clinicians (doctors, nurses, pharmacists etc.) is an essential factor to ensure success.[21,22] The involvement and participation of clinicians in the process allows for the EHR to be designed /modified to fit local needs, and develop a sense of ownership by the users. This will further assist in the system gaining acceptance.

Stakeholder involvement: All stakeholders need to be actively involved in the process of EHR implementation. The involvement of top management is always critical for success. The IT section and their support services also need to be part of this process in order for these divisions to understand the clinical work process, which will ensure that the technology fulfill the user's expectations.

The involvement of the community through various structures (hospital board, Non Governmental Organization, patient interest groups) is also equally important as a means to get the public corporation as transparency of process and access to information are people's constitutional rights. Participation from community representatives will provide the community with an opportunity to understand the rationale of the system and to raise any concerns (e.g. issues surrounding confidentiality etc). This understanding and participation enable easier acceptance of the EHR. Therefore the participation of all stakeholders at the EHR implementation committee is essential to maximize success.

Investment strategy: There is a need to have a clear commitment in terms of the budget allocation from national, provincial and institutional levels, along with a clear spending process in place at the facility. There is a need to ring fence the budget for the EHR implementation, and to appropriately budget for the future IT infrastructure, considering the available facilities. This will facilitate the sustainability and the success of the project. [23]

Local vision: It is important to have a clear local vision regarding the EHR project, as it is this that informs people of the ultimate goal. In addition, the organisation must identify local issues and recognize barriers to the implementation of the project to enable them for intervention.

Information management: The benefit of an Information System is dependent on its data quality. Hence, the establishment of processes to address data quality issues is critical.[19] Maximizing the data quality at all levels should be an active part of the project implementation.

EHR Implementation committee: An established EHR implementation committee with Chief Executive or an equivalent as chair for the project is mandatory.[19] The use of a 'consultant' to chair the committee will not derive adequate support from the employees, and will not be sustainable in the long run. The committee should be able to anticipate and influence requests from both end users and management.

Project management leadership: Having an experienced project manager in a full time post (someone who will move the agenda forward with minimal dependency on management consultants) is crucial for success and sustainability. [24]

Technical infrastructure: The organisation must have a thorough understanding of the types, costs, standards and plans for all IT systems, as well as a strategy for future development. The dynamic development of hardware and software in the IT field makes the understanding of IT systems, and its applications, vital for success. This ongoing development result in additional expenditure for the organisation and the health community needs to have the capacity to manage this as part of the future development.

Human resource: Comprehensive assessment of the required Information Management Technology personnel types, skill levels, etc, is very important, as a lack thereof will directly impact on the project implementation. It is understood that within the life cycle of an organisation new personnel join, even as others leave, and there should be a process in place to assess and train staff with the future in mind.[25] Developing a culture of 'sharing knowledge' among employees will ensure that the organisational knowledge base is adequate at all times.

Thus, knowledge management should be a key strategy in the EHR implementation project.

Change management: Protti, in 1999, did not include "change management" as one of the CSF. However, he discussed the importance of 'change management' and 'culture' as risk factors in his report. The experience from the failed IT projects in the past two decades, and the attribution of the implementation failure to people and organisational issues warranted the inclusion of change management in the CSF score card.

The heightened focus on the socio-technical approach of information system implementation further support this. There should be clear and established strategy and process in place to manage change in the organisation as well the technology Therefore it is vital to have an accepted change process in place. Change management should have multiple strategies to achieve the desired change, both in people and the organisation.

Nine out of the 11CSF from Protti's Model remained the same in the SA version. However, LIS Programme board was replaced by EHR Implementation committee. This was due to the difference in the basic administrative structure between the South African and the United Kingdom's health systems. The CSF of supporting the General Practitioners Practices, Primary Care Groups and PCTs was removed and change management was included as it covered a broader area of support during the implementation.

The CSF scorecard should be completed by the project manager/Chief Executive Officer/ Officer in charge along with IT person in-charge. The instrument can also be completed by the project committee members to obtain an overall sense. The organisations which fell short can go through the exercise at a later stage and re-evaluate their state of readiness.

Scoring: Each CSF is scored on a scale of zero to three. On this scale, a score of three implies that that particular CSF is 'fully in place' according to the definition of the CSF, and zero implies it is not in place at all. A score of one is close to not ready (zero), and a score of two is close to being ready (three). Any CSF scoring zero or one is taken as falling critically short in the preparation process of EHR implementation. It indicates that the situation needs urgent attention and serious intervention to rectify the shortfall. The choice of 0-3 as the score was selected to avoid a neutral number being the midpoint such as 1-5. This is to ensure that a decision is made as to whether the CSF is in a state of readiness or not. [19]

Scoring by numbers should be taken as an indicator rather than absolute, as this exercise aims to identify the organisation's state of readiness before implementing the project. The CSF scorecard allows a maximum score of thirty three (11 factors x3). If an institution scores less than sixteen overall, then it should be expected that in order to achieve successful implementation, a great amount of work is needed in the organisation. [19]

It is also important to avoid situations where the total score may be more than sixteen, but in which some of the critical success factors are scoring zero or one. In a complex system like health care, the performance of one critical factor influences the others, either positively or otherwise and the importance of the interrelationship between the factors needs recognition. Achieving a balance among the factors is as equally vital as their individual performance.

BSC - Strategic Planning and Management Framework

Table 1 – BSC four perspectives

User perspective *(Customers' & stakeholder's view)*	***Business value perspective*** *(DoH view)*
Mission To add value to health service delivery **Key Question** Would the EHR fulfill the needs of the clinical community? **Objectives** Establish good relationship with the user community (clinicians) Clinician Involvement Satisfy end users of EHR Clinical Initiative Linkage Stakeholder Involvement	**Mission** To add value to the SA Health System **Key Question** Would the EHR implementation accomplish its goal and contributing value to the South African Health System? **Objectives** Ensure that the proposed EHR project provide business value to the health system Local Vision Control EHR project costs Investment Strategy
Internal operations perspective *(process based view)* **Mission** Implement EHR project in an efficient and effective manner **Key Question** Would the EHR project be implemented in an efficient manner? **Objectives** Anticipate and influence requests from end users and management EHR Implementation Committee Provide cost effective training that satisfies end- users and ensures data quality Information Management Effectively manage EHR related problems that arise Project Management Leadership	**Future readiness perspective (***Innovation and learning view*) **Mission** Deliver continuous improvement in the EHR and prepare for future challenges **Key Questions** Is the EHR implementation prepared for potential changes and challenges? **Objectives** Anticipate, prepare and act on EHR related changes needed in the future Change Management Continuous upgrading of skills through appropriate training and development Human Resource Conduct research into emergin technologies for the SA health system Technical Infrastructure

The Balanced Score Card (BSC) is an instrument meant to assist organisations in proactively planning their performance

in line with the organisational strategy, rather than evaluate the organisation on its performance as a retrospective exercise. [26, 27].The original BSC was developed for the corporate sector, and thus the perspectives were designed with terminology to suit the corporate scenario.

Protti, for his work with National Health Services, modified the original BSC with appropriate terminology of the perspectives to better suit the context and the purpose of health institutions as 'Four Possible Perspectives in an Information Management and Technology' for health. The authors use Protti's terminology with some modifications in order to better suit the context of the South African health system. [19]

The purpose of this tool as a strategic planning and management framework is to assist health organizations in strategically planning for the implementation of EHR, and then later assessing and reviewing their performance according to their strategic goals. At this juncture, the framework will be used as an instrument to systematically work on their strategy, with the intension to improve or enhance the performance, taking into consideration the four different perspectives.

Following the concept of the BSC as a performance management tool, and the importance of the relationship of the perspectives to each other, the CSF were packaged into one of the four perspectives. The placement of the CSF in different perspectives allows one to understand the importance of the CSF against the backdrop of the total performance of the organisation, as well as the interdependence of the factors. The CSF can thus be easily linked to the specific strategic goal, and be followed up. The CSF in different perspectives also allows one to look at the balance among the different factors in each perspective, a vital component for success.

It will also allow the health organisations to align their objectives in different perspectives to achieve their vision, as well as enhance the performance of the other perspective. Mapping the strategy of the organisation in this manner will also create a common understanding among the employees. [28] The tool will act as a transparent strategic framework for all the employees in the organisation, and may yield better cooperation and understanding towards EHR implementation. It is hoped that developing a visible common objective will benefit the organisational culture in acknowledging and accepting change with less resistance.

Validation of the Assessment Toolkit

The development process of the assessment toolkit included a validation process. A panel of international and national experts critiqued the instrument related to its theoretical underpinning, content and format. There was a general consensus from the experts that the proposed toolkit to be an important development, as there is a need for such an instrument. They also found that the timing of the development of the toolkit was appropriate in the context of South African EHR policy and implementation process.

The selection of the CSF was found to be both relevant and appropriate, with the inclusion of change management to the CSF seen as necessary. The BSC theory of looking at the performance of the organization through four different perspectives (modified by Protti) was accepted as relevant and appropriate. The experts agreed that the critical success factor score card would be able to provide valuable information about the state of readiness of the institutions, whilst the four perspective matrix would assist the institutions in identifying shortfalls within the perspectives, and in developing interventions towards achieving the strategic goals of the implementation project. The matrix also provides insight into the future performance of the organisation.

The experts were of the opinion that the toolkit had the potential to contribute positively towards the successful implementation of EHR in South Africa.

As part of the validation a pilot study was conducted on priority ranking and weighting of the CSF by health workers. Clinicians' involvement and investment strategies were two of the CSF scored highly by the health workers. The study showed that the importance placed on the CSF by doctors and nurses were different and probably based on their workflow. Further, the importance given by the health workers to the four perspective matrixes, (BSC) was not equal in that health workers did not consider the business perspective as important as the other three perspectives. The survey showed that there was correlation between the ranking and weighting of the CSF.

From the information gathered from this pilot study, it is recommended that a full scale study is needed to understand the health professionals views regarding the CSF, workflow and other issues related to EHR implementation.

The tools developed in this study integrate the CSF with the Balanced Score Card matrix. Therefore the state of readiness assessment, the strategic planning of the implementation as well as the future assessment of the implementation will be a continuum rather than three unlinked exercises. It will assist the planners, managers and the health workers to see the interdependency between the CSF and BSC.

In conclusion the toolkit developed to assess the state of readiness of health organizations in South Arica to implement EHR has the potential to assist the organisation towards a better EHR implementation path. The second tool of BSC matrix will further guide them in moving the strategy to action plan and increase the probability of success.

A future study in the Eastern Cape is planned for a real world testing and validation of both instruments developed in this study.

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Monitoring diseases across borders: African regional integrative information systems

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Abstract

In African countries, communicable diseases remain the chief cause of a heavy disease burden. Regional economic, political and social integration bring new challenges in the management of these diseases, many of which are treatable. Information Communication Technology (ICT) applied through electronic health systems has the potential to strengthen healthcare service delivery and disease surveillance within these countries. This paper discusses the importance of well-defined e-Health strategies within countries and, in addition, proposes that countries within regions collaborate in planning for health information exchange across borders. It is suggested that particular attention be paid to technical and data standards enabling interoperability, and also to issues of security, patient privacy and governance.

Keywords:

Health information systems, Electronic health records, Standards, Medical records.

Introduction

In many regions across the globe the 21st Century is witnessing an increase of economic, political, and social integration. Some refer to it as the Globalization of this century. In Africa, the regional organizations formed in response to this are guided by political and economic treaties and policies. These organizations include the Southern African Development Community (SADC) and the Common Market of East and Southern Africa (COMESA). A consequence of this economic and political integration is increased cross-border movement of people within the regions of the Member States (MS) included in these treaties. Besides sharing common social and cultural values, the MS also share common health challenges threatening the livelihood of the region's population. In most regions of Sub-Saharan Africa communicable diseases especially Human Immuno Deficiency Virus (HIV) and the resultant Acquired Immuno Deficiency Syndrome (AIDS), Tuberculosis (TB) and Malaria pose the greatest threat to the well-being of the population.

The increase of population movement across MS means changes in the dynamics of communicable diseases. A typical recent scenario was the deadly outbreak of cholera that started in Zimbabwe in the month of August 2008 [1]. By the end of 2008, the disease had been reported in four neighbouring countries: Botswana, South Africa, Mozambique and Zambia. Cases were also reported as far afield as Katanga, the southernmost province of the Democratic Republic of Congo [2]. This is an illustration of a classical case that clearly highlights the need for regional health information exchange of medical and health data between neighbouring countries or regional MS. Many neighbouring countries and regional MS collectively appreciate the scourge of communicable diseases and have pledged to actively participate in the control of these diseases through declarations and protocols at national, regional, continental and international levels. Fundamental to the control of these diseases has been the pledge to share health information for the common goal of controlling these diseases across MS. Real examples of these in Africa include:

- The Abuja Call (May 2006) for Accelerated Action Towards Universal Access to HIV and AIDS, Tuberculosis and Malaria Services in Africa in which African Union MS pledged, among other issues, to ***strengthen data management and surveillance systems*** of each of these diseases.
- SADC Protocol on Health in which MS pledged, among other issues, to ***standardize regional disease surveillance systems*** to facilitate collation of information which has a regional impact.

As cross-border movement increases and the ensuing spread of diseases presents more of a threat, it becomes critical that regionally integrative health information systems are made a core component of any regional economic and political initiatives. This will facilitate the flow of critical information and knowledge across borders to enable the delivery of safe healthcare services, the continuity of patient care and the effective monitoring of diseases across borders.

Health Information Systems & eHealth

At the fifty-eight session of the World Health Assembly (WHA) in May 2005, delegates adopted a resolution to establish an eHealth strategy for the World Health Organization (WHO), indicating that there is urgency for MS to have well-planned eHealth services for their respective countries. The main rationale for this strategy is derived from the potential for Information Communication Technology (ICT) to transform healthcare service delivery. ICT has had a profound impact on many aspects of human development such as banking, commerce and communication. ICTs enable information sharing across geo-political boundaries, providing opportunities for co-operative development in many areas, including healthcare. Despite this, the uptake of ICTs in healthcare has been relatively slow and less progressive than in other sectors of modern society. The use of ICTs in health is broad and diverse. It ranges from population based record systems that monitor disease trends, through electronic surveillance systems which capture patient related data for health care or administrative purposes, to patient-based electronic medical record systems. Electronic Medical Record (EMR) systems improve the quality of care by "improvement in legibility of clinical notes, decision support of drug ordering including allergy warning and drug incompatibilities, warning for abnormal laboratory results, support for program monitoring, including reporting outcomes, budgets and supplies, support clinical research and management of chronic diseases such as diabetes, hypertension and heart disease" [13] . Furthermore, the access to accurate and precise information by healthcare service providers reduces medical errors, reduces duplication of data entries, and strengthens decision support tools within a health system [14]. Electronic information systems within a specific area of health such as public health disease surveillance systems enhance the response intervention times to disease outbreaks such as cholera. Through disease surveillance systems, coupled with Geographic Information Systems (GIS), it is possible to effectively monitor disease spread spatially and implement coordinated and appropriate control measures based on real time data access.

Electronic health information systems, used either for patient care delivery or population based disease surveillance, have the potential to support the exchange and transfer of health information across borders. It can strengthen the cross-border continuation of patient care in chronic cases like antiretroviral therapy for HIV and AIDS patients. It can also strengthen regional capacity to mobilize resources and respond collectively to disease outbreaks, such as the outbreak of cholera experienced in Zimbabwe in 2008.

A collaborative regional eHealth Strategy can provide the framework for building and implementing health information systems in a coordinated way that allows for regional integration. It is vitally important that developing countries develop such a strategy as early as possible to avoid the risk of overspending and the heavy costs incurred in systems adoption and reengineering.

Challenges & Opportunities

Health care providers and policy makers in developing countries are daily faced with the challenge of making decisions that allow them to get the most out of scarce resources. The efficient resource utilization they seek is characterized by:

- Little or no wastage of resources.
- Provision of quality tools for healthcare providers despite limited market availability.
- Provision of real solutions addressing the health priorities of the population and communities.
- Delivery of healthcare services at the lowest cost while adhering to safe care protocols.
- Providing healthcare services to vulnerable communities despite time constraints and the shortage of healthcare professionals.

Meeting these requirements would have a positive impact on the quality of services that health systems can deliver to their communities in a timely manner. In reality, the healthcare needs of populations in developing countries remain actively unmet due the challenges faced in realizing these efficiencies. In addition, health care expenditure in these countries remains extremely low compared to the developed world. Developing countries account for 84 percent of world population, contributing 93 percent of the worldwide burden of disease. However, they account for only 18 percent of global income and 11 percent of global health spending [6].

Table 1- Global comparison on per capita total expenditure on health for the period 2005-2006 (International dollars per person).

Region	Year	
	2006	2005
World	163,301	155,880
Developed Countries	115,847	111,509
Developing Countries	47,448	44,346
Monaco	7,154	5,447
United States of America	6,714	6,347
South Africa	869	811
Burundi	15	17
Rwanda	210	136
Zimbabwe	147	146

Source: Available from URL: http://earthtrends.wri.org/text/population-health/variable-1264.html

Table 1 above compares the per capita expenditure on health in international dollars per person in the years 2005 and 2006, effectively demonstrating the global expenditure disparities. In 2006, the world per capita expenditure on health in international dollars per person was 163,301. Of this amount, the developed countries spent a cumulative amount of 115,847

compared to 47,448 spent in developing countries. Focusing on sub-Saharan Africa alone, the expenditure was 7,030 of the 47, 448. Even for the most developed country in Sub-Saharan Africa, i.e. South Africa, its per capita expenditure per person was 869 compared to 6, 714 of the United States [7].

The impact of inequality in health services expenditure on individuals begins in childhood. The world average life expectancy, less than 60 years towards the end of the 1970s, now surpasses 74 years [8]. This statistic does not reflect lack of progress in developing countries, especially in the Sub-Saharan Africa region. A girl child born today can expect to live for more than 80 years in Japan, but for less than 35 years if she lives in Swaziland [9]. The factors contributing to global variation in life expectancy are quite varied. However, one key determinant is the variation in disease burden. According to WHO, the main causes of illness and death in developed countries are cancer, respiratory diseases, cardiovascular disease and conditions of the nervous system. In the developing world, communicable diseases are the main causes of the disease burden. The principal causes of death, which correlated with WHO reporting, include respiratory infections, HIV and AIDS, infections at birth, diarrhoeal disease and tropical diseases such as malaria [10].

As the leading causes of death in developing countries are communicable diseases which are treatable, there is an enormous opportunity to lessen the burden of disease. Health care service providers and policy makers acknowledge the need to prioritise scarce resources for disease prevention and curative services rather than for auxiliary services. ICT can be an effective support in the delivery of these services by significantly strengthening information systems available to clinicians and personnel, e.g. through electronic patient records and decision support services. In addition, on the basis of benefits highlighted above through ICT tools, it is essential that the health authorities of these countries allocate reasonable resources towards ICT implementation. This would also be in line with an eHealth Strategy for MS as recommended by the World Health Assembly (WHA). It is strongly suggested that health information systems should be implemented - not as a nice-to-have tools - but as part of a comprehensive eHealth strategy.

ICT in Health: Implementation Challenges

The implementation of ICT in health is a high risk process for health systems, since these initiatives are not always successful, resulting in the waste of scarce financial resources that could better have been used in saving lives. Hard lessons have been learnt when ICTs in health fail due to implementation challenges. A documented case scenario is found in the electronic health information system for the Limpopo Province in South Africa [11]. The initial objectives of this system were noble, notably to:

- Make patient information available where the patient is currently being treated.
- Improve patient administration procedures, resulting in shorter waiting times and better service.
- Improve revenue collection.

This project was one of the biggest health informatics projects in Africa, at a cost of nearly £14m, it represented 2.5% of the province's annual health and welfare budget. For various reasons the system implementation failed, clearly demonstrating the need for prudence, caution and foresight in the implementation of ICT.

Despite such failures, ICT in health in the form of Electronic Medical Record Systems and Public Health Information Systems continue to be developed and implemented in Sub-Saharan Africa - albeit at a slow pace compared to the rest of the world. The benefits of these systems to health care delivery and quality of life to populations of developing countries are undisputed and profound, to the point that failure to adopt these systems would undermine human development and well-being. A number of systems have been successfully deployed into clinical workflows [13] for patient care and disease monitoring and evaluation [14]. Though these systems have been deployed at site level, none have been demonstrated to be scaled up to wide areas of implementation between different data sources and different health information systems. There is no demonstration that these systems are capable of exchanging health information for continuity of care (for patient level data) or for the co-monitoring of infectious diseases such as HIV and AIDS, and TB. There are currently no documented cases where two or more health systems in Sub-Saharan Africa can exchange health information data. As healthcare is interplay of various service providers, each requiring different aspects of the same data, the exchange of information should surely be a critical component of healthcare delivery.

Policies Recommendations

The business of healthcare is fundamentally a collaborative process, involving different healthcare service providers utilizing different components of the same global health data. Data generation and utilization for decision makers does not follow a linear process. The diversity of health information systems requirements has largely contributed to the development of disparate non-communicating systems. Current health systems have been motivated mostly by the need to report statistics (as secondary data) for government authorities and/or funding agencies [12]. The collection, storing, revising and delivering health data has become increasingly important to demonstrate the health status of its communities, vulnerable groups and society in general. It is an unnecessary wastage of scarce resources for developing countries south of the Sahara, currently with minimal penetration of electronic health information systems, to struggle through the same hard lessons learnt in developed countries. Developing countries have a unique opportunity to demonstrate the usefulness of ICT tools in addressing their health challenges.

Though various factors contribute to the successful implementation of ICT in health [11,13,15,16,19], we believe that an enabling environment that allows for multiple health information systems exchanging data securely is fundamental to meet health service challenges particularly in achieving continuity of care across the geo-political divide while significantly optimizing resource usage in resource limited settings.

It is critical that developing countries establish harmonized frameworks or policies around health information systems management for their respective countries. This approach will ensure an effective collaboration between all the entities requiring health data. Recommendations include:

1. Security Framework: Ensure secure sharing of health data between health service providers making use of the same health data [15-17].
2. Governance of Health Data: Ensure that data elements are aligned with healthcare delivery, i.e. the numbers and description of health data elements are consistent with the current workflow of healthcare delivery services [18].
3. Adherence to Available Standards: Establish a collective approach to health information systems implementation within countries, with standards adopted and maintained at the technical, practice and policies level, e.g. utilization of an Electronic Health Standards such as Archetypes [18].
4. Interoperability or Integration Platform: Ensure semantic interoperability in the exchange of data within the health information system. This is critical for ensuring that accurate communication occurs within a collaborative health groups. Avoid duplication of virtual data within the health system [18].

Regional Recommendations for Africa

In order to achieve regional health information exchange for patient or disease monitoring across geo-political boundaries, it is recommended that regional bodies such as the Southern African Development Community, World Health Organisation Inter-Country Support Teams, the respective Ministries of Health and other stakeholders etc. collaborate in harmonising the electronic health information systems frameworks/policies as they are developed in developing countries. Currently, there is minimal inter-country collaboration with the possible risk of incompatible information systems either for patient care or regional reporting needs between countries.

It is recommended that countries and regional bloc MS build their electronic systems with the foresight of regional information exchange. In summary, this can be done through the following minimal recommendations;

- Ministries of Health, regional organisations such as SADC, WHO, UNAIDS and funders regularly consult to formulate common standards and information security protocols for regions.
- The adoption of a common information exchange format e.g. HL7.
- Common legal and ethical considerations for electronic data transmission and usage across geographic borders.
- Common patient identifier properties across regions.
- Common de-identification (anonymisation) techniques.

Through addressing only the above minimum requirements, developing countries south of the Sahara can significantly revolutionize health service provision, thus producing outstanding returns on investments.

Discussion

Current authors' knowledge and experience within the discipline of Health Informatics strongly demonstrates that it is possible to build successful electronic health information systems that are capable of scaling from one healthcare facility to regional information systems requirements by following some of the recommendations described in this paper. Sub-Saharan Africa has a unique opportunity as it has so many examples to learn from. The technological implementation of ICT in health has matured to the level of fully utilising its potential.

However, lack of collaboration and consultation between all healthcare stakeholders puts Africa at risk of the disaster of vertical data silos that cannot benefit an already impoverished population.

Conclusions

Collaboration in the development of national eHealth strategies, ranging from the work of in-country stakeholders to inter-country consultation, facilitates a cost effective enabling environment for the exchange of health information between sites, scalable to inter-country information transfer.

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A Socio-Technical Approach to Continuity of Care and Electronic Records in the South African Context

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Abstract

Paper-based techniques of record keeping are contributing greatly to the discontinuity of patient care among healthcare providers. To achieve continuity, access to the information contained in medical records collected by various healthcare providers is necessary. To improve the sharing of information contained in these medical records the use of electronic methods of record keeping as opposed to paper-based records becomes very important. Even though the benefits of using electronic methods of record keeping are widely documented, the majority of South African healthcare practitioners still use paper-based methods. This paper describes an explorative study to determine barriers to the adoption of electronic records in the private primary care sector of South Africa. An interpretive approach using a socio-technical systems theory perspective was used to conduct the study. Based on the analysis of the socio-technical subsystems in the South African context it was revealed that there is not sufficient information available on the barriers to adoption of electronic records and further research will be necessary to identify the barriers to the adoption of electronic records.

Keywords:

Computerized medical records systems, Medical records, Medical informatics

Introduction

Saltman, Rico, and Boerma define continuity as "the degree to which a series of discrete health care events is experienced as coherent and connected, and is consistent with the patients' medical needs and personal context" [1]. Continuity of care can further be defined based on various dimensions, including informational, longitudinal, and interpersonal continuity [2].

To achieve informational continuity it is necessary that relevant medical, social, and personal information about a patient be available to a healthcare provider at the point of care to ensure appropriate care for the patient. Longitudinal continuity refers to patient care delivered at a single point of care, involving a single medical record over a period of time, leading to growing knowledge of the patient by the healthcare provider(s) delivering the care. Longitudinal continuity should not be confused with interpersonal continuity. Longitudinal continuity simply implies a pattern of visits over time, while interpersonal, or relational continuity, refers to a particular type of longitudinal continuity. Interpersonal continuity involves an ongoing relationship based on personal trust between a patient and a healthcare provider. The patient normally trusts the healthcare provider to assume responsibility for the patients' overall health care [1-4]. According to Saultz these dimensions of continuity can be arranged in a hierarchy of increasing complexity starting with the need for informational continuity to ensure longitudinal continuity. It is also implied that longitudinal continuity is required to ensure interpersonal continuity [2, 5].

In the past the various dimensions of continuity was easily achieved since most patients received the majority of their care from the same healthcare provider from the cradle to the grave. In modern society it is highly unlikely that a patient will receive care from the same healthcare provider from cradle to grave. Even at a primary care level there is a trend towards the development of group practices where patients do not necessarily consult with the same General Practitioner every time that they visit the practice. Patients also move between different practices and healthcare providers freely. All of this makes it increasingly difficult to achieve longitudinal and interpersonal continuity of care. Informational continuity of care is thus becoming more and more important to ensure consistent, high-quality care for patients delivered by various healthcare providers [6-8]. When patients move between healthcare providers it often results in a loss of information leading to gaps or discontinuities of care [9]. To achieve informational continuity access to the information contained in medical records collected by the various healthcare providers are necessary. To improve the sharing of information contained in these various medical records the use of electronic methods of record keeping as opposed to paper-based records becomes very important [8, 10].

While various forms of Information and Communication Technologies (ICTs) are used in the South African healthcare industry to perform financial and administrative functions such as billing, the majority of South African healthcare practitioners still use paper-based methods of record keeping when it comes to patient's medical records. Paper-based

techniques of record keeping are contributing greatly to the discontinuity of care among healthcare providers and are widely considered to be inadequate in the face of an industry that is continually growing in both complexity and sophistication [11, 12]. Even though it is clear that paper-based patient medical records are becoming increasingly inadequate healthcare providers in South Africa have rarely made an effort to adopt the necessary technology, such as electronic medical records (EMRs), which will enable them to store patient medical records electronically. Many healthcare providers do not even have a computer in their consultation room. According to research by Cochrane and Ramokolo analysts estimate that only between 7% and 10% of general practitioners and specialists will be purchasing Electronic Health Records (EHRs) within the next three to five years [13].

A literature review indicated that research in the South African context is mostly focused on the implementation of hospital information systems [14] and telemedicine systems [15] in public healthcare. There is a lack of research focusing on the reasons behind South African healthcare providers' hesitance to move away from paper-based medical records.

Research Objectives

This paper describes an explorative study to determine barriers to the adoption of the necessary technology to replace paper-based patient records with EMRs in the private primary care sector of South Africa in order to improve informational continuity of care. The authors will focus on a primary care level as a starting point since primary care is the main entry point into the healthcare system for the majority of patients and it is at this level that the bulk of a patient's medical record is generated. The focus will also be on primary care in the private healthcare sector of South Africa since very little or no research in health informatics in South Africa focuses on the private care sector. Another motivating factor for focusing on the private primary care level is the South African government's plans to implement a National Health Insurance (NHI) in the future. Once the NHI is implemented more and more patients that were previously served by primary care facilities in the public care sector will now be served by primary care facilities in the private sector. This will also make EMRs even more necessary to improve informational continuity of care as patient will move back and forth between public- and private healthcare facilities.

Materials and Methods

An interpretive approach was used to conduct the study and a socio-technical systems (STS) perspective was used to investigate barriers to the adoption of EMRs in terms of the social, technological, and environmental subsystems. Since this paper forms part of the exploratory stage of a more comprehensive research project, the primary technique of a literature survey was employed as a suitable research method. A literature study of books, journals, the Internet and electronic databases was conducted to determine the barriers to the adoption of EMRs in South Africa. The findings of the literature study are subsequently described. The conclusions drawn from the observations made in this paper will contribute towards the design of further instruments to gather data (for example, surveys and structured interviews).

When significant changes are introduced in an organization that involves work redesign, it has been suggested that a socio-technical systems approach should be followed to ensure successful adoption of the changes [16, 17]. Originally developed over 30 year ago at the Tavistock Institute of Human Relations in London by Emery and Trist, with significant contributions also made by Cherns, the concept of STS was originally associated with organizational development and the re-design of work systems in offices, manufacturing environments, and the mining industry to improve the performance and effectiveness of organizations.

STS theory is based on the argument that an organization is open to influences from its environment, and that the organization is a combination of both social and technical components that must work together to accomplish tasks. The organization is thus divided into three interdependent subsystems, namely the social, technological, and environmental subsystems. The social subsystem represents the people inside the organization using technology and knowledge, the technical subsystem, to produce a product or service valued by the environmental subsystem, which includes customers, suppliers, government bodies, and other stakeholders that interact with the organization [16-19]. The concept of joint optimization also features very strongly in STS theory to ensure that the organization is designed in such a way that both the social and technical subsystems are optimized, instead of simply designing the technical subsystem without any regard for the social subsystem and then simply fitting the people to the technical subsystem afterwards. The manner in which the social and the technical subsystems interact with each other to meet the demands of the environmental subsystem plays an important role in the overall success of the organization.

Results

The introduction of an EMR (technical subsystem) will involve a significant change in the way that the healthcare provider performs his daily tasks, as well as in the tasks performed by the employees of the practice (social subsystem). Various stakeholders such as patients, medical aids and other healthcare providers will also be affected, and various policies and regulations as specified by the South African Government and Department of Health (DoH) will also have to be considered (environmental subsystem). The technical, environmental, and social subsystems in the South African context will be discussed in this section.

The technical subsystem

As previously mentioned, publicly available research focused on the South African context is mostly directed towards the implementation of hospital information systems and telemedicine systems in public healthcare. In the public sector there is literature available on a few cases of Electronic Health Records (EHRs) being installed in some hospitals [13]. An EHR is defined as [20]: *"A comprehensive, historical file of personal health information stored electronically that is*

compiled from the multiple healthcare providers treating a patient or evaluating their conditions over the course of that patient's health history." The literature is not clear on the context that the term EHR is being used in, and it could also be that they are actually referring to an Electronic Medical Record (EMR). An EMR contains patient information kept electronically by a single provider, such as a clinic, hospital, general practitioner, or other provider [21]. Pathology, radiology, or other laboratory test results can be uploaded into the EMR where the functionality is available. An EHR is a superset of various episodes of care provided by various healthcare providers [22].

Perceived technical barriers to the implementation of EHRs in South Africa include the relatively poor standard of Internet connectivity, as well as the high probability of hardware theft. For an EHR to be feasible it is imperative that all users are able to access the EHR online, but in South Africa Internet connectivity is expensive, relatively unreliable and slow [13].

The environmental subsystem

Patients form part of the environmental subsystem and during 2006 a study into the attitudes of South African patients towards using paper-based and electronic medical records was developed by Accenture and executed by AC Nielsen. The findings of the study will be discussed below [23].

The problem of discontinuity of care was highlighted by the study wherein 51% of respondents indicated that they repeatedly had to recount their medical histories when visiting different healthcare providers. Apart from the time wasted, the fact that most patients do not have the knowledge to recount their full medical histories accurately, and in sufficient detail, is a major problem. According to the study, South African patients see electronic health records as a solution to many of the problems associated with paper-based health records. In fact, 50% of respondents on medical aid are willing to pay between R20 and R100 extra per month to have their health records maintained electronically. One would assume that it would be respondents in the highest income groups that are willing to pay for electronic medical records. This is not the case. It is, in fact, the mid-income groups that are most willing to pay for this service.

Concerns relating to the use of paper-based health records range from those of privacy and confidentiality, to that of a healthcare provider not having vital medical information available at the point of care. The overall perception amongst South African patients is that electronic medical records will improve the quality of healthcare that they receive. This perception is not isolated to a single racial group, but is common to all the major racial groups in South Africa. Patients are also of the opinion that electronic records can ensure better privacy, confidentiality and integrity of health data than paper-based records.

The results of the survey demonstrate the importance of finding a solution to the problems associated with paper-based techniques of record keeping in the South African healthcare industry. With 54% of respondents being very to extremely concerned about the fact that their various healthcare providers do not have their full medical records, the problem of discontinuity of care is certainly an issue that should be addressed.

Another stakeholder that forms part of a primary care practice's environmental subsystem includes the South African DoH. According to Dr Shaheen Khotu, chief information officer for the DoH, some of the problems with the current paper-based system (in the public sector) include the time spent by healthcare personnel to locate patient records, instead of spending the time looking after patients, as well as the negative impact on the quality of care that patients receive due to a lack of vital information and misinformation [24]. There are also various initiatives in the South African public healthcare sector to replace inefficient paper-based patient records with electronic patient records. So, while there are efforts made in the public sector to improve continuity of care, the same cannot be said for the private sector.

The social subsystem

As very little publicly available information on the barriers to implementation of EMRs in the private sector in South Africa could be found, it was decided to draw a preliminary analogy from literature covering the international scene. The major concern from healthcare providers in the private sector centres around the costs involved in implementing EMRs. Perceptions are that these systems require considerable investment, without significant evidence of value, cost effectiveness, or Return On Investment (ROI) [3, 10, 11]. Adopters of these systems are not reimbursed for the cost and time spent to implement and use the systems, which also cause reservations towards adopting EMRs. There are also concerns about the usability of these systems and the impact that the use of an EMR will have on the consultation with a patient [25]. Literature on the South African perspective that the authors were able to locate echoed the international concerns. High start-up costs and concerns about the usability of these systems all indicate that it will be necessary to find an incentive to convince private practices to adopt EHRs and EMRs [13].

Discussion

Paper-based techniques of record keeping are contributing greatly to the discontinuity of care among healthcare providers and are widely considered to be inadequate in the face of an industry that is continually growing in both complexity and sophistication [11, 12].

It has been widely cited that the use of EHRs can improve the quality, safety and efficiency of healthcare delivery [21, 26]. An EHR is expected to enable continuity of care by consolidating all of a patient's health information in a single place. This will ensure that a provider has all the relevant information on which to base decisions when treating a patient. While this is the ideal, the reality is that this level of inter-provider interoperability is not likely to be achieved in the foreseeable future [27]. One of the barriers that must be overcome before the potential of an EHR can be realized is the lack of EMR implementation [27, 28].

While an EMR contains patient information kept electronically by a single provider, an EHR is a superset of

various episodes of care provided by various healthcare providers [22]. The American Society for Testing and Materials' (ASTM) Continuity of Care (CCR) and Health Level Seven's (HL7) Clinical Document Architecture (CDA) standards may be used to incorporate information representing various episodes of care contained in various EMR's in a single EHR [29].

Other components that can aid in improving continuity of care include personal health records (PHR) and electronic prescribing (e-prescribing).

A PHR is an electronic application, normally Web-based, that allows an individual to capture, access, and manage his own health information [28]. A PHR is owned and controlled by the individual and represents a repository of the individual's health information and allows the individual to have a lifelong summary of all of his health information in one convenient place. An individual can allow his healthcare provider access to his PHR, which can be a valuable source of information for improving care [27, 28].

While e-prescribing does not directly contribute to the continuity of care, it is still considered an important contributor to the vision of an EHR. E-prescribing is a valuable step towards medical practice automation, and even healthcare providers that are skeptical about implementing EMRs appreciate the benefits of e-prescribing, which can aid in recognizing the benefits of interoperability between healthcare providers. While continuity of care plays an important role in the quality of care that a patient receives, the importance of e-prescribing should not be overlooked as it reduces errors caused by handwritten prescriptions, and it is possible to build a history of all medications that have been dispensed to a particular patient. This enables the automated checking of interactions between medications and also ensures that an accurate medication list can be available at the point of care [20].

Figure 1 depicts a model of how the technological components that have been discussed above could work together to improve informational continuity of care while a national EHR is not available yet. If healthcare practitioners can be convinced of the benefits of adopting EMRs, standards such as CCR and CDA could be used to share information between healthcare practitioners to improve informational continuity of care.

While it is clear that the necessary technology and standards are available to make up the technical subsystem, further research will be necessary to determine whether private primary care practices in South Africa are aware of the benefits associated with EMRs and willing to spend the necessary funds on the hardware, software, and training necessary to make use of EMRs. In terms of the environmental subsystem there seems to be support from patients and the DoH for the use of EMRs, but the authors will use landscaping techniques to identify and investigate additional environmental stakeholders in the South African context that may have an impact on the implementation of EMRs, for example medical aids and other healthcare providers involved when patients are referred from primary care level. Very little research has been done to investigate the social subsystem. Observations made from international literature will contribute towards the design of further instruments to gather data on the social subsystem and barriers to the adoption of EMRs in South Africa.

Conclusion

Based on the explorative analysis of the social, technical, and environmental subsystems in the South African context it was revealed that there is not sufficient information available on the barriers to adoption of EMRs in private primary care in South Africa. Further research efforts will focus on gathering further data on the barriers to the adoption of EMRs in order to develop a socio-technical framework to encourage adoption of EMRs to improve informational continuity of care.

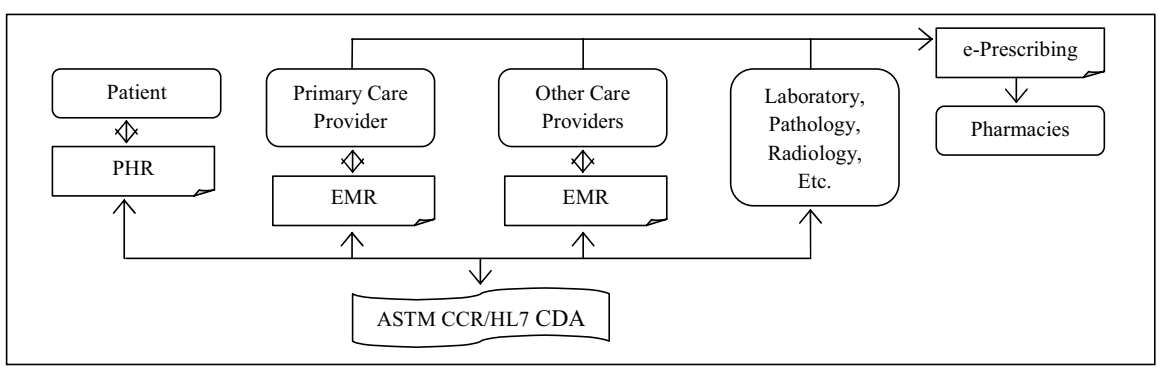

Figure 1 - A technological model to improve continuity of car

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Implementing OpenMRS for patient monitoring in an HIV/AIDS care and treatment program in rural Mozambique

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Abstract

We have adopted the Open Medical Record System (OpenMRS) framework to implement an electronic patient monitoring system for an HIV care and treatment program in Mozambique. The program provides technical assistance to the Ministry of Health supporting the scale up of integrated HIV care and support services in health facilities in rural resource limited settings. The implementation is in use for adult and pediatric programs, with ongoing roll-out to cover all supported sites. We describe early experiences in adapting the system to the program needs, addressing infrastructure challenges, creating a regional support team, training data entry staff, migrating a legacy database, deployment, and current use. We find that OpenMRS offers excellent prospects for in-country development of health information systems, even in severely resource limited settings. However, it also requires considerable organizational infrastructure investment and technical capacity building to ensure continued local support.

Keywords:

Computerized medical record systems, Developing countries, Mozambique, Rural health, HIV

Introduction

Mozambique, a country in sub-Saharan Africa, has a severe generalized HIV/AIDS epidemic with a national HIV prevalence rate of 16% and roughly 1.5 million persons living with HIV/AIDS, including 100,000 children [1]. The national health care system is subject to severe resource limitations, in large part a consequence of both a struggle for independence from colonial rule, and a subsequent civil war. In recent years, Mozambique has received substantial international development support, with the reconstruction of a national health system as a major focus area.

In response to the severity of the HIV epidemic, the Mozambique Ministry of Health (MOH) began an intensive ART expansion program in 2004. With support from international donor organizations, including the United States' President's Emergency Plan For AIDS Relief (PEPFAR) program, most urban centers and large hospitals now provide a range of HIV related services. Human resource capacity as well as infrastructure to support a care and treatment program for a large number of patients is much improved. However, the vast majority of Mozambicans live in rural areas, and implementing HIV care and treatment services in these areas remains very challenging.

Vanderbilt University Institute for Global Health and its affiliate non-governmental organization (NGO) Friends in Global Health, LLC (FGH) have been working in Zambézia province, Mozambique, since February 2007. The province is the largest in population size, with almost 4 million inhabitants, and second largest geographically (approx 100.000 km^2)[1]. It is a predominately rural area, with the provincial capital city as the only real urban center. The HIV prevalence is slightly higher than the national average, at 19%. The overall aim is to develop a comprehensive model for rural HIV services provision that integrates health and social services. The program currently provides technical assistance to local health authorities in 12 out of 17 districts in the province, with direct support at the principal health facility in each district. Major program elements include adult and pediatric care and treatment, prevention of mother to child transmission, and child-at risk services.

All MOH health facilities that provide HIV services use a standardized paper based patient monitoring system. It includes a facility register and a patient based paper chart, as well as a patient card that is issued on enrollment in a care program. The system suffers from redundancy due to a large number of forms and many form fields that do not correspond well with a compact data set suitable for resource constrained settings [2]. In a recent assessment, the number of data elements in the current system was found to exceed the WHO recommended set of HIV specific data elements by more than

[1] Data from the 2007 census, available online at: http://www.ine.gov.mz/censo2007/rdcenso09/zambezia/q1

a factor of two[2]. Furthermore, there is extensive use of non-coded data fields in the forms, which in general decreases the usability of data for analysis. A review and revision of the complete paper based system is included in the strategic information plan for HIV.

The rapid expansion of HIV services has already resulted in high patient enrollment numbers, and further growth is anticipated. A high patient volume inevitably results in a documenting and reporting burden on already heavily taxed human resources in the health facilities. Avoiding this scenario is a primary motivation for pursuing an electronic patient monitoring system. A growing body of evidence from case studies suggests that the use of electronic medical records in developing countries can contribute to improving the health care system [3-7]. The World Health Organization, in its recent progress report on universal access to HIV treatment, reiterated its position on the importance of strategic information, and the building of systems that improve data quality [8]. In assessing potential impact of the overall technical assistance program from FGH in Mozambique, we identified the implementation of a health information system as a key opportunity in strengthening the integrated HIV care and support program.

This paper describes our implementation of an electronic patient monitoring system for the setting described above. It includes the choice of the Open Medical Record System [9] framework, its adaptation to the local context, the actual implementation and deployment of the application, creating a local support team, information technology challenges, and current use.

Methods

Choosing the OpenMRS framework

To determine a suitable implementation path for an electronic patient monitoring system we evaluated several such systems in use both in Mozambique, and elsewhere. While we found electronic data capture relatively common, applications are typically only used internally by each organization. Within Mozambique an exception was the electronic patient monitoring system created by the *International Centers for AIDS Care and Treatment Programs* (ICAP, affiliated with Columbia University, USA). While limited in functionality or options for feature extensions, this Microsoft Access desktop database application included essential Portuguese language support, and a reasonable correspondence to the Mozambique patient monitoring system. ICAP graciously allowed FGH to use this system as an interim solution in the health facilities supported in the early phases of our program while we developed our own approach.

As the most suitable candidate for a system that will provide long term growth in supporting a range of health services, as well as facilitate eventual needs to support health services research, the Open Medical Record System (OpenMRS) emerged with the broadest set of necessary features. OpenMRS is an electronic medical record (EMR) system framework [9]. The framework is under continuous development to expand capabilities towards an increasingly comprehensive set of EMR functions [10-11]. It is also characterized by a collaborative development model, and the emergence of an "implementers' network" [12] that provides a community oriented mechanism to support new adopters, disseminate lessons learned, and establish best practices. Most deployments to date are in low or middle income countries. While larger scale or multi-facility implementations of OpenMRS typically depend on technical support from external partners, there is a strong trend towards locally sustainable development models. When an implementation incorporates a technology transfer and health information systems capacity building aspects, the implementation can increasingly be supported through local or in-country technical staff.

Electrical power and telecommunication infrastructure

The electrical power grid in Zambézia benefits from the proximity of a reliable source of electric power, a hydro-electric dam. As a result, those health facilities connected to the grid also have relatively reliable electrical power. Power infrastructure limitations still exist in three districts, but the implementation of a permanent solution for each of these sites is already in progress.

Internet connectivity at a health facility is another important objective both for general Internet access, and also to enable a health information exchange with other sites or with a regional data repository. A national telecommunications infrastructure project is underway expanding a terrestrial fiber optic network that will eventually reach all districts in the country. In Zambézia, broadband subscriber services (dedicated circuit or DSL) are gradually becoming available. We consider this to be the most promising infrastructure for long term sustainability and are adopting this service in each district where it is provided. Wireless data services based on GPRS or better are also expanding coverage area, but real world availability and data rates in rural areas remain limited. As an overall strategy we anticipate heterogeneous connectivity options for the supported health facilities.

Scope of the initial implementation

Both power and communication infrastructure concerns dictate a key macro-level architecture decision. We implement an independent EMR server at the primary district health facility, provided the facility is connected to the power grid. Access to the system is provided through a local area network and data entry terminals. This approach, while requiring more IT infrastructure is more robust than a centralized implementation. In addition, a program in multiple districts crosses administrative boundaries. Without MOH approved policies on data sharing in place we opt to keep the individual EMR repositories unconnected. Where grid power is not yet available we implement for a laptop based solution, with corresponding constraints on data availability.

While we aim to implement an electronic patient tracking system we also expect that paper based record systems will re-

[2] Patient Monitoring System Assessment, Technical report prepared by the University of California, San Francisco, for the Mozambique Ministry of Health, 2009.

main in place for the foreseeable future. Electronic systems used for retrospective data entry can provide easier access to information for the health care worker and thereby lead to improvements in providing care. True evaluation of the impact of a health information system on patient outcomes is much more challenging because the use of a health information system is rarely an isolated intervention [13]. Our direct objectives therefore are focused on improving the health care process by making clinical data available and useful.

Results

Customizing the OpenMRS framework

The OpenMRS concept dictionary, the representation of all clinical knowledge in the system, has been created to match the paper based system, and has been fully translated into Portuguese. The web based user interface has also been translated into Portuguese (although internationalization support of the web based interface remains somewhat incomplete), and localization of the patient registration section supports a structure for providing rural patient addresses.

The *de facto* application for form data entry in OpenMRS is through the use of Microsoft InfoPath. An electronic form was created to correspond to each of the paper forms with improvements in data coding and with implementation of data validation logic. OpenMRS report building functionality, available as extension modules, lacks some desired features, e.g. archiving persistent reports. However, creating an interim reporting solution has been relatively straightforward, and we expect to replace it with standard capabilities in due course.

Migration of legacy databases

The adoption of an interim database presented both an opportunity and a challenge. The databases enabled for data mining of the content, which revealed that clinicians were using their own (mostly) consistent coding schemes in some of the plain text fields on the paper forms. This provided us with an easy opportunity to improve the field values in the corresponding OpenMRS forms. The challenge came in mapping the source database model onto the OpenMRS data model to automate the data migration. A utility was created to automate the migration of all patient records from the legacy databases to OpenMRS, but the accidental complexities of the source database made creating this mapping a labor intensive process.

Deployment

Standardized Information Technology setup

For ease of maintenance and support, we select only COTS hardware in a standardized configuration. An uninterruptible power supply (UPS) can provide backup power for two hours, and a power conditioning unit protects against intermittent power quality problems. For the OpenMRS server, we employ a low-voltage and small form-factor hardware platform that has much lower power consumption than conventional server class hardware. The default configuration is a rackmount server enclosure but to accommodate very dusty conditions we can also select a fanless enclosure, at the cost of performance. High reliability data storage is realized through redundant hard drives. The server runs an open source operating system and does not require any proprietary software.

Space constraints are a consideration in all health facilities, and it is in general not possible to allocate a dedicated space to host a server. As a solution, we install a self contained system in a compact (approx 50 cm tall) rack-mount cabinet. The cabinet ensures basic physical security and effectively provides a "server room in a box" (see Figure 1). The cabinet is wall mounted, and raised to conserve floor space. For any site, the cabinet is grounded for electrical safety, and in addition to the equipment mentioned above also contains a basic unmanaged switch to create the local area network (LAN) for the data entry terminals. For sites with internet access the cabinet further contains the broadband modem, which is paired with a Cisco router.

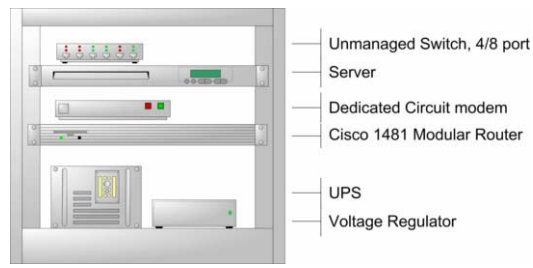

Figure 1 - "Server room in a box." A compact rack-mount system holds the OpenMRS server, and peripheral equipment for networking and power conditioning.

For data entry, standard configuration laptops are used but they rely on their own batteries for backup power as opposed to the UPS. In all current setups the LAN is a wired configuration, although wireless connectivity has also been tested when the LAN switch is extended with a wireless access point.

Management

In a distributed setting with facility based servers, the ability to reduce technical support overhead of the operational systems is critical. A web based server administration tool is configured with simple modules so that facility staff can handle database backups and basic server management. For networked facilities, it is also possible to remotely monitor the installed systems with a network resource monitoring application[3]. The application registers network resources that support the Simple Network Monitoring Protocol (SNMP). The status of the server, managed networking hardware, the UPS equipment, and the status of the OpenMRS database can be monitored centrally, and continuous link monitoring indicates when connectivity is lost.

Using the system

Data management

The quality of the information in an EMR has been shown to have real impact on the use of the data, and training of the data

[3] We employ the Zenoss product: www.zenoss.org

management staff has been identified as a critical factor in maintaining good data quality [14]. In the FGH program each health facility is supported by two data entry staff. A regional supervisor oversees data entry in three districts, and a centrally located coordinator oversees the complete team and process. We consider the data entry staff as an integral part of a comprehensive approach to data quality. Prospective candidates for data entry staff positions are screened on problem solving ability. If accepted, a two week training program follows. The first week is primarily classroom based, with an introduction to the entire patient monitoring and tracking process. This includes training in location of missing information and resolution of anomalies in the paper chart by directly contacting the health care providers. This is followed by classroom training on using the actual data entry tools. The second week occurs in the field, where they are immersed in the actual environment of the health care facility, with close supervision from trainers, more experienced data entry staff, and supervisors. During the first weeks of actual field work new staff are monitored by supervisors until considered experienced.

A data quality assurance process is implemented using a data quality assessment instrument. For a group of measurements critical to the current reporting requirements, we compare the electronic and paper based data. Errors are categorized according to missing data elements on the paper record or in the electronic record, or actual mismatch in values between the paper and electronic record. Early sample runs of the tool have already allowed us to use the results to improve training for those fields where common errors occurred. We do not employ a double data entry scheme.

Reporting

The FGH program generates reports in three formats, reports for the MOH each month, reports for PEPFAR, and reports for the US based HIVQUAL quality improvement program. For the MOH, any discrepancies between the reports generated from the EMR, and a corresponding report using only the paper based system must be adequately explained. In a recent audit of the patient monitoring system for multiple sites a formal process was followed to resolve discrepancies. Here the power of the EMR presented a clear advantage because most discrepancies were found to be the result of a lack of analysis on the paper record data to correctly identify patients in lost-to-follow-up status, and the report generated from the electronic system proved more accurate.

Use by the program clinical and technical teams

The main use of the data outside of reporting is by the district and regional community health teams which use the data to find patients who do not appear at the health facility in time to obtain their medication. The “active follow-up” teams use custom reports to identify patients that should be tracked down and reminded or encouraged to return to the clinic for treatment. In some locations, clinicians with an active (volunteer) interest in health information technology are using the system for ad-hoc analysis of patients in their care. There is no institutionalized use of the data for direct patient care at the moment.

Current Status

The first OpenMRS installation for FGH was put in use in November 2008, only weeks after the first dedicated health information systems staff member joined FGH in Mozambique. The initial OpenMRS sites were in districts where the legacy database was never used, and at the time of writing some legacy sites remain to be migrated. Per July 2009, the number of patients ever in care in all districts is 26893, ranging from 567 to 4469 patients for individual facilities.

Conclusions and Discussion

The current work represents the (near) completion of the first phase in adopting OpenMRS for the FGH program in Zambézia. Throughout the process we have been able to take a long term perspective, focusing on building capacity in Zambézia province to ensure our continued ability to evolve the application.

To determine the actual impact of timely and accurate data, the data will ideally be used in routine clinical practice which can be used to evaluate real improvements in health care delivery and, ultimately, improved patient outcomes as a result of improved care. Several installations of OpenMRS described in the literature have illustrated how this can be done, and we intend to follow these examples to demonstrate utility. Initially we will be providing patient specific alerts or reports at the time of a patient visit.

There is also an increasing focus on building sustainable health information systems. As metrics for determining sustainability emerge, we will be evaluating our approach by comparing against these metrics [15]. The emerging capacity within FGH will be applied to engage the regional health officials in defining a strategy to improve the access to and use of health information for decision and policy making within Zambézia, and to use this strategy to guide ongoing development efforts.

In the development of regional capacity in Zambézia new opportunities are also emerging. In recent years, health information systems have been of great interest at national planning levels of the Mozambique MOH. The department of health information systems within the MOH is evolving a national policy for building a health information infrastructure and an e-health strategy. Key aspect of the strategy is to balance the adoption of health information technology with the capacity to use it within all levels of a health care system [16]. There is also a deeper understanding on the reasons why information systems may fail in a given context [17]. In Mozambique, there are no large scale implementations of commercial enterprise solutions for facility-based health information systems. However, for some applications for aggregate level information, in-country developed systems have been deployed.

Recent changes to national policy include a restructuring of the interaction with partner organizations. An organization that wants to develop a data collection or analysis instrument (paper or electronic), is required to describe and document the instrument, as well as disclose findings resulting from its use

to the MOH. This process will improve transparency on informatics related activities in the country, while at the same time encouraging innovation in the context of specific regional constraints. The other key element is the development of national expertise on health system strengthening through linkages between the MOH and academia in Mozambique that are also considering OpenMRS and other open source technologies for health information systems.

As an implementing partner for the PEPFAR program in Mozambique tasked with the provision of technical assistance to the MOH both at the national level and at the local level, we are faced with an opportunity to investigate solutions that benefit the HIV services in particular, and the health system as a whole. The current work represents in-country capacity development, harmonization with emerging e-health policies at a national level, and creation of a system that fits the needs of Zambézia province. In turn, a successful demonstration of health information technology in Zambézia may benefit others seeking to follow a similar approach.

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Combining Vital Events Registration, Verbal Autopsy and Electronic Medical Records in Rural Ghana for Improved Health Services Delivery

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Abstract

This paper describes the process of implementing a low-cost 'real-time' vital registration and verbal autopsy system integrated within an electronic medical record within the Millennium Village cluster in rural Ghana. Using MGV-Net, an open source health information architecture built around the OpenMRS platform, a total of 2378 births were registered between January 2007 and June 2009. The percentage of births registered in the health facility under supervision of a skilled attendant increased substantially over the course of the project from median of 35% in 2007 to 64% in 2008 and 85% midway through 2009. Building additional clinics to reduce distance to facility and using the CHEWs to refer women for delivery in the clinics are possible explanations for the success in the vital registration. The integration of vital registration and verbal autopsies with the MGV-Net information system makes it possible for rapid assessment of effectiveness and provides important feedback to local providers and the Millennium Villages Project.

Keywords:

Africa, Birth records, Community health information systems, Electronic health records, Ghana, Health information systems, OpenMRS, Verbal autopsy, Vital statistics.

Introduction

A global agenda to address the overlapping vulnerabilities of poverty, underdevelopment and ill-health has recently been articulated in the United Nations Millennium Development Goal (MDG) framework [1]. Reducing premature death among children and among women during childbirth have been identified as urgent priorities, with specific time-bound MDG targets. The Millennium Villages Project (MVP) has been previously described and involves the systematic delivery of a package of proven health and development interventions, with the aim of accelerating progress towards the Millennium Development Goals [2].

The MVP is among the first applications of a multi-sector community health and development intervention. Interventions in agriculture, infrastructure, economics, education and health are being simultaneously introduced to village units of 1,000-10,000 households. This intensity and scale, combined with the diversity of MVP contexts, provide an unprecedented opportunity for better understanding the contribution of economics, infrastructure and health to human development. Lessons learned from the project have enormous potential to inform policy and program development in Africa and elsewhere for the coming decades.

In parallel to enhancing access to proven interventions, global health gains require the generation of high quality health information that can be used to guide program delivery [3].

Recent calls for 'information reform' to improve bottom-up approaches to the generation and use of information has the potential to revitalize locally-based health information systems and provide data on access of care, and critical health outcomes that can be used directly to improve local practice and reduce deaths [4].

While addressing maternal and child death rates are overriding concerns of two of the MDG targets, tools for the systematic measurement of mortality have evolved relatively recently. Currently more than half of deaths in developing countries go unregistered. With vital registration data often missing, incomplete and inaccurate, informed decisions regarding how and where to best intervene are often difficult to make [5].

Vital registration (monitoring of births and deaths) and verbal autopsies have been put forth as a potential strategy to address the need for real-time information to inform the targeting and improve coverage with essential public health interventions. Verbal autopsies (VAs) are "a procedure to exploit the information provided by the relatives of a deceased person to reconstruct the events and symptoms that preceded the death so as to deduce a medically acceptable cause, or causes, of death" [6, 7].

Despite the potential for vital events monitoring and VAs to inform intervention strategies, there has been much less inter-

national experience in this regard [8]. VA data has limited use, because of long time delay between vital event identification, VA data collection, cause of death determination, and data aggregation/analysis. However, some important preliminary work has been undertaken in a diversity of settings including the use of VAs to inform programs to address diabetes in the Ukraine [9], assess care seeking for malaria in Tanzania [10], understanding health seeking behavior, to guide the targeting health system interventions to improve TB diagnosis and treatment initiation in South Africa [11], and to guide improvements in the quality of community and hospital care to reduce infant mortality in India [12].

Medical records are often a key source of information to obtain the complete picture about births and deaths. [13] Integration of vital registration with clinical systems such as hospital records has been suggested using linkage software. [14] However, the work required to implement vital registration systems in low resource, rural communities with historically low access and/or utilization of health delivery systems should not be underestimated. [15] Capturing the complete picture of vital events often requires integration of multiple sources including the community, health facilities and other sources. [16]

When viewed holistically, the importance of vital events information, the existence of multiple primary data sources, the resources required to implement the system, and the value in reusing the data to assist with program management and patient care, it is likely that integrating vital registration and verbal autopsies with electronic medical records close to the communities will be beneficial.

This paper describes the process of implementing a low-cost 'real-time' vital registration and VA system within the Millennium Village cluster in rural Ghana. Implementation is currently in progress; however, we present preliminary data from the system and underscore ways in which these data can be used to inform and strengthen health systems and service delivery.

Materials and Methods

MVP Bonsasso, Ghana

Bonsaaso Millennium Village is located in the Amansie West District in the Ashanti Region of Ghana. The village is an agglomeration of 30 communities with 5769 households and has an estimated population of 30,000 people, of which 23% are women with reproductive age (15-49 years). When the project started in 2006 there were only three health centers within the cluster. The nearest hospital where surgery could be performed is the Agroyesum Catholic Mission Hospital which is about 27 km away from the village. In Bonsaaso, the nurse-population ratio in 2006 was 1:5,452. At the Regional level, nurse-population ratio was 1:3,082 and the doctor-population ratio was 1: 31,477. Due to the dispersed nature of the communities, coupled with poor condition of roads, inadequate transport services, access to the health facility posed enormous challenge to the people at the beginning of the project.

Currently there are 7 clinics and a medical store operating in the village that have reduced the distances people have to travel to access health care (see Table 1). Other changes between 2006 and 2009 are also shown.

Table 1 – Comparison of infrastructure between 2006-2009

Infrastructure/Human Resources	2006	2009
Number of Clinics in Cluster	3	7 + store
Average Distance to Reach Clinic	8.5 km	3.5 km
Health Clinic Staff	3	71
Midwives	2	7
Community Health Ext. Workers	0	28

Overview of the MGV-Net Vital Registration and Verbal Autopsy (VRVA) System

The Millennium Global Village-Network (MGV-Net) has been described previously and is an open source health information architecture built around the OpenMRS platform. [17] In the Ghana MVP site, vital registration and verbal autopsies are being integrated into MGV-Net to provide this critical information at the community level to facilitate decision-making and assist in the delivery of care. The VRVA system has a number of components that will be highlighted briefly below:

- **Community Health Extension Workers (CHEWs):** In all MVP sites, CHWs or CHEWs have been introduced to maximize the delivery of health information and services to households in the project clusters. There currently a ratio of 1 CHW to every 100-200 households, with household visits taking place every 1-2 months. CHWs are supported by an MVP Health Coordinator (doctors or allied health professionals), and provide a spectrum of health interventions to target households. Furthermore, CHWs are aware of vital events in households (births and deaths) very quickly.
- **Verbal autopsy specialist:** the VA specialist is non-clinical health worker specially trained in the VA methodology. VA specialists have the primary responsibility for conducting VAs.
- **VRVA tools:** have been developed for adults/maternal deaths and child deaths with two main components:
  - *Birth registration form:* questions to evaluate the circumstances of child birth, including location, attendance of skilled professional, and condition of the child.
  - *Cause of death module:* questions to assess signs and symptoms experienced by the deceased in the time preceding death. The module was derived from previously validated VA tools and consists of both close and open-ended sections as per best-practice guidelines.

- *Social autopsy module:* a specific module has been developed to include details regarding the social circumstances surrounding death. It includes information on health seeking behavior, access barriers to health care, communication, transport, and economics.

- **Data entry and algorithmic assessment of cause of death/social autopsy diagnosis:** All VRVA forms are entered into an OpenMRS database monthly. In order to facilitate a rapid generation of critical information for targeting interventions, a series of algorithms has been employed. These are established, valid techniques for determining the probable cause of death [18-24]. Selection criteria for algorithm were sensitivity and specificity greater than 50% and 75%, respectively as well as an estimated cause specific mortality rates (given sensitivity and specificity) within 40% of prevailing rates. Additionally, algorithms to assess the social circumstances leading up to death are also employed. This innovation eliminates the need for dual physician-based assessments, which can be both expensive and create a long time delay in generating 'real time' information for program managers.

- **Community Morbidity & Mortality Rounds:** the broad aim of the system is to generate information on the cause and social circumstances surrounding death to inform the delivery of health and development interventions on the ground, in real-time. Data collected on cause of death will be compiled and form the basis of a community 'morbidity and mortality rounds' – conducted by clinic staff, VAS, and the CHWs. These meetings will provide a forum for engaging with the medical and social autopsy data with appropriate recommendations being made regarding the introductions of new health programs, modifications in the delivery or targeting of existing health programs, or the need to liaise with other sectors such as infrastructure, education or nutrition to address other remediable concerns.

Status of Implementation in Ghana

Prior to 2008, data on births and deaths were collected by community volunteers. In January 2008, data collection responsibilities were transferred to the CHWs. This data is currently collected on paper and transferred to OpenMRS using retrospective data entry. MVP has recently tested entry via forms submitted from a Java-enabled mobile phone using an application based on the JavaROSA platform. In addition, we are in the process of rolling out data entry via ChildCount+, based on RapidSMS, a UNICEF-sponsored, SMS-based client on mobile phones. Mobile-based data collection will hasten the transfer of data from the community to the clinic. In particular, mobile technologies will lessen the lag time between death identification and the verbal autopsy interview, which further promotes the 'real-time' utilization of community-based health information.

Clinical Integration

At the time of this article, vital registration information has been reviewed by MVP office and clinic staff in Ghana. It has yet to be integrated clinically with daily operations of MVP clinics. However, plans are already underway to use the newly available information to create alerts and reminders for childhood immunizations and for the care and follow-up of newly delivered mothers. Registration of pregnant women in the medical record will also allow for improved antenatal care as well as identification and referral at the time of delivery if necessary. The MGV-Net infrastructure, involving OpenMRS, SMS and other mHealth technologies, is also consistent with work being done elsewhere in Ghana by the Mailman School of Public Health, the Grameen Foundation and the Bill and Melinda Gates Foundation.

Results

Birth Registration

Our initial analysis of the Bonsasso data focused on birth registration. A total of 2378 births occurred in the project area between January 2007 and June 2009. These are shown in Figure 1. The sharp decrease in total births at the end of 2008 was thought to be due to increased family planning efforts earlier in the year.

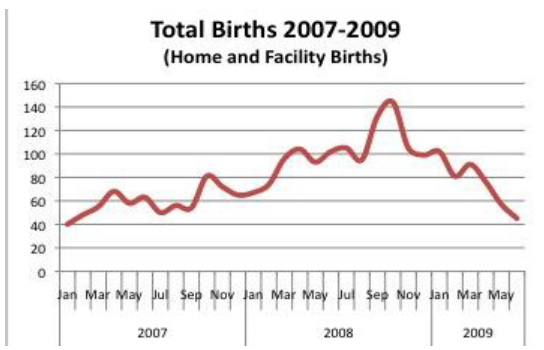

Figure 1- Total Births within the Bonsasso MVP cluster from 2007 through 2009.

According to community-based interviews administered to each new mother, the percentage of births within the project area that took place in a health facility increased substantially over the course of the project as shown in Figure 2 from a median of 35% in 2007 to 64% in 2008 and 85% midway through 2009.

Figure 2 - Percentage of all births occurring in a health facility versus home from 2007 through 2009.

In addition to MVP sponsored clients, the MVP clinics services patients from outside the intervention area. Seventy percent of facility-based births were to woman who resided within the MVP site and 30% were to woman who lived outside the cluster of villages as shown in Figure 3.

Figure 3 - Proportion of woman who gave birth in MVP facilities who lived in the MVP site at the time of birth.

Death Registration and Verbal Autopsies

At the time of this article, piloting of the death registration and verbal autopsy program is still ongoing while an external validation of mortality rates is undertaken. The likelihood of underreporting is very high given the emotional and social sensitivities of death within a household; therefore, a cross-sectional validation is recommended. Reporting of mortality and cause of death trends will be reported once implementation is completed and the results are validated.

Discussion

We present a novel application of a 'real-time' vital registration and VA system integrated within an open source electronic medical record in rural Ghana. This paper demonstrates the design and feasibility of the system as well as highlights its potential relevance as a tool to assist in monitoring intervention effects and facilitating improved coverage with essential maternal–child health services.

During implementation several challenges and limitations of the system were evident. Registration of births appears to be accurate and easy to implement given the modest cultural sensitivity; however, high community mobilization and awareness efforts of the CHEWs is required. Like many other community-based monitoring systems, CHEWs may underestimate deaths, particularly newborns, if families refuse to disclose them. Facility-based deaths that are included in the medical record will be more accurately reported, but most rural deaths happen at home. Home-based verbal autopsies may not provide a less complete picture of cause of death as clinic-based diagnoses, particularly pediatric deaths, which are often complex to assess. Further research and local validation of algorithms is needed. However, this VRVA system, including mobile death reporting, is valuable for quickly identifying patterns in the medical and social circumstances surrounding death.

In relation to the preliminary results presented, dramatic increase in skilled birth attendance can be attributed to several possible explanations. The construction and staffing of additional clinics in the MVP site and reducing the distance to the facility both seemed to contribute towards ensuring reliable supply of high quality care. It is also likely that training the CHEWs to refer women for delivery may have also had an effect on accelerating the demand for safe delivery services..

It is still too early to fully interrogate the potential of having detailed birth and death data available to MVP at the community level. The initial analyses of birth information have provided important detail about the numbers of births within the MVP site and the relative contribution of those living outside the cluster of villages. The marked reduction in overall births and the shifting of births from the home to skilled attendant deliveries in the clinics over the period of the project is encouraging. The impact of higher skilled birth attendance on child survival within the MVP site is currently under study. The integration of vital registration and verbal autopsies with the MGV-Net information system makes it possible for rapid assessment of effectiveness and provides important feedback to local providers and MVP. We hope that such timely and practical information will lead to improved quality of programming and of local delivery of care.

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Adopting the National Structure of Nursing Documentation is Consequential in the Development of Care

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Abstract

When healthcare units adopt the national structure of electronic nursing documentation, the process requires managerial support in nursing development as well as theoretical education arranged prior to the implementation. According to the experiences of the pilot units in the Central Finland Health Care District, nursing core data documentation in accordance with the national structure promotes care planning, clarifies and constructs documentation and furthermore unifies the documentation system. The change process gives rise to juridical aspects of documentation as well as a critical evaluation of the documentation contents. The early period of implementing the new theoretical aspect and proceeding from paper-based to electronic documentation required learning, training and agreement on common policy. In health care practice, there is at present one collective structure and model for nursing documentation based on national guidelines. A documented nursing plan is available when a patient is transferred between units or even into extended care. The structured care plan is also helpful when new nurses are introduced to praxis. The continuity of care is at stake when employees are transferred between units to meet the demands of resource allocation.

Keywords:

Core data, Nursing, Information systems, User training

Introduction

The law on using electronic social and healthcare client data in Finland was passed on July 1, 2007. Accordingly, the information in electronic health records (EHR) must be structured in order to support decision making in patient care as part of health management and the acquisition of health policy information. [1, 2]

According to the legislation, every electronic patient record must follow core data structures. The core data structures consist of essential health and care documentation that must be coded as defined so that it can be archived nationally. [3, 4]

The Nursing Minimum Data Set (NMDS) is a part of the EHR core data set. The Finnish Ministry of Health and Social Affairs has set the core data structure as a national goal for nursing documentation. The core data in nursing includes nursing diagnoses, nursing interventions, intensity of care and summary on discharge. [4] Nursing documentation is done by choosing headlines under different phases of the nursing process that can be complemented with free text. The documentation is based on the nursing core data that comply with the Finnish Care Classification (FinCC). [5]

Structured Nursing Documentation – a Pilot Study in the Central Finland Health Care District

The Central Finland Health Care District participated in a national electronic nursing documentation project titled *HoiDok* in 2005–2007 and in the national development of structured nursing core data. The goal of this development was to unify and standardise nursing documentation and to connect it with interdisciplinary core documentation of patient history, the national code server and the national archive. [6, 7] Finnish nursing documentation is based on the nursing decision making process, the nursing core data (NMDS) and the Finnish Care Classification (FinCC). The FinCC includes the Finnish Classification of Nursing Diagnosis/Needs (FiCND), Nursing Interventions (FiCNI) and Nursing Outcomes (FiCNO). [5, 7] The participants of the pilot study were nine hospital units of different specialties. These represented psychiatric and somatic care, and both wards and outpatient departments. In addition, a technical application of nursing documentation titled *WHOIKE* was utilised as part of patient data recording. [7]

Both theoretical education and case-based training were arranged at the hospital while the electronic application of nursing documentation was prepared for implementation. Nursing documentation will generate an interdisciplinary document that consists of daily notes done by several professionals engaged in patient care. During the training sessions, nurses and care providers received theoretical education of the nursing process. The training focused on structured data models following the national guidelines as well as on the legal aspects of documentation. A theoretical model of the nursing process was also introduced and its use rehearsed. The FinCC was explored with the help of case studies and examples. The training content was tailored to the units' needs and expectations. Every unit had one person engaging with the manager to plan and enable the personnel's participation in the training sessions.

The units also appointed one or two super users to support the implementation and utilisation. The documentation training was arranged immediately before the implementation. [9, 10]

The implementation of nursing documentation was accomplished in phases in the nine units during a two–month period from December 2006 to February 2007. The units made accurate plans describing the implementation date, volume of users, the final date of completion and plans for user support. (*Fig 1).*

The assessment of the implementation revealed that seven units achieved their goals well. In two units, the preparation for electronic documentation was insufficient. In the wards, every patient had a structured nursing document within two months. In the outpatient departments the transfer phase took over six months.

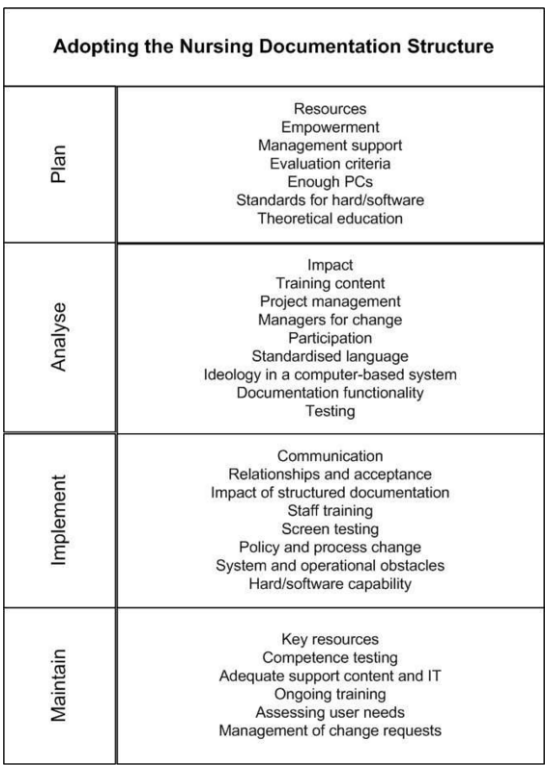

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Figure 1- The adoption model for structured nursing documentation [9, 10]

The evaluation from the units shows that successful implementation of structured nursing documentation requires managerial support, commitment to development and intense co-operation with managers and super users. Implementation must be executed with a careful design, realistic schedule and organised support. [10] It is important to immerse profoundly in the nursing process, classifications and the ideological significance. All professionals participating in patient care must determine both the meaning and relevance of documentation. Learning a new method of documentation takes time and is dependent on a well-operating application.

In May 2007, a survey was carried out in two of the pilot units after five months' use of electronic nursing documentation. Based on the results, some amendments were made in both the classifications and the application. A renewed application was implemented in February 2009. The pilot projects in structured documentation continued until September 2007. Based on some critical issues raised in user comments and requests, both operational and user interface usability alterations were implemented in January 2008. [9, 10]

Increasing the Use of Structured Nursing Documentation

Before increasing the use of structured nursing documentation, several information events were arranged for nursing managers and leaders. The units also received general directions on how to prepare for the implementation. During the lessons in the wards, theoretical studies were organised for both the super users and support persons. The actual training sessions for the application use were held from February 2008 to April 2008. Two training facilities with PCs were in constant use. Over 2000 nurses attended the training sessions.

Every unit made their own implementation plan that was executed immediately after the training. At present, structured nursing documentation has been adopted in all the psychiatric and other hospital wards as well as in the outpatient departments. A regional training program and implementation are under process. For example in the health care in Jyväskylä, a gradual switch is being made to structured nursing documentation.

The Impact of Structured Nursing Documentation

The impact of documentation in nursing has increased considerably in recent years. In previous years it was enough to record some of the interventions to be made, and nursing documentation lacked a legal function. Nowadays the demand for precise documentation is increasing, and the central function of documentation is to serve patient care planning, intervention and assessment and promote the continuity of care. Documentation also provides information to patients and establishes legal protection for both the patients and the personnel. With daily documentation, it is possible to explain and estimate how appropriate the treatment a patient receives is.

Developing structured nursing documentation has clarified and firmed the content of documentation. Some outpatient departments have considerably increased the volume of their documentation following the nursing process. Structured nursing documentation has enabled the units to also develop other functions. Through nursing documentation, change-of-shift reporting has taken the form of silent reporting. Orders can be prescribed in EPR by doctors, and the information is forwarded to the nursing documentation.

Nursing intensity is measured by a national system called *Rafaela*. Nursing documentation notes about ward intensity are available when workload is measured. A search engine enables patient information to be available to all users. Information can be retrieved according to the nursing sector, nursing process or the nursing period.

The implementation of structured nursing documentation increases the time consumed in storing data. However, it is obvious that in the long run, when the personnel have become familiar with the structure and the classification, documentation becomes precise and quality ameliorates. Structured nursing documentation accumulates significant patient data.

Discussion

The application of nursing documentation (*WHOIKE*) does not yet fulfil the structured nursing documentation standards completely. The structure of documentation is efficient but the user interface requires improvements to the usability. Some doctors are not satisfied with the use of the components and the terminology in the classifications. The documentation following the nursing process can appear abstract when implemented, and it takes time to visualise the new way of updating patient care.

Now it is time to confer, further develop patient care and make records to serve interdisciplinary documentation. It is important to find a common understanding of the consequential information documented into the nursing care plan. This means specific demands for the software application, user interface and usability.

Nowadays nurses read or retrieve doctors' documentation from different forms. At the same time, doctors inspect nursing data from a Nursing View frame or Nursing Plan frame. In the future, all information can be retrieved by similar search methods. The new nursing application includes a Daily Monitoring frame as well as a Medication frame; this will additionally enhance the significance of integrated software. Adopting a single recording principle for the patient records will improve visibility and usefulness and benefit patients in nursing planning, intervention and assessment. During the care period, the nursing document is vital for an individual patient's care.

A national study revealed that it takes about 3–6 months to learn the nursing documentation structure. When structured nursing documentation is carried out for a few months, it speeds up the recording and also guides documentation. Overlapping documentation has decreased, and documentation is more specific. The quality of the nursing documentation content has improved, and it has become more uniform and patient-orientated. Information is up to date, and the continuity and security of nursing care have improved. [7]

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Chapter 6.

Public Health Informatics

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Symptoms from Patients as the Primary Information Source for Real-time Surveillance

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Abstract

The aim of this study was to identify whether patients could become the primary data source for symptom based real-time surveillance. The study investigated people's attitude towards providing symptom information electronically before a consultation, and how they preferred to carry out the reporting. Data was collected by distributing questionnaires to 83 respondents. The results show that 96 percent of the respondents had a positive attitude towards providing information about their symptoms to the GP's office as soon as possible after falling ill. Over half of the respondents preferred to use e-mail or a web-interface to perform this task. Eighty four percent were willing to have their symptom data stored in their EPR and 76 percent agreed that the GP might access and present the symptoms together with the prevalence of matching diseases in order to assist the diagnostic process during the next consultation. This study indicates that patients could become the primary data source for symptom based surveillance in countries with high e-readiness.

Keywords:

Doctor patient communication, Electronic symptom reporting, Disease surveillance, Syndromic surveillance, Social networks

Introduction

The importance and relevance of disease surveillance and management is emphasized through the recent swine-flu pandemic, and through the facts that infectious diseases account for around 25 percent of all deaths in the world [1]. However, studies show that traditional disease surveillance systems struggle with a considerable reporting lag that limits early detection and timely response to outbreaks [2, 3]. Consequently, there is a demand for new electronic surveillance systems capable of eliminating unnecessary delays, and reducing the risk of data corruption [3].

Methods exploiting clinical data that exist at a stage before a confirmed diagnosis, e.g. symptoms, are commonly referred to as syndromic surveillance [4], or symptom based surveillance. Typically, in syndromic surveillance the frequency of illnesses is monitored using a specified set of clinical features (e.g., fever and respiratory complaints, skin rashes, diarrhoea) in a given population of a given geographic region, regardless of specific diagnoses [5]. It is the real time nature of the syndromic systems that makes them valuable for outbreak monitoring and detection [4]. Syndromic surveillance is considered useful for general public health, quality improvement, epidemiology, patient safety and research [4]. However, perhaps most important is its usefulness in clinical medicine [4], where it can make clinicians aware of community trends and enable them to issue the right tests and improve their diagnostic assessment [6].

Ideally, information should be entered once and used often [6]. Secondary use of clinical data, for instance structured documentation from the electronic patient record (EPR), unstructured narrative text, or laboratory results, is expected to have an enormous potential [7]. Today the necessary technologies are available to extract and present surveillance data from EPRs, laboratories, and hospitals [8]. However, the validity of a syndromic surveillance system depends on the quality of the collected and presented data, both in terms of representativeness and completeness [9]. One of the most challenging steps in utilizing such systems and technologies is to define the optimal data sources [10]. Unfortunately, data sources such as ICPC codes, free-text fields in the EPR, and data generated in conjunction with laboratory orders and results might have serious limitations [11]. One explanation is that the data entered into the EPR by the general practitioner (GP) is intended for other purposes than disease and/or syndromic surveillance, and produced in a different context. In general, use of data for secondary purposes influences data quality [12]. Consequently, the information must be disentangled from the context in which it was produced [12], and transformed into the new context of disease or syndromic surveillance. This process is particularly challenging with regards to real time data.

The Patient as the Primary Information Source

Thus, at the present, the challenge is to collect real time data of proper quality that is produced also for the purpose of disease or syndromic surveillance. Since patients could be seen as the GP's primary source of information on the current prevalence of infectious diseases [13], it seems appropriate to exploit this primary source further by collecting symptom information directly from the patients. In countries with high e-readiness, such as Norway where at least 80 percent of the population (15 years and older) are Internet users [14], this information could be reported electronically. This represents a new approach to syndromic surveillance that might provide

more data of better quality than what is available today, and at an earlier stage. One of the core questions is, however, if patients would be willing to provide this symptom data.

This paper presents an investigation of people's attitudes towards providing symptom information electronically before a medical consultation and how they prefer to carry out this type of reporting. Further, the study investigates to which degree people acquire information prior to the medical consultation.

Methods

Data collection was performed by distributing 83 questionnaires among the population of the city of Tromsø in Northern Norway during March 2009. A convenience sample was drawn by approaching people directly, and having them fill out the questionnaire immediately after agreeing to participate. Data was collected at diverse public locations, including a student hostel, the university library, a research centre, the airport, and various social venues (cafés). However, attitudes towards health and information technology could be envisioned to vary based on age, gender, and level of education. In this regard the sampling procedure aimed to approximate a representative distribution of these demographic variables in the sample. The respondents were at least 16 years old as this is the requirement to consent to participation in health related research projects in Norway. Foreigners received the questionnaires in English. The questionnaires were piloted on a small sample.

The questionnaire consisted of 13 items, which represented a combination of multiple choice and free text (comments), and prioritization of alternatives. In addition to demographics (age, gender, nationality, and level of education) participants were asked several questions aimed at assessing their attitudes towards providing their GP with symptom information using electronic media. This also included items concerning medical visits (last 12 months) and whether or not they acquired information about symptoms and problems prior to the medical consultation. The questionnaires contained no information identifying a person or questions regarding personal health status. Respondents spent 5-10 minutes completing the questionnaire. Three questionnaires were excluded from the analysis due to incomplete answers. Selections of free-text responses were subject to a content analysis identifying dominant themes related to the specific questions. SPSS 16.0 was used for the statistical analysis.

Results

Demographics

A total of 80 questionnaires were included in the survey. The sample characteristics are show in Table 1. The youngest participant was aged 16 years, the oldest 70 years, and the age mean was 36.7 years. A higher proportion of females (81 %) than males (58 %) reported having visited the GP in the last twelve months.

Table 1 - Numbers of participants in each category of the sample. Tromsø, Norway, March 2009

Nationality	Norwegian: 77			Foreign: 3	
Gender	Female: 36			Male: 44	
Age	[16-22]	[23-32]	[33-42]	[43-52]	[53-70]
n	20	15	16	13	16
Education	Primary and lower secondary school: 5			Upper secondary school: 30	
	Undergraduate: 16			Bachelor/Master: 29	

Acquiring information prior to the medical consultation

The majority of the respondents (68 percent) had visited their GP during the last 12 months, while 31 percent had not. Also, the majority (78 percent) of the respondents usually had a clear opinion about their diagnosis before they visited the GP, while 14 percent answered "seldom" and 5 percent "never". An independent samples t-test was used to show that there was a significant difference between those who had visited their GP in the last 12 months (mean = 1.16), and those who had not (mean = 1.44) with regard to "having a clear opinion about the diagnosis" prior to the medical consultation (scale, 1 = "often", 2 = "seldom", 3 = "never"), $t = -2.18$, $df = 74$, $p < .05$. Respondents were asked to select up to four sources for their "opinion about the diagnosis". Sixty nine percent answered that they made use of previous experience, 55 percent discussion with family, friends, and colleagues, 41 percent searched the Internet, and 19 percent medical books. Four respondents commented that they had some level of medical education. Information based on, partly or mainly, newspapers represented only nine percent, TV/radio eight percent, and information from pharmacies eight percent.

The respondents were asked if they used the Internet to check out or "Google" their symptoms prior to a consultation. Sixty one percent did, 41 percent frequently, 20 percent more infrequently, while 35 percent never did. Of those who used the Internet, 16 respondents commented by free-text that they conducted this kind of search because the information on the Internet is available and easy to access. Sixteen respondents commented that they conducted this search to clarify their symptoms, and to get a preliminary idea about the nature of their problems. Nine respondents commented that they used the Internet to diagnose themselves, where six of these nine emphasized that they did not intend to consult a GP if they were successful. Of those who never used the Internet, 10 respondents commented that they had not needed that due to not having been ill, or not having symptoms they did not recognize. The remaining eight respondents expressed a lack of interest in symptoms and uncertainty with regard to quality of information on the Internet.

Providing information prior to the medical consultation

Nearly all of the respondents, 96 percent, had a positive attitude towards providing information about their symptoms to the GP's office as soon as possible after falling ill (61 percent "yes", 35 "maybe"). Only one of the positive respondents commented on why, and that was because "this is the future - it has to be done like this", while two sceptical respondents found this approach too time consuming.

The positive respondents preferred to provide the GP with this symptom information as soon as possible after becoming ill, 39 percent by e-mail, 25 percent by web-interface, and 13 percent by the mobile phone Internet service (WAP). Thirteen percent preferred to provide this information by a computer or PDA at the GP's waiting room.

A linear multiple regression analysis was performed to investigate which variables could predict the respondents "attitude towards providing symptom information prior to a medical consultation using electronic media". Variables were selected based on a correlation analysis and theoretical assumptions (Table 2). Model 1 accounted for approximately eight percent of the variance of the dependent variable. The analysis showed that the attitude towards providing symptom information prior to a medical consultation was predicted by "medical visits in the last twelve months (yes/no)".

Table 2 - Summary of multiple regression analysis for Age, Gender, Level of Education, and Medical visits, and Pre-consultation use of the Internet predicting Respondents' attitudes towards providing symptom information electronically. Tromsø, Norway, March 2009.

Model	Variable	B	SE B	β
1	(Constant)	.98	.19	
	Medical visits	.33	.13	.28**
2	(Constant)	.92	.39	
	Medical visits	.27	.15	.23
	Age	-.00	.00	-.09
	Gender	.02	.13	.02
	Level of Education	-.02	.07	-.03
	Pre-consult Internet	.21	.14	.18

Note. **p < .05; **p < .01; R^2 = .08 for Model 1 (p < .05).*

The respondents were asked for their opinion regarding possible re-use of the reported symptoms. Eighty four percent of the respondents were willing to have their reported symptom data stored in the EPR at the GP office. In addition, 76 percent accepted that the GP might access and present the symptoms alongside the prevalence of matching diseases in order to assist the diagnostic process during the next consultation.

Regarding the storage of reported symptoms in the electronic journal system, four respondents commented that this would provide better documentation related to their problems, and would be a good way to update their personal health record. Further, four respondents commented that the fact that the GPs would be able to repeatedly access the reported symptoms could play a positive role in having their case thoroughly investigated. This, in turn, would be beneficial for them as patients, and maybe also save time. One person had the opposite view, worrying that "the info would lead the GP to be 'sloppy' ". On the other hand four commented that privacy and security had to be guaranteed. Two respondents were unhappy with electronic storage in general and afraid that unauthorized people (e.g., insurance companies) could get access to the data.
As to presenting the symptoms alongside the prevalence of the diseases matching the symptoms, two respondents commented that this might help the GP to identify the patient's problem and contribute to a more effective and time-saving consultation, while two commented that this is a tool that must be used with extreme caution not to scare people.

When asked if they would be willing to report the symptoms directly into a surveillance system without going through the GP's office/system, 43 percent were positive, 49 percent were negative, while nine percent did not reply to this question. Five sceptical respondents worried about the quality and would like the GP to confirm their symptoms before using them for surveillance. Of the positive respondents, two answered that they would report the symptoms since it would help early detection of diseases, four commented on the importance of anonymity, and one expressed concern whether the quality would be sufficient.

The respondents were asked for suggestions and user requirements with regard to how they wanted to provide information to such a system, the output they would like to receive, and other functional requirements. Security was highly prioritized by six respondents. For a surveillance system without GP's involved, the respondents suggested that the patients should be kept anonymous. Further, six respondents commented that it is most important that such a system is extremely easy to use (e.g., easily accessed, no need to set a lot of parameters, easily comprehensible information and questions). If possible, visual guidance should accompany the questions. Three respondents wished to have a response from the system with regard to diagnosis and possible treatment.

Respondents were asked to select up to three sources that they would trust when presenting them surveillance information. Eighty nine percent answered that they would trust their GP, 70 percent the Norwegian Institute of Public Health, and 60 percent the local university. Only 10 percent would trust the Internet, six percent the TV, three percent Google Flu trend, and between one and three percent would trust the local or national newspapers.

Discussion

The results show that the respondents are predominantly positive with regard to providing symptom information electronically to their GP. Ninety-six percent of respondents indicated that they would be willing to do this immediately after feeling ill. Over half of the respondents indicated that they would prefer to use e-mail or a web-interface to perform this task, rather than WAP-interface or technology in the GP-office's waiting room. This implies that people are motivated to use the most readily available technologies, and the technologies with which they are accustomed. Also, it points to a preference towards home-based solutions. Further, the respondents accepted that their symptoms could be stored in the EPR system. This will enable the GP to access these data at future consultations and present these alongside the prevalence of local diseases matching these symptoms, in order to assist in the diagnosing process.

In general, it appears that "medical visits (last twelve months)" is a central variable in this context. First, the variable is included in the regression model (Table 2, Model 1) as a significant predictor of respondents' attitudes towards providing symptom information. However, this model only ex-

plains 8 percent of the variance in the dependent variables. Thus, several other variables, not included in this study, are also relevant in explaining people's attitudes towards providing symptom data electronically. Second, having visited the doctor during the last twelve months is associated with being more likely to form an opinion about one's own diagnosis. However, the meaning of this variable is somewhat ambivalent, as it might both reflect a respondent's attitude towards health (i.e., being preoccupied with health issues) and indirectly, health status (i.e., visits equals poorer health). Inclusion of other variables (health status and other health-related attitudes) would be necessary to understand this relationship better.

The majority of the respondents were sceptical regarding reporting symptoms directly to a surveillance system without going through the GP's office. However, this still might be a possible approach since the 43 percent expressing a positive attitude could be sufficient to provide a representative outbreak picture.

Research on computer-mediated communication (CMC) has indicated that mediated communication is often associated with higher levels of self-disclosure [15]. These findings have been replicated for medically relevant communication, in both pre-clinical and clinical settings [16-21] and in anonymous, peer-support settings [22]. In sum, people appear more willing to disclose socially sensitive health information using CMC. They report more and/or more serious symptoms, and they comment that it feels easier disclosing their health problems in an anonymous setting. It seems worth mentioning that this is apparently irrespective of whether the information will be seen by health professionals at a later stage [e.g., 17], thus rendering the patient non-anonymous for all practical purposes. Our findings related to this published evidence support the viability of a patient-centric symptom-reporting tool.

The presented study utilizes a non-probabilistic sampling technique, and this limits the generalizations that can be drawn from the data. However, we believe that the care taken to ensure approximate representation with regard to gender and age allows for generalization to a certain extent. The fact that more females than males in our sample reported having visited the GP during the last twelve months underlines this viewpoint by reflecting the general population's behaviour regarding the use of health services. The sample is probably unrepresentative in terms of older age groups (50+), and the group with low level of education (only five participants).

Based on this survey we know the respondents say that they would report symptoms. However, we also know that there is a considerable gap between people's intentions/attitudes and their behaviour. Consequently, there is a need for studies that investigate if people/patients actually are able to report symptoms electronically. As to the willingness to report symptoms, encouraging experiences have been gained from large-scale volunteer efforts. This includes free and open source software development, distributed computing, and the Wikipedia project [23]. Evidence directly relevant to syndromic surveillance has also been published. Epidemiological data has been gathered from patients using web based questionnaires [24], and websites like "whoissick.org or sicklike.me, which ask users to enter their symptoms, demonstrate that consumers are willing to actively participate in surveillance" [25], (p. 8). The Great Influenza Survey in Netherland and Belgium (www.degrotegriepmeting.nl), which is based on weekly voluntary online participation of the population, supports this impression. We believe that future disease surveillance systems will be a combination of patient-centred symptom reporting systems, and surveillance systems utilizing other both formal and informally sources.

Conclusion

This study supports the hypothesis that patients could become the primary data source for symptom based real-time surveillance. In a patient-centred symptom reporting system the data would be produced for the purpose of surveillance, which would simplify the production of surveillance information of proper quality, provided that the symptoms are reported with sufficient quality. However, in order to draw a final conclusion, larger studies are needed.

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Electronic Surveillance of Healthcare-Associated Infections with MONI-ICU—A Clinical Breakthrough Compared to Conventional Surveillance Systems

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Abstract

Surveillance of clinical entities such as healthcare-associated infections (HCAI) by conventional techniques is a time-consuming task for highly trained experts. Such are neither available nor affordable in sufficient numbers on a permanent basis. Nevertheless, expert surveillance is a key parameter for good clinical practice, especially in intensive care medicine. MONI-ICU (monitoring of nosocomial infections in intensive care units) has been developed methodically and practically in a stepwise manner over the last 20 years and is now a reliable tool for clinical experts. It provides an almost real-time view of clinical indicators for HCAI—at the cost of almost no additional time on the part of surveillance staff or clinicians. We describe the use of this system in clinical routine and compare the results generated automatically by MONI-ICU with those generated in parallel by trained surveillance staff using patient chart reviews and other available information ("gold standard"). A total of 99 ICU patient admissions representing 1007 patient days were analyzed. MONI-ICU identified correctly the presence of an HCAI condition in 28/31 cases (sensitivity, 90.3%) and their absence in 68/68 of the non-HCAI cases (specificity, 100%), the latter meaning that MONI-ICU produced no "false alarms". The time taken for conventional surveillance at the 52 ward visits was 82.5 hours. MONI-ICU analysis of the same patient cases, including careful review of the generated results required only 12.5 hours (15.2%).

Keywords:

Electronic surveillance, Accuracy, Time expenditure, Healthcare-associated infections, Intensive care unit, MONI-ICU.

Introduction

Surveillance of clinical entities such as healthcare-associated infections (HCAI) by conventional techniques is a time-consuming task for highly trained experts who, in clinical settings, neither are available nor affordable in sufficient numbers on a permanent basis. Many published surveillance studies have been performed with either additionally budgeted (scientific) staff or with information technology (IT) tools specifically developed for the studies and not used later. Nevertheless, continuous expert surveillance is a key parameter for good clinical practice (GCP), especially in intensive care medicine [1,2]. Furthermore, healthcare authorities increasingly demand the installation and regular use of HCAI surveillance by healthcare institutions [3] as a part of quality management (QM). However, this sound demand is often overruled by financial constraints or simply by the unavailability of a suitable workforce at the local or regional level.

For a long time now, we have been attempting to bridge these gaps by establishing a fully automated computer-based system for early recognition and continuous monitoring of HCAIs [4–6]. The foremost challenge was to obtain reliable surveillance data from intensive care units (ICUs) without the need to employ additional documentation staff and statisticians.

When developing MONI-ICU, our main clinical concerns were the following:

- Its reliability and accuracy in clinical terms and its acceptance and adoption by clinical experts; possibly lowering infection rates and costs through (almost) real-time monitoring.
- Compliance with international standards and HCAI case definitions such as those issued by the Centers for Disease Control and Prevention (CDC) in Atlanta, USA [7], the European HELICS criteria [8], or the German KISS definitions [9].
- Timeliness of the obtained results for early identification of infection: both in the individual patient and in the patient population of the healthcare institution.
- Full technical and organizational feasibility with no need for additional staff for documentation or analysis.

Technically, MONI-ICU possesses the following components and characteristics to enable its fully automated mode of operation and wide acceptance by clinical users:

- Data import interfaces to the intensive care medical information or patient data management systems (PDMSs), the laboratory information system of the mi-

crobiology department and, last but not least, to the respective hospital information system.

- "Raw" measured and observed medical data coming from these information systems are entered into a stepwise pipeline of aggregation and interpretation, eventually to draw conclusions with regard to the presence or absence of HCAI conditions according to their definitions (cf., [6,10]).
- Extensive adoption of fuzzy set theory and fuzzy logic methodologies to allow for graded intermediate and final results [10]; this permits immediate identification of borderline cases and trends.
- Deployment of MONI-ICU as modern web-based, Java-programmed system with routine operation within the intranet of the healthcare institution [11]; it is based on a service-oriented architecture.
- Representation of the necessary medical knowledge and processing steps in Arden Syntax [11–13], a standard programming language fostered by Health Level Seven (HL7) and adopted as an American National Standards Institute (ANSI) standard.
- Presentation of explanations that describe how and why the intermediate and final results were calculated.

Technical Background

MONI-ICU relies on the following three components in terms of both method and practice: (1) Data sources that provide the respective structured medical data; (2) a medical knowledge base with computerized knowledge about all relevant clinical entities in the system; and (3) a processing algorithm that evaluates, aggregates, and interprets medical data in a stepwise manner until they can be mapped into the given HCAI definitions.

Additionally, graphical user interfaces display the daily results while reporting tools summarize the patient-oriented outcome.

Specifically, MONI-ICU's systems consist of the following:

Data sources: MONI-ICU is connected to 12 ICUs at the Vienna General Hospital where adult intensive care patients are treated. These ICUs are all equipped with Philips Care Vue PDM systems that collect clinical, laboratory, and nursing data over time. The patients' administrative data is transferred from the hospital's information system into the PDMSs and is thus available for MONI-ICU. However, a separate data interface was established between the laboratory information system (LIS) of the microbiology department (the LIS there was developed by the municipal authorities of Vienna) and MONI-ICU.

Furthermore, all PDMS data are restored daily and made available for further software systems, such as MONI-ICU, in a so-called information support mart (ISM). ISM is a relational data base containing a number of MONI-ICU specific tables, and is filled at night. In the morning about 5–6,000 data items are waiting to be processed by MONI-ICU.

Medical knowledge base. MONI-ICU contains an extended number of algorithm- and rule-based knowledge to recognize and interpret relevant data constellations that finally contribute to the decision as to whether a certain HCAI is present or not. By the use of fuzzy set theory and fuzzy logic, presence of HCAI is tagged with its calculated certainty. The required medical knowledge was defined by a small team consisting of an infection control specialist and a knowledge engineer. It was a difficult task, which was facilitated by the availability of standards [7–9]. For more details the reader is referred to [6,10].

Processing algorithm. The inference process is started daily at 5 am. For each patient (a maximum of 96 in the 12 ICUs), the entire knowledge base is applied. Processing is done in a stepwise manner: first, medical data are checked for plausibility and algorithms are applied to calculate intermediate numerical values such as means and scores; second, the patients' measured, observed, and calculated data are interpreted and classified into normal or the respective pathological classes (increased, decreased, …). Then, the abstracted and intermediate results are aggregated by the use of clinically meaningful rules. Finally, all included HCAI definitions are evaluated. As a result the (definitions of) HCAIs are fulfilled, not fulfilled, or fulfilled to a certain degree by the respective patient data. Quite often, patient data from the last few days are also taken into account.

A surveillance screen allows the infection control user to obtain an overview about all 12 ICUs, the patients, and the HCAI results. Moreover, detailed explanations containing the intermediate clinical results, and—if requested—the "raw" measured and observed patient data can be demanded by simple mouse clicks.

The results of MONI-ICU on the surveillance screen (we call it cockpit surveillance) are accessed from the rooms of the infection control unit at the Vienna General Hospital. Clinicians at the ICUs are directly contacted by the infection control staff when necessary.

Aims of the Clinical Evaluation

The objective of the clinical evaluation presented here is to perform the following two comparisons:

- Surveillance results generated automatically by MONI-ICU and those generated in parallel by trained surveillance staff and attending clinical experts using patient chart reviews and other available information. The data collected by human staff were taken as a clinical "gold standard" and then compared with the Moni-ICU results.
- Objective comparison of the time period taken to manually analyze patient charts on the one hand, and applying MONI-ICU as well as reviewing the results presented on screen on the other.

Methods

The clinical "gold standard"

From November 2006 to February 2007, trained surveillance staff together with attending clinical experts reviewed patient charts and other available information twice weekly, thus collecting data from 1007 patient days (two ICUs with together 16 beds, for adult patients, 99 admissions of > 48 h duration; refer to Table 1). All data were collected at the Vienna General Hospital, a 2,200-bed teaching and tertiary-care hospital.

The European HELICS [8] definitions for HCAIs (which are to a large extent identical with US-based CDC [7] definitions) were applied for the identification of HCAI episodes. The top-level main episodes are (with onset > 48 h after admission):

- septicemia (blood stream infection, BSI),
- central venous catheter-related infection (CRI),
- central venous catheter contamination (CCO – no infection!),
- pneumonia (PN), and
- urinary tract infection (UTI).

For more details on these entities and several variants of them, we refer the reader to [8].

Table 1 – Patient Data

	ICU 1	ICU 2	total
# Admissions > 48 h	56	43	99
Patient days	471	536	1007
Average duration of stay (days)	8.4	12.5	10.2

In addition, the time taken by the surveillance staff to review patient charts was recorded and summed up. The recording was performed in 6-minute units.

MONI-ICU surveillance

The above selection of patient data was again analyzed. This time the analysis was performed by automatically accessing the respective PDMS data, the data from the microbiology laboratory, and data from the admission department of the Vienna General Hospital. The complete analysis of the selected cases was done with MONI-ICU [actually, a programmed prototype of the present system].

Again, the time taken to load the results on the screen, select patient data and review the results, including the backward-chained inference and calculation path to the "raw" patient data, was measured and recorded for comparison.

Both, the results of infection surveillance and the time taken for two independent cycles were then compared.

Results

The following results were obtained:

MONI-ICU correctly identified the presence of one of the above-listed HCAI conditions in 28/31 cases (sensitivity 90.3%) and their absence in 68/68 of the non-HCAI cases (specificity 100%). Thus, an overall accuracy of 97% was achieved (cf., Table 2). Of the three undetected cases, two were due to missing microbiological data in the MONI-ICU database (a transfer error in data input) while one was due to a missing parameter in one rule definition.

Table 2 – HCAI Conditions Correctly / Falsely Identified or Missed by MONI-ICU

	Condition present "gold standard"	Condition absent "gold standard"
Condition present "MONI-ICU"	28/31 (90.3%)	0/68 (0%)
Condition absent "MONI-ICU"	3/31 (9.7%)	68/68 (100%)

The time taken for conventional surveillance was 52 ward visits comprising 82.5 hours (incl. 7.2 hours of walking) for human data collection and analysis. MONI-ICU analysis of the same 99 admissions took 12.5 hours at the MONI cockpit, which was roughly 15% of the time taken for conventional surveillance (cf., Table 3).

Table 3 – Time Expenditure for Conventional (Human) and MONI-ICU Surveillance

	Conventional surveillance	MONI-ICU surveillance
Time spent	82.5 h (100%)	12.5 h (15.2%)

Discussion

Automated surveillance by MONI-ICU is much faster and less dependent on human factors than conventional (manually operated) surveillance. High specificity of the results of surveillance is of paramount importance, as false alarms would rapidly and strongly discourage clinicians from accepting such a tool.

As the missing cases in MONI-ICU surveillance were due to rectifiable technical errors, a sensitivity of 100% can be achieved.

Investing resources in the development and programming of MONI-ICU is meaningful, as it provides reliable surveillance data rapidly. In general and also for the future, time and know-how must be invested so that MONI-ICU can keep pace with

advancing clinical expertise and adapted to the users' specific needs. The users, in turn, benefit from this time investment because their daily surveillance becomes rapid and precise.

Requirements for MONI-ICU and challenges:

- Availability of a suitable electronic PDMS; any additional manual data entries is counterproductive!
- Sufficient data of adequate quality must be stored and be accessible in PDMS. Its functionality is hindered or blocked by improper use or changes in interfaces to other clinical and institutional data systems. Similarly, sudden software and/or hardware changes in remote components of the healthcare institution's IT network may cause unexpected breakdowns. MONI-ICU requires a smoothly functioning IT environment.
- Clinical experts must be available and willing to cooperate in tuning and updating the system. Continuous cooperation between the MONI-ICU provider, the local IT management, the surveillance team, and clinical experts is indispensible.
- Funding the development and installation as well as continuing support of the system to keep in pace with advancing clinical expertise and case definitions are also necessary.
- Being understood and accepted by intended users. The reluctance of medical and other experts to entrust knowledge to an electronic system, the fear of being replaced by it in the long run and similar prejudices may prevent potential users from getting acquainted with its qualities.

Conclusions and Perspectives

MONI-ICU generated no "false alarms", thus demonstrating high specificity. Its sensitivity was reasonable even with the applied MONI-ICU prototype, the data of which are shown here. After having modified the rule definition and corrected the data input, its sensitivity has now been optimized, and re-evaluation of the presented data is under way. Regular updating is a basic feature of MONI-ICU in order to keep pace with advancing clinical expertise. In fact, MONI-ICU may be used as a tool for challenging current definitions for HCAIs and for investigating their validity.

With MONI-ICU as an add-on to PDMSs, regular and continuous surveillance of HCAIs is feasible even with a small workforce. This opens great possibilities for GCP, QM, and benchmarking routines in healthcare institutions. Likewise, MONI-ICU may be used as a tool for clinical science. Although it was primarily developed for continuous surveillance, its features offer clinical decision support directly at the ICUs in the form of alerts and reminders.

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Using ProMED-Mail and MedWorm Blogs for Cross-Domain Pattern Analysis in Epidemic Intelligence

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Abstract

In this work we motivate the use of medical blog user generated content for gathering facts about disease reporting events to support biosurveillance investigation. Given the characteristics of blogs, the extraction of such events is made more difficult due to noise and data abundance. We address the problem of automatically inferring disease reporting event extraction patterns in this more noisy setting. The sublanguage used in outbreak reports is exploited to align with the sequences of disease reporting sentences in blogs. Based our Cross Domain Pattern Analysis Framework, experimental results show that Phase-Level sequences tend to produce more overlap across the domains than Word-Level sequences. The cross domain alignment process is effective at filtering noisy sequences from blogs and extracting good candidate sequence patterns from an abundance of text.

Keywords:

Biosurveillance, Automatic data processing, Medical informatics applications, Investigative techniques

Introduction

Many factors in today's changing societies contribute towards the continuous emergence of infectious diseases. In response, Epidemic Intelligence (EI) has emerged as a type of intelligence gathering which aims to detect events of interest to the public health, from the unstructured text of news and outbreak report.

In a typical Epidemic Intelligence scenario (Figure1), disease reporting events (i.e. victim, location, time, disease) are extracted from raw text. The events which are considered to be relevant for detecting an emerging disease are annotated with additional information (such as threat or severity level) and then aggregated to produce signals. The signals are intended to be an early warning against potential public health threats, and the epidemiologist uses them to assess risk; or corroborate and verify the information locally and with international agencies.

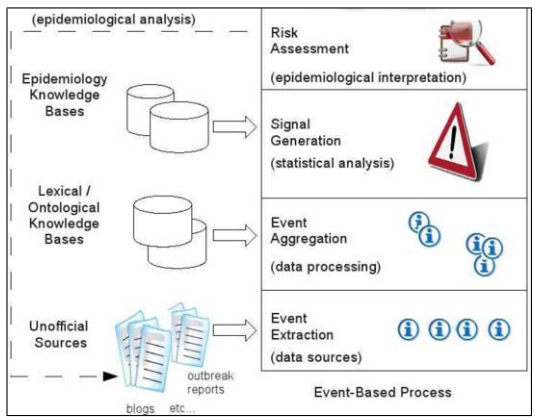

Figure 1- Epidemic Intelligence Scenario

In such a scenario, the diversity of the sources plays an important role in the intelligence gathering process. Medicine 2.0, social medical blogs and other forms of user generated content can be seen as an additional source. These sources are of significance, since those who experience as well as treat disease first hand, and describe their experiences in blogs and other forms of social media.

These present-day systems use news and outbreak reports as sources of information to support intelligence gathering. Moderated systems, (GPHIN, ProMED-Mail [5] ARGUS [9]) rely upon the interpretive and analytical expertise of analysts to filter and extract information about health threats. In automatic approaches such as MedISys [7], HealthMap [2], and BioCaster [1], all stages of the document collection, filtering and processing is done with little or no human intervention. Disproportionately, these systems do not take user-generated content, such as blogs, videos and twitters into account.

In order to fully realize the value of using Medicine 2.0, several challenges must be considered. First, acquiring information relevant to public health events from blogs requires filtering a huge number of irrelevant sentences. Those sentences which are irrelevant, or of poor quality need to be filtered out before any events can be extracted. Second, since natural language is inherently ambiguous, there are many ways to express

the same meaning. Particularly for social media, the complexity is increased given its volume, variety, evolution and informal nature (i.e. interspersing of subjective and factual information, many contributing authors with different styles, topic drifting prose and special lingo) [6]. Finally, abundant well labeled corpora, suitable for supporting many of the tasks in epidemic intelligence – is scarce or non existent.

In this work we seek to overcome these shortcomings, by demonstrating the underlying premise that if two sources discuss the same things - disease outbreak victims – then the languages have common linguistic structures. Thus, the symbols in one corpus can be used to identify them in another one.

In order to better understand which structures are potentially useful for extracting events from the sentences of blogs, we investigate how to transfer sentence structures acquired from a moderated data source (ProMED-Mail), and how this can be leveraged for the structures detection process within a new and less amenable one (MedWorm blogs), based on the commonality of the two used languages.

In this exploratory analysis we seek to understand the following questions with regard to a cross-corpora alignment:

- When do corpora align?
- What type of features (linguistic structures) best characterize such an alignment?

Methods

We cast the problem of Cross Domain Pattern Analysis as a alignment problem where the alignment sought is among the sentences of ProMED-Mail and MedWorm (see ***Figure 2***). In this approach we compare the sentence structures acquired from an auxiliary source (ProMED-Mail), to see if sentences relevant to outbreak reporting can be detected in a target domain (MedWorm blogs).

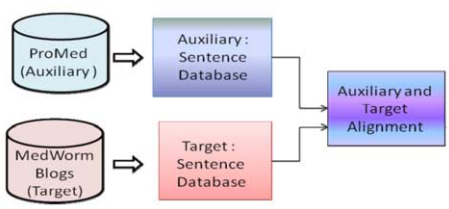

Figure 2- Cross Domain Pattern Analysis Overview

Structural Representations for Sentences

The sentences from each domain can have different levels of structuring (see Table 1). At the token level, the order of the individual words is considered unimportant; and can consist of (1a) the original word of the sentence (1b) a word's stem or (1c) a word's named entity. At the next structural level, one or more tokens can be sequenced lexically. For example, the named entity tokens derived from the Unified Medical Language System[1] (UMLS) concept identifiers (CUI) or the semantic classes (TUI) can be used to define a token sequence based on named entities (2a). An example sequence constructed from named entities using CUI and TUI is shown in ***Figure 3***. Finally, at the highest structural level, the sentence can be represented as a parse or dependency tree; respectively capturing the structure and semantics of the sentence.

Table 1-Structural Representations for Sentences

Structural Level	Example Representation
1. Token	a) Word b) Stem c) Named-Entity
2. Sequence	a) Token Sequence b) Phrase (i.e.: noun, verb)
3. Hierarchical	a) Parse tree b) Dependency tree

Sentence Database

Given a structural representation applied to all the sentences, in both the auxiliary and target domains, we construct a **Sentence Database.** An example sentence from a sentence database using the UMLS concept identifiers and semantic classes is shown in ***Figure 3***.

A 23 **year old** (C0419638, T061) **woman** (C0043209, T098) from Thanh **Hao** (C1435591, T116) **Providence** (C1227418, T005) died of **bird flu** (C0016627, T047) on **Wednesday** (C0585027, T079)[22 **April** (C1332090, T028) 2009]	
UMLS CUI Sequence	<C0419638,C0043209,C1435591, C1227418, C0016627, C0585027, C1332090>
UMLS TUI Sequence	<T061,T098,T116,T005, T047, T079, T028>

Figure 3-Example Sentence with Sequences Constructed from Named Entities using CUI and TUI

Definition: Cross-Domain Pattern Analysis

Given: a) a Sentence Database for an auxiliary domain, b) a second Sentence Database for a target domain and c) a comparison metric; Cross Domain Pattern Analysis is defined as follows:

Find an alignment between sentences having the same structural representation, of the form X -> Y, where X is a structure from the auxiliary domain; Y is a structure from the target domain and X is aligned with Y when the value of the comparison metric used is above a threshold value.

[1] http://www.nlm.nih.gov/research/umls/

Results

Experimental Goals

In order to automatically determine suitable sentences for extracting events from the sentences of blogs, we align sentence structures acquired from ProMED-Mail and MedWorm blogs. The goal of these experiments it to understand: 1) when corpora align and 2) the type of linguistic sentence structures best characterize such an alignment.

Data Collection

ProMED-Mail data was collected directly from the website[2], and MedWorm blogs via RSS. The blog data was collected by We used the blog urls from the RSS feed to get the full content of each blog post. The data for the outbreak reports was collected during an eight month period from January 1, 2009 through August 12, 2009. This coincided with the known outbreak period of the Swine Flu influenza, which reached pandemic status in June, 2009 [3]. The total amount of data used is shown in *Table 2*.

Sentence Structures

To construct the Sentence Databases for the auxiliary and target domains, the documents were first split into sentences using the Stanford Parser[4]. Next, several structural representations for each sentence were produced, this included: a) stems; b) TUI sequences, c) phrase sequences and d) parse tree (see ***Table 1***) . Stems were created using the Porter Stemmer available with Apache Lucene[5], the phrases were obtained by using MetaMap and both the parse and dependency trees were constructed using the Stanford Parser.

Table 2-Summary of the Amount of Data Used

	ProMED Mail	MedWorm Blogs
Documents	1,129	2,171
Sentences	32,518	130,487
Tokens	542,229	1,489,686

Pre-Filtering and Alignment

Pre-Filtering: Not all sentences were used in the Cross Pattern Alignment process. We exploited the characteristic style of ProMED-Mail, where the information about an outbreak is typically expressed in the first sentences of the text. We experimentally used the top-3 sentences. For blogs, we used the top-10. Documents below a 300 Kb size were not included in the experiments.

A*lignment:* To align the structures across the domains, sentence structures of the same type from the target and auxiliary domains were compared using three similarity metrics; one for each structural level; the range of values for all scores were bounded by 0 (not similar) and 1 (equal).

Experiment I: Token Level Alignment

In this section, we present a token level alignment for terms in appearing in both corpora. The metric used for comparing tokens was based on the use of wildcards concatenated with stems. For example , the stem "outbreak" was concatenated with a wildcard to allowing matching morphological variations of the token. The salient terms are visible in the word clouds for MedWorm (***Figure 4***) and ProMED-Mail (***Figure 5***)

Figure 4-MedWorm Stemmed-Word Cloud

Figure 5-ProMed-Mail Stemmed-Word Cloud

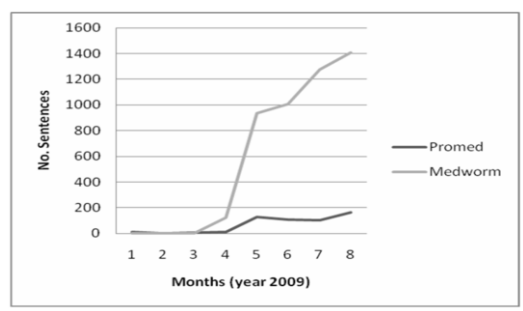

Figure 6-Total Sentences per Month for "h1n1"

[2] http://www.promedmail.org
[3] http://www.who.int/csr/disease/swineflu/updates/en/index.html
[4] http://nlp.stanford.edu/software/lex-parser.shtml
[5] http://lucene.apache.org

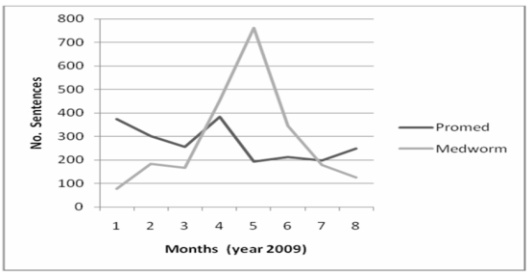

Figure 7-Total Sentences per Month for "outbreak"

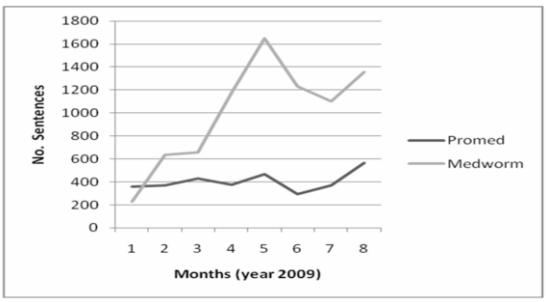

Figure 8-Total Sentences per Month for "virus"

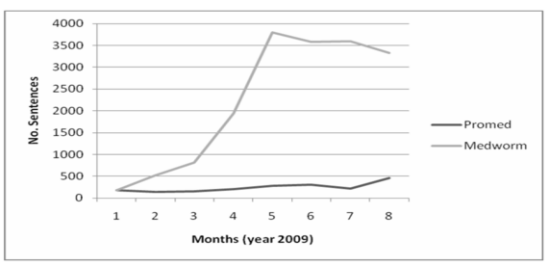

Figure 9-Total Sentences per Month for "flu"

Experiment II: Sequence Level Alignment

In this section, we present a sequence level alignment. The similarity metric used was based on our implementation of a string comparison algorithm which computes the longest overlapping contiguous subsequence of named-entity tokens. The score was normalized by the length of the longest sequence. Pairs with no named entity tokens in common received a score of 0. If all named-entity tokens in the sequence matched, one-for-one, then the pairs received a similarity score of 1.0.

Alignment of Token Sequences

Table 3 depicts the overlap between the sentences in ProMED-Mail and MedWorm for TUI and CUI Word-Level annotations varying the sequence lengths. The overlap between TUI annotated ProMED is far greater in number than the CUI annotations since several CUIs map to the same TUI semantic class. However, we notice that when the length of the sequences exceeds three, the proportion of overlap between ProMED and MedWorm for both types of annotations remains relatively the same.

Table 3-TUI and CUI Sturcture vs. Sequence Length

Number of Aligned Sentences Between ProMED-Mail and MedWorm Using TUI and CUI		
Sequence Length	TUI	CUI
3	6,105	422
4	130	136
5	30	20
6	15	16
7	10	9
8	8	6

Alignment of Phase Sequences

For the Phrase level structures were constructed by using the sentence chunks produced by the MetaMap parser. These chunks were then sequenced together to form the phrase sequences used in the experiments. Pairs of Phrase sequences were considered similar if there was and exact match.

Table 4-Phrase Sturctures vs. Sequence Length

Number of Aligned Sentences Between ProMED-Mail and MedWorm Using Phrases	
Sequence Length	Phase Structure
3	1,180
4	202
5	2

Experiment III: Hierarchical Level

For the hierarchal level, the parse tree for each sentence was used; to compute similarity for this structure, a tree kernel was used (http://dit.unitn.it/~moschitt/Tree-Kernel.htm). The results for tree alignments proved to be much less effective than the above methods, as no scores above .5 were obtained.

Experiment IV: Sequence Quality

In Experiment IV we examine the quality of the sequences with respect to the disease reporting task. ***Table 5*** shows the percentage of overlapping sequences which contain the semantic classes Population Group, Geographical Location, Temporal Concept or Disease. As can be seen, the percentage of sequences containing mentions to population groups and diseases are roughly the same for low support (10 % – 20%). Notably, as the support increases, the proportions change significantly and more overlapping sequences contain mentions to groups (30% support) and geographical location (%40 support).

In addition, we made a human assessment of the cases with a very small number of overlapping sequences. We find that these patterns contain interesting subsequences from which good candidate patterns can be built. One such subsequence

contains the location, disease and public health agency involved in responding to the event: e.g.:

TUI: Vietnam (Geographic Area), **from the disease** (Disease or Syndrome), **Health Ministry (**Health Care Related Organization)

Table 5-Sequence Quality Based on Entity Types

Sequence Quality Bases on Outbreak Report Named Entity Types				
Support Percent	Group	Geographical	Temporal	Disease
10	306	73	150	178
20	31	7	2	82
30	18	2	1	2
40	4	82	0	3

Discussion

The experimental goals of this work were to determine if an increasing level of abstractions in representing sentence sequences play a role in characterizing the sentential patterns between moderated and blog information sources.

In our analysis, we have seen that Phase-Level sequences tend to overlap more than Word-Level sequences. This can be explained by the fact that phases aggregate words and thus there is less variation across domains for these aggregations.
When aligning mined frequent sequences, the support played less of a role than the sequence lengths. Although very small numbers for higher sequence lengths were obtained, we believe this to be encouraging and demonstrate the ability of our approach to filter noise from large amounts of blogs data which a relative small about of human interpreted data.
We also experimented with other types of annotation such as POS and mined rare sequences instead of just frequent ones. Although not presented, these results showed less promise.
A notable limitation of the match phase used in these experiments is that the absence of a „sliding window" to align subsequences with a sequence. More rigorous matching could be used and is considered as future work.

Conclusion

In this work we motivate the use of medical blog user generated content for gathering facts about disease reporting events to support biosurveillance investigation. Given the characteristics of blogs, the extraction of such events is made more difficult due to noise and data abundance.

We address the problem of automatically inferring disease reporting event extraction patterns in this more noisy setting based our Cross Domain Pattern Analysis Framework.

The experimental results show that Phase-Level sequences tend to produce more overlap across the domains than Word-Level sequences and that the cross domain alignment process is effective at filtering noisy sequences and the extracting good candidate sequence patterns from an abundance of text.

As future work, we would like to take into account the significance of the errors associated with the annotation process itself. Also for the future work, we intend to examine how rules can be applied across the domains. Finally, we also intend to compare how the quality of the learnt patterns compares with patterns which are induced from predefined entity pairs in a greedy approach.

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Improving general practice based epidemiologic surveillance using desktop clients: the French Sentinel Network experience

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Abstract

Introduction: Web-based applications are a choice tool for general practice based epidemiological surveillance; however their use may disrupt the general practitioners (GPs) work process. In this article, we propose an alternative approach based on a desktop client application. This was developed for use in the French General Practitioners Sentinel Network. Methods: We developed a java application running as a client on the local GP computer. It allows reporting cases to a central server and provides feedback to the participating GPs. XML was used to describe surveillance protocols and questionnaires as well as instances of case descriptions. An evaluation of the users' feelings was carried out and the impact on the timeliness and completeness of surveillance data was measured. Results: Better integration in the work process was reported, especially when the software was used at the time of consultation. Reports were received more frequently with less missing data. This study highlights the potential of allowing multiple ways of interaction with the surveillance system to increase participation of GPs and the quality of surveillance.

Keywords:
Sentinel surveillance, Software, Communicable diseases

Introduction

The use of computerized information systems is increasingly common in General Practitioners (GP) practices [1]. Such systems may run as local applications on desktop computers and guarantee very quick response time and good integration in the clinical process. This is for example the case with most electronic patient record software. By contrast, other systems are based on interaction with distant servers through web browsers with typical larger response time that may limit integration in everyday's practice.

In the French Sentinel Network (FSN), an electronic epidemiologic surveillance system operating in France since 1984, a web based interface has been the preferred way of interaction since 1996 [2]. The FSN is based on a nationwide network of voluntary GPs who report cases of several conditions, mostly childhood and acute infectious diseases. Estimates of disease incidence are computed from GPs reports and used for public health decision making.

The satisfaction surveys of GPs participating in the surveillance alerted us to the fact that interaction with the website could be a limitation to the doctors' persistence in surveillance. Indeed, with this system, GPs must periodically log in to a secure web site and report cases using a dedicated interface (see Figure 1). This process is difficult to perform during consultation, and leads to delays in reporting. As public health decision makers are increasingly expecting near real time reporting and analysis of data [3-4], it is relevant to try and integrate the surveillance process more directly in the GP clinical process, so that cases may be reported almost in real time.

In this article, we describe how we redesigned the electronic web based surveillance system for better integration into the GPs work process, using a java-coded application run as a client on the local GP computer. While making case reporting easier to the GP, the solution also allows for real time data collection (on a daily basis). Furthermore it allows deployment of new surveillance items in real time. Finally, we report how this software was received by participating GPs.

Materials and Methods

Surveillance information model

The surveillance information model is split in two abstract models. The metadata model describes the surveillance protocol and the report data model describes the structure of the reported data. The implementation of the above model is presented using Unified Modeling Language (UML) in Figure 2.

Metadata model

The metadata model describes the surveillance protocol for a disease (or a medical condition). It consists of the definition of a **Disease** class holding the case definition in plain text, a unique identifier and a flag indicating whether reportable items, used to collect individual data about reported cases have been defined.

These reportable items are described by a set of combined classes. A first class (**Form**) acts as a container for **Item**

classes which specify the labels and types of data (text, numeric). Presentation and validation information is linked with the list of reportable items via classes **Group** (grouping items for display), **Choice** (set of acceptable values), **Parameter**, (named parameters like limits, validation pattern) and **Dependency** (dependencies between fields).

Report Data model

Cases of disease are observed by an Agent (here a GP) during a given observation period. Reports to the surveillance system are described by the **Declaration** class and is composed of an **ObservationPeriod** holding start/end dates and activity during the period (full time or not) with a set of **DiseaseCases** (for each disease included in the protocol). This last class is a set, possibly empty, of **Cases**, observed for the disease. A Case may hold individual data according to the **Items** in the form model associated with the disease. Each **Declaration** instance also includes references to the version number of the surveillance protocol, an agent identifier and the count of cases by disease.

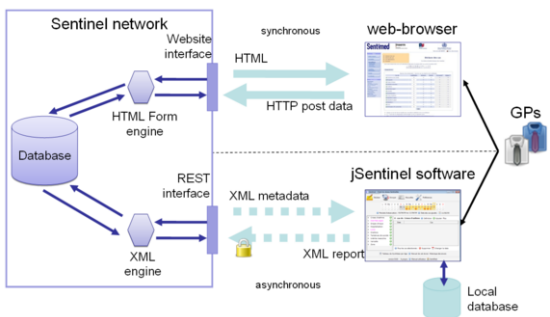

Figure 1-Overall architecture of the French Sentinel Network for epidemiologic surveillance. GPs may report data using a web based interface or a desktop client.

Client/Server model implementation

Two packages were defined and used to generate the set of XML schema files used in validation process (Figure 1 & 2). Files conforming to the **Metadata** model package are deployed from a central server to client applications to update surveillance protocol, while data sent from client application to the central server are expected to conform to the **Report** package description.

Available operations (authentication, push data to server, etc) are handled using a REST (Representational State Transfer) service interface: HTTP operations (GET, POST) are used to make an operation on a resource identified by an URL (Uniform Resource Locator), for example, the GET request to the URL https://[server]/metadata is used as the endpoint to get last metadata version. All exchanges use HTTPS protocol.

Metadata package XML files are instantiated on the server side from protocol descriptions stored in a database. Getting a file from the server is split in two operations: first, the server send an XML manifest file containing the version number available requested file and then the requested file is sent if it is new to the client.

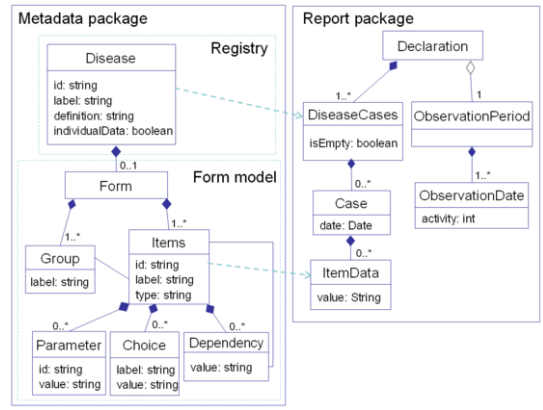

Figure 2- Surveillance information model. This model is used to generate XML files structure and XSD files

Desktop client implementation

We developed "JSentinel", a lightweight desktop Java application for surveillance and report. The application uses a modular architecture: a core component provides the basic functions like networking (http client), version management and updates, XML and Graphical User Interface (GUI) support.

A graphical library was developed using Java Swing components to display forms. This library transforms reportable items (conforming to the Form model) described in the metadata package (Figure 2) into a graphical form for data entry. It also handles data validation according to constraints defined in Dependency and Parameter class in the model, and displays an alert when an error is detected.

Main functionalities are packaged into "modules" which are interfaced with the core component and graphical user interface library. The four available modules (surveillance, news, update and preference) are described below.

Modules description

The Surveillance module allows data collection according to the surveillance protocol. It provides a GUI to collect case descriptions conforming to the **Metadata** XML package. If individual reportable items are required, the corresponding XML file containing the reportable items description according to the form model (Figure 2) in the Metadata package is passed to the GUI library to dynamically create a form and return the data entered. Data corresponding to reported cases are stored locally in an XML file conforming to the report package.

The Update module handles the synchronization of data with the server, downloading and inserting new files as required.

The News module provides a news reader user interface using Really Simple Syndication (RSS) and can be configured to

read several RSS sources and this source definition could be deployed within synchronization.

The Preferences module provides a user interface to define options and connection parameters.

Using the client

The client software is a point & click / menu driven application. The surveillance module user interface, presented in Figure 3, shows the list of diseases created from the downloaded metadata XML file, and the reported number of cases for each disease. If required, reportable items for the selected disease are listed in the right panel and may be filled in by clicking on the panel. A top bar shows a calendar displaying the observation period and activity level (half-time or full-time on a daily basis). Help and documentation is available, as well as summary displays of past reports for each GP.

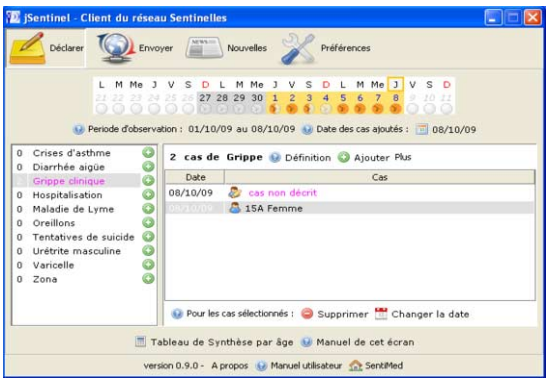

Figure 3-Screenshot of the jSentinel software. Diseases are listed in the left column. Two Influenza Like Illnesses (=Grippe) are currently being reported with one individually described Results

Deployment of the software

The software was developed and tested with 20 voluntary GPs, it was then made available for download and use for all GPs in the network. Two months after deployment, we invited all GPs who had used the client at least once to participate in a short survey. This survey explored GPs satisfaction with the new client software on several dimensions: time spent collecting and reporting cases, access to information about the network. Objective indicators related to the use of the system were also computed: frequency of connection, number of reported cases, completeness of reports (% cases with individual data) and persistence of use. When possible, we compared these indicators between GPs using JSentinel client and those using the web based interface.

Results

Software Utilization

209 GPs (out of 415 providing data) used JSentinel at least once over the first 9 months of availability (January - September 2009). During this period, 133 GPs used JSentinel more regularly than the web interface (those will be referred as JSentinel users) and 279 used the web interface (referred further as Web users). 3 GPs used both equally (but had very few connections) and were excluded from comparisons. Among JSentinel users, 60% used only the JSentinel software to report their cases. Proportion of weeks with at least one report for each GP was not significantly different during the evaluation period (median 63% inter-quartile range (IQR) [25%; 83%]) from the previous year (median 70% IQR [27%; 90%]) for JSentinel users.

Impact on surveillance data

The median time lag between 2 successive declarations for GPs using the website was 6 days with an inter-quartile range (IQR) of [3;8], but it was 0 days ([0;2]) for JSentinel users ($p < 0.001$) showing that daily declarations were common for the client software users. From January to September 2009, the median number of cases by week of observation was 5.13 cases for web users and 5.50 for client's users (not significant). These results are presented in Table 1.

Age and sex (common reportable items for all conditions included in the surveillance protocol during the year 2009) were fulfilled for 96% of reports from JSentinel and 91% from website declarations ($p < 0.001$).

Qualitative evaluation

107 GPs (out of 168 who used the client at least once during the 2 months following the deployment) responded to the evaluation survey. 95% reported spending less time reporting cases using the client, 59% agreed to say the client helped them to provide exhaustive reports and 83% agreed to say the client helped them not to forget reporting. Reasons most frequently mentioned to explain the client's help were the ability to report cases during consultation and desktop availability.

Table 1- Characteristics of participating GPs and changes in surveillance according to Web / JSentinel use.

	Web	JSentinel	p value
Use of Electronic Medical Record *% (N)* [1]	95.5% (233)	99% (126)	0.06
Days between consecutive reports, *median [IQR]*	6 [3;7]	0 [0;2]	< .001
Reported cases per week, *mean ± sd*	5.5 ± 5	5.1 ± 3	0.5
Report completion	91 %	96 %	< .001

[1] *data available for 89% of GPs*

Discussion

Making GPs persistent in reporting cases is a continuing challenge in voluntary based epidemiological surveillance systems [5]. Our users' survey confirmed that better integration of surveillance within the GP clinical process was a key element for participation. Indeed, desktop availability made it possible to describe cases quickly, allowing the additional work required for surveillance to fit in the consultation time. Another positive effect of the better integration of surveillance in the clinical process was the reduction in reporting delays. Indeed, most GPs sent data the day they were input, when the delays could be larger using the web based interface. However, some GPs preferred the web interface over JSentinel: these included GPs with a non computerized practice, as well as those who felt that using JSentinel took more time than reporting cases only once a week. Loss of time is often reported as an obstacle to adopt eHealth solutions [1].

In designing JSentinel, we aimed at developing a content management system for epidemiologic surveillance rather than a closed software for the FSN. For example, JSentinel includes an automatic newsreader functionality using a RSS stream reader. This function is used to provide rapid feedback to the GPs, and to deploy epidemiological alerts, as well as to maintain motivation in surveillance data collection. It has been suggested that making this information available may improve clinical decision rules, for example in the presence of epidemics [6].

The content management system approach of our architecture is further illustrated by the way the surveillance details are described. Indeed, these were all packaged (details on surveillance data presentation, capture and transmission) in XML files that are dynamically interpreted within the JSentinel software. Thus, the system is easily extendable to include new diseases. For example, modification of the influenza-like illness surveillance protocol to include influenza pandemic specific questions (risk perception, specific vaccine, etc) could be achieved in a few hours. JSentinel may also serve as a platform for data collection outside the routine surveillance protocol.

We developed our own data description using XML based on an abstract but simple model for continuous disease surveillance. There is indeed no well adopted standard for epidemiological surveillance, with most systems using ad hoc descriptions [7]. Contrary to clinical epidemiology, where Operational Data Modeling CDISC standards [8] has been put forward due to requirements by the Food and Drug Administration, initiatives for public health data standardization are still in their infancy. Our set of XML files may serve as a first step for allowing integration of heterogeneous systems in a unique framework.

Electronic data collection methods have become increasingly common for epidemiologic surveillance. Terminal based solutions were rare but existed before the internet [9]. Web based solution are now broadly used in surveillance system. Thanks to the web architecture based on W3C standards, web forms provide simple and flexible way to collect data since web browsers are only in charge of presentation and all data treatment could be done on the server side (forms definition, validation of data and storage). In our experience this data collection method has some limitations when especially when the working process of the users is not fully web-oriented and/or when permanent internet connection is not available or acceptable (for security reason or patient's home visits).

Another promising solution is the use of existing EMR software for surveillance purpose [10-12] . This solution has for example been implemented for syndromic surveillance to collect data (sex, age, chief complains, etc...) in existing software from Emergency Department or General Practice.

The real extent of the overlap between data required for public health surveillance and that entered in the Electronic Medical Record (EMR) content is an debate [13]. In case of emerging health issues and research the actual overlap is not clear cut.

In such cases, some specific data may be valuable which are of little use for the care of the patient: these would include for example contacts for a transmissible disease, detailed data on exposure or the environment, and so on. This type of data would be difficult to extract from the EMR, as the GP is unlikely to request them unless it is in a well defined surveillance protocol.

For surveillance of common diseases, one may expect that most of the data required may be in the EMR although it may be entered with little structure so that automated extraction is difficult.

Better integration of surveillance in the GP work process is therefore likely to pass by direct interaction with the EMR. This calls for standardizing the way data is stored in the EMR, so that automated extraction is possible; this also requires standardizing interaction between EMRs and surveillance systems to guarantee interoperability. Some solutions have been tested using the Clinical Document Architecture [14] or Archetype-based models [15] but they are generally based on a unique or few type existing software.

We did not pursue this goal here because there is a very large diversity in EMRs used in France by GPs; these have no capabilities for interoperability; and proprietary formats for data storage are common. Implementing a dedicated tool to extract from each EMR is clearly a dead-end, as it is not maintainable.

A further issue is that privacy of medical data is a stronghold in French regulations, so that third party software may not be allowed to perform automated scanning of EMRs. Pushing information from the EMR to the surveillance system would be better in this respect, although an authorization would still be required.

Implementing a standalone software was therefore the only viable solution that could be used by every Sentinel GPs regardless their choice of EMR. Our XML files may be a first step to base interoperability of such EMRs with surveillance system. Example files and schemas could be found at http://www.sentiweb.fr/xml/jsentinel

Future developments will proceed along two lines: 1 - industrial data standard to represent metadata considering specific (CDISC) or generic solutions (XForms) [16] as recommended by Retrieve Form for Data Capture published

by Integrating Healthcare Enterprise initiative [17] ; 2 - improve integration or communication with existing EMR.

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Attempting to predict the fate of an ongoing epidemic. Lessons from A(H1N1) influenza in USA

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Abstract

A simple method is proposed for predicting the fate of an epidemic outburst from early data. The method is based on the Richards model, and linearizations are proposed for obtaining preliminary values. A second step with nonlinear estimation fed with preliminary values as initial guess values may be attempted if field conditions allow the computation. The method was tested on data from 2001 dengue outbursts in both Havana and Winward Islands (French Polynesia). Predictions were satisfactory and an attempt of true prediction based on daily data for the 2009 H1N1 influenza outburst in the USA was undertaken. Comparison of early predictions with actual values obtained 3 months later suggests that some of the discrepancies are not due to method's inacuracy, but to real improvement of infection rate as the H1N1 outburst proceeded. The method can be applied in any setting where cumulative number of cases is properly recorded.

Keywords:

Mathematical Model, Epidemic prediction, Dengue, Influenza A(H1N1)

Introduction

In 2001 both the Cuban capital and French Polynesia were affected by dengue epidemics. Both places belong to the high dengue risk tropical belt, and dengue was known to both populations. In Cuba half a million persons (more than 5% of the country's population) suffered from Dengue-1 in 1977, whereas 300 000 were affected by dengue-2 in 1982 [1]. In French Polynesia, 17% of the population caught the disease during the 1989 dengue-1 epidemic [2]. An epidemic of Dengue-2 affected Santiago de Cuba in 1997, but was succesfully controled [3].

The 2001 Havana dengue-3 epidemic lasted for almost 9 months[1]. Dengue-1 was flagellating French Polynesia for 10 months. In spite of similar time course, one epidemic affected less than 0.6% of the population of Havana, whereas the other involved 16% of French Polynesians [2].

The paid prizes, however, were similarly high: In Cuba , huge human and financial resources were diverted to curb the epidemic. In French Polynesia, pediatric health infrastructure almost collapsed [2].

These two examples may illustrate the spoil caused by epidemics worldwide. Fighting them is a major public health challenge, and no country can proclaim to be completely safe [4]. Public opinion apparently sees the solution to most of epidemics in the development of vaccines as well as in their availability [4-5].

It seems reasonable to assume that the success of public health response to an epidemic also depends on the possibility to early predict its time evolution [6].

Here, we maintain the viewpoint that early prediction of an ongoing epidemic is a task approachable in a medical informatics framework. We recognize that only the first steps are being made in that direction. Thus, deeper theoretical work is needed together with closer collaboration with public health authorities. At the same time the task is not very appealing for theoreticians. For data miners relevant information appears when huge data sets are analyzed and sophisticated methods are applied. In the case of early prediction of an ongoing epidemic, computations are based on rather coarse approximations to small sets containing between 2 and 10 data points. The soundness of such a task can be negligible mathematically. However, when figures have deal not with abstract numbers, but with human beings under threat the motivation may find a proper space.

As an illustration, the method described in this paper predicted, based on early data available on weeks from 3rd to 10th of the outburst that the cumulative incidence of dengue hemorrhagic fever (DHF) for Windward Islands in French Polynesia would be between 6 and 11 cases/1000 inhabitants. Real cumulative incidence, determined after week 40, totaled, 3.07. Closer to this figure were estimates obtained with standard nonlinear approximation methods, but only available after the 10th week. Standard methods failed for the early stage, and our early forecasts, though relatively rough, could be very valuable as a guidance for preparing public health response during the most critical stage of epidemic fighting. For Havana, on the basis of data available from weeks 3rd till 5th, the total number of cases was predicted between 2 700 and 7 000, 45% of the actual number of cases: 12 889.

During the preparation of this manuscript, an attempt of "true" prediction was undertaken for H1N1 epidemic in the USA. A very important step is model selection [7-9].

A very useful expression for incidence rate was derived theoretically from the classical SIR model developed by Kendrick and McCormick 70 years ago[10]:

$$Incidence=A*4/(\exp(b*t-c)+\exp(c-b*t))^2 \quad (1),$$

where A corresponds to the maximum incidence and Tau=c/b is the time from the beginning until the peak of the outburst . For realistic conditions, this approximation is satisfactory, in particular, it fits nicely to a more complicated model for dengue fever conveyed by the mosquito[11].

As an illustration, in figure 1 incidence data for Winward Islands DHF are fitted to model 1.

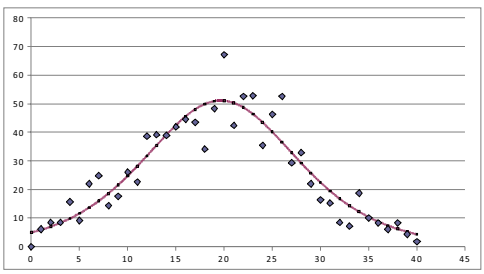

Figure 1-Theoretical bed occupancy with DHF patients in Leeward Islands[2]. Abscissa: Week since the starting of the epidemic; Ordinates: Percentage of theoretical bed capacity. Solid line was estimated from equation (1) using the Hooke Jeeves method.

Incidence data tend to be noisy, but cumulative incidence combine the advantages of a smooth filtering with faithfulness to original data; when little is known about the mechanisms of the ongoing disease, it is advisable to select the simplest models being capable of adapting to different possible variants. For cumulative data S(t), the Richards model can be valid [12-14]:

$$S(t)=K/(1+\exp(R(Tau-t))) \quad (2)$$

K corresponds to the total number of cases and equals

$$K= (S(0)*(1+\exp(R*Tau)) \quad (3)$$

Tau has the meaning of the peak time for incidence; the basic reproductive number R_0 (defined as the average number of secondary cases generated by one primary case) can be estimated as

$$R_0=\exp(T_g*r) \quad (4)$$

Where T_g is the transmission time, or the mean time between the appearance of symptoms in the primary case and the appearance of symptoms in a secondary case [12]. For dengue fever a value of T_g=2.71 weeks has been accepted [14].

There are several approximation methods to fit data into nonlinear models, such as Simplex, Hooke-Jeeves, Gauss-Newton, that have been implemented in different commercial statistical packages. These allow, in principle to simultaneously estimate several parameters from a data set. However, straightforward estimation beyond the domain of observed values with a highly nonlinear function, is not always reliable. As an example, Hooke Jeeves approximation for DHF in Windward Islands yielded cumulative incidence estimates surpassing 40 000, obviously a senseless value. In other words, data are behaving as those typical for ill-posed inverse problems. A practical way to try to deal with this kind of drawbacks is via limiting the space of possible solutions, and imposing to the them certain plausible requirements. In this case, the use of linearizations and manual stepwise estimation of values seems to be recommended. The rationale of our method is based on this philosophy.

Materials and Methods

General Description of the Prediction Method

The first step to linearize the Richards model is as follows. If R(Tau-t)>>1, the expression for S(t) (2) can be seen as S(t)≈ exp (R(t-Tau)), thus the value of R can be obtained from the slope of the curve log(S) vs time.

The next attempt to linearize is via a Taylor expansion of the exponential function. Expanding it, and having deal with realistic numerical values, we found that a good approximation for inverse values of expression can be:

$$(1/S(t))^{(1/4)} \approx -(R(t-Tau)) \quad (5)$$

The right side becomes equal to zero when t=Tau; thus from the relationship between the 4th root of the inverse of the cumulative data and elapsed time, it is possible to obtain a good guess for the time to the peak of the outburst (or "turning point" in the terminology of Richards model [14]) .

From the determination of Tau and R, the value of parameter K can be found from (2) for any value of time t. These estimates obtained "by hand" are subsequently entered as initial guess values for a Hooke Jeeves estimation of data into function (2). Two parameters are fixed an the third one is estimated. After several iterations a refined set of parameters is obtained. In some practical situations, the computer demanding nonlinear estimation step can be omitted.

Results

Dengue hemorrhagic fever in Leeward Islands, French Polynesia

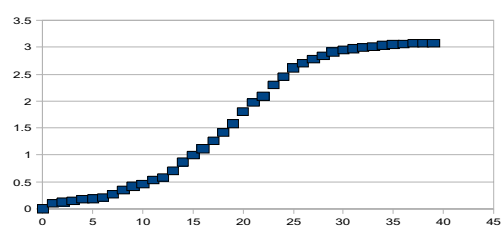

Figure 2-- Cumulative incidence of DHF in Leeward Islands [2]. Axes: Week since the star vs Cumulative incidence.

Hooke Jeeves estimation from the whole data set yielded: K=3.16, R=0.22, and T(weeks)=18.59.

The basic reproduction number (R_0) can be calculated as R_0=1.82 based on a 2.71-weeks transmission time (T_g) [14].

The application of the our method for early prediction based on data from weeks 3rd to 6th, yielded the following values (Table 1):

Table 1-- Early predictions for the Richards model parameters. DHF. Leeward Islands

Week	T	R	K
3	19.6	0.22	6.22
4	21.7	0.20	6.45
5	24.1	0.19	7.17
6	28.1	0.16	7.37
Geometric Mean	23.2	0.19	6.79

Assuming a transmission time of 2.71 weeks, a value of R_0=1.67 is obtained. As appreciable, predictions for T and R are satisfactory whereas for parameter K early estimates roughly doubled the final outcome. We regard that, in practical terms this information is valuable, especially considering that they were given 8 months before the end of the outburst. This value of R_0 is in agreement with other reports using the Richards model for its estimation [14].

Havana dengue-3 epidemic, 2001

The model estimated focumulative numbers for dengue fever cases reported for Havana [1] yielded:
R=0.31
Tau=18
K=12900
(R_0=2.31)
Early estimates for weeks from 3rd to 5th are shown in Table 2.

Table 2 -- Early predictions for the Richards model parameters. Dengue Fever, Havana.

Week	T	R	K
3	11.5	0.42	2661
4	15.33	0.38	6904
5	14.38	0.36	3786
Geometric Mean	13.64	0.39	4113

(R_0=2.88)

In this case the prediction for cumulative number of cases are below 50% of the actual value.

This discrepancy respect to parameter K might reflect our previous finding that Havana Dengue epidemic behaved as several independent outbursts. Curiously, this value is concordant with the predicted size of the early outbreak [11].

An attempt of true prediction: H1N1 in the US.

The possibility for real a priori predictions about an ongoing epidemic came with the advent of H1N1 flu epidemic in the US. Since the first notification of two H1N1 cases in April 2009, the Centers for Disease Control (CDC) were informing, on a daily basis, all the confirmed cases of H1N1 [15]. The information was freely available for any Internet user.

From the beginning of the outburst, predictions were based on a combination of estimates based on the linearizations described above, and then using these estimates as initial guess values for a Hooke Jeeves estimation.

Figure 4 is showing the cumulative cases numbers for the US H1N1 Flu outbreak.

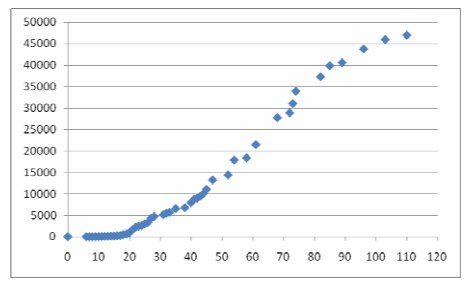

Figure 3-- Cumulative cases of H1N1 in USA(2009). Legend: Abscissa: Day since the starting of the epidemic; Ordinates: Cumulative cases. Redrawn from daily CDC reports [15]

A Hooke Jeeves estimation yielded the following "final" estimates, K=48234.3, R=0.070, and T(days)=63,67.

A value for T_g=2.3 is plausible for influenza A(H1N1) [15-16], corresponding to R_0=1.17, which is in agreement for the first early report in the range of R_0=1.4-1.6 for H1N1 in Mexico [17].

For days from 7th to 20th the following predictions were obtained (Table 3)

Table 3-- Early predictions for the Richards model parameters. H1N1 flu outbreak, US (2009).

Days	Tau	R	K
7	43.98	0.19	9197
8	37.68	0,228	9477
9	22.26	0.577	43541
10	20.9	0.575	20584
11	19.68	0.566	8108
12	28.07	0.30	9990
13	30.07	0.34	38919
14	28.76	0.336	21442
15	31.94	0.331	47121
16	31.97	0.327	44800
17	32.20	0.317	38013
18	29.35	0.328	20252
19	30.89	0.328	32863
20	30.78	0.328	31685

Geometrical mean values were:

Tau	*R*	*K*
29.3	***0.345***	***22576***

(R_0=2.11)

Discussion

Predictions in all the three examples differed from the "true" values obtained from complete data sets. In order to assess the reliability of the method, it is necessary to explore possible sources of disagreement.

Total number of cases (K). At early stages of the epidemic the parameter K is estimated as a nonlinear function of the estimates of Tau, R, and the number of cases at time zero (expression 2). Small errors in either Tau or R can lead to large differences in the estimated value of K. Moreover, the incidence reported at time zero can easily vary in a large relative quantity as it can be the difference between 1 and 2 cases, a situation very likely in everyday practice of data reporting. Thus early estimates for K between 50% and 150% of the "actual" value can be regarded as "acceptable". We expect that this range expected cases, predicted several months before the end of the outburst may be a useful figure for decision makers.

In data for Havana and French Polynesia, early predictions for Tau were between 70% and 130% of the final values. This was not the case for H1N1 in the US where the early estimate for Tau was 45% of the "final" value.

Similarly, estimates for parameter R were similar to "final" values for dengue outbursts in both French Polynesia and Havana (at least 75% of final values), but very divergent for H1N1 in US (almost 500%).

These differences between early predictions and final values can be due either to inaccuracies of the method or to specific features of the data.

We tried to explore method's predictions for parameters Tau and R using simulated data with two different parameters sets. One set corresponds to early estimations for H1N1 and the other set containing the final values. If the accuracy of early prediction is poor, it is to expect that no differences will be found between predictions for each data set.

These results are summarized in Table 4. Predictions reflect the geometrical mean from 19 estimations (from day 2 till day 20). As obtained, estimations in this range of values were clearly different between data sets. The largest difference was for parameter Tau and was 65% of the actual value (19 vs 29.6). For parameter R early predictions were very accurate, better than 97% of actual values.

Table 4-- Early Predictions for model parameters for two simulated data sets. Geometrical means for the first 20 days are shown.

Week	T	R
real	29.26	0.345
estimate	19	0.344
%	65%	100%
real	60	0.07
estimate	65.6	0.068
%	109%	97%

Thus simulation results suggest that differences in the estimates for parameter r are not due to inaccuracies of early prediction. An additional reason for this conclusion might be the dependence of estimates for r as the epidemic proceeded.

Data fitted to an exponential decay curve(r^2 =0.84), and might reflect a real reduction in parameter r, and, subsequently of the basic reproductive number as the epidemic proceeded. Given the nature of this epidemic with an unknown virus and the subsequent strong response by health authorities it is to expect a sharp reduction of infectivity after the initial days of the outburst.

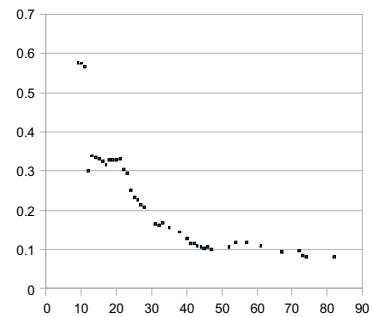

Figure 4-- Time evolution of estimates for parameter R estimated for reported H1N1 cases in USA(2009). Legend: Abscissa: Week since the starting of the epidemic; Ordinates: estimate for parameter R until the given day.

For parameter Tau , a trend towards the increase was also appreciated (r^2=0.91).

Taken together, the reduction in parameter R with increases in parameter Tau can be interpreted as a positive impact of public health decisions to fight the epidemic in the US. As it is known, reducing transmission rate without a reduction of a number of susceptibles leads to an elongation of Tau [8].

Limitations of the present study.

As any research with modeling of real data, the present study is limited by reporting accuracy and under-reporting. In the case of H1N1 in the US, only CDC confirmed cases were studied, these numbers reflect only a small fraction of real H1N1 cases. However, our results might be regarded as a good reflection of the real dynamics of the epidemic.

Limitations related to the method include model selection, limitations of theoretical approximations assumed, as well as those related to assumption abiding under real circumstances. Richards model has been applied for the description of SARS as well as dengue fever and seems to be a good first choice model for different outbreaks. To approximate nonlinear functions with coarse linearizations is always accuracy-costly, and randomness, can additionally hinder theoretical predictions. Simulations suggest that for realistic sets of parameters, excelent accuracy is chieved for R; acceptable predictions can be obtained for Tau and 50-200% or real K-values, based on early estimates from the first 3-5 weeks of an outburst lasting for almost 20 weeks. Assumptions are necessary for getting nice models, but they are not always congruent to reality [17].

Richards model is good for a spatially homogeneous population with parameters unchanged with time. We showed earlier that the 2001 dengue epidemic in Havana corresponds to several independent isolated foci (a nice result from spread prevention measures [11]). It is to expect that for the US, the outbreak can be represented as well as several relatively independent clusters. By actively fighting the spread of the disease, infection parameters change. This is not assumed in the model. The proposed method apparently detects changes associated to intervention measures. The main advantage of the method, is that it can be applied in any setting where an epidemic outbreak appears. A table of logarithms a pencil and a sheet of paper are the only requirements.

Thus a simple method has been proposed for early prediction of the fate of an ongoing epidemic. Its application to real data suggest that some of the discrepancies between early predictions and values obtained at the end of the outburst are not necessarily due to the poor accuracy, but to spatial heterogeneity of the outbreak, or to the impact of prevention measures taken during the time of the outbreak.

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Design and Assessment of a Common, Multi-National Public Health Informatics Infrastructure to Enable H1N1 Influenza Surveillance

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Abstract

Public health organizations in different nations face similar needs for gathering and analyzing population health data to detect and manage infectious disease outbreaks, including outbreaks of the 2009 Novel H1N1 Influenza A virus or "swine flu." This paper presents our progress to date on the design and assessment of a multi-national public health informatics infrastructure for data collection and disease surveillance. This initial work, under the aegis of an open health tools collaborative, lays the foundation for best practices in patient care and public health preparedness in the national health IT sector. This multinational collaboration is the first to identify essential electronic health record (EHR) data sets as well as standard public health informatics indicators to electronically monitor a notifiable public health condition internationally.

Keywords:

Semantic interoperability, Crosswalk, Public health informatics; H1N1, Surveillance, Electronic health record, EHR, Open health tools, OHT, Open source software

Introduction

With advent of a severe *Novel H1N1 Influenza A* pandemic in the 2009-2010 season, there is a need for improved awareness and response in national public health efforts. As a result of increased cases globally of H1N1 Influenza A, the need is both emergent and evident for increased and integrated multi-national surveillance and tracking for the pandemic.

Comprehensive large-scale surveillance requires the integration of health IT data streams including point-of-care electronic medical record data into national and international influenza surveillance systems [1, 2]. At present, there is minimal or no integration between the clinical delivery systems and public health organizations in the organizations and national settings studied, a gap targeted in the focus of this work.

Recognizing this gap, this study sought to address the following problems: (i) identifying what are the known national-level data information sources within countries (ii) coordinating overlapping public health informatics efforts across nations in the face of limited budgets for response; (iii) the feasibility of analyzing public health data in a cross-national manner. This paper is designed to help provide an insight into the international e-health information streams and data sets available to allow consistent world-wide surveillance and assist in bridging this identified gap between clinical delivery and public health contexts.

This collaborative endeavor identified the existing national data streams that can be used to answer surveillance questions as well as identify indicators of importance to public health management of influenza. The multinational collaboration is comprised of individuals from various United States institutions and worldwide public health systems, including the [US] Centers for Disease Control and Prevention (CDC), the [US] Indian Health Service (IHS), and the Office of Health Protection (OHP), Australian Government Department of Health and Ageing Canberra, Australia, in all case bridging both informatics and epidemiology divisions of each organization.

The objective of the multinational collaboration is to foster sharing among major e-health programs globally to promulgate common knowledge for health information technology best-practices in patient care and public health preparedness. The initial focus of this study has been centered on the determination of de-identified health IT data streams contained within point-of-care electronic medical records. These data streams provide a content source of rich medical information that the authors are asserting can be a critical asset for use in national influenza surveillance systems to prepare for and respond to the worldwide pandemic. Moreover, our findings are that sufficient commonalities exist

among existing health IT data streams in different organizations so as to allow for their use in cross-national pandemic influenza surveillance. This information is a necessary foundation for the dynamic sharing of information across the different institutions and countries involved. Based on the feasibility analysis presented here, further work will continue in order to develop a set of common data specifications for e-health-based large-scale multi-national surveillance systems.

Methods

The design and assessment method used in the study consisted of four main steps. First, a set of three test cases of national-level public health systems were chosen through which to conduct the assessment. These were the US Indian Health Service, the Australian National Influenza Surveillance Systems, and the United Kingdom Health Protection Agency.

Second, an exercise to evaluate the existing e-health data streams available in the context of each health system was undertaken. Third, a consensus set of key Novel H1N1 pandemic surveillance indicators was selected for the underlying multi-national surveillance system design. Fourth, each indicator in the consensus set was cross-walked against the e-health data streams to evaluate the feasibility of integrating these streams for multi-national pandemic surveillance.

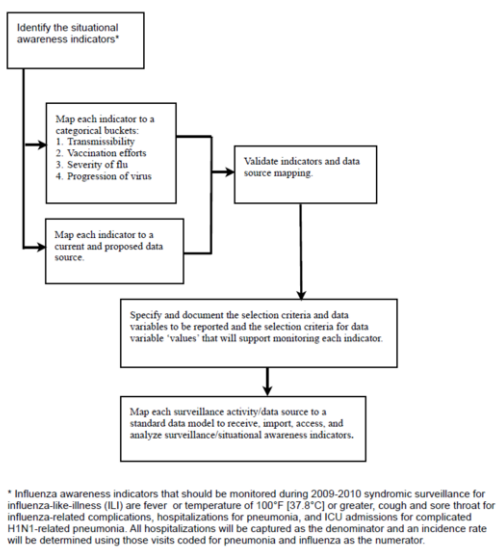

Figure 1 - Design and assessment process for an e-health-based pandemic surveillance system

Results

Each of the three health systems chosen were comparatively evaluated against the coupling of population based and individual-patient based health data streams used for surveillance. This relationship spanned from very tight coupling at the US Indian Health Service, to indirect coupling in the UK NHS, to traditional parallel data streams in the Australian health system (see Table 1).

Table 1 - National Health System Data Streams

Health System	Integration Level	Representative Data Streams
Indian Health Service (United States)	Tightly integrated population and patient based data streams with record-linked aggregates	Resource and Patient Management System (RPMS) and Point of Care (POC) EHR – Electronic Health record with integrated public health functions including syndromic and case-based surveillance
Department of Health and Ageing (Australia)	Traditional hybrid system with sentinel, case-based, and population-based surveillance without row-level case reporting	- Laboratory confirmed influenza surveillance - GP sentinel surveillance - ED sentinel surveillance - Laboratory surveillance - ICU surveillance - Community absenteeism - National syndromic call centre surveillance - Online syndromic survey
National Health Service (United Kingdom)	Patient-based national identifier-linked case reporting with de-indentified aggregates	- NHS Care Record Service ["Spine"] for case-based and sentinel provider surveillance - Call Center for Syndromic Surveillance

The varied level of coupling between the population aggregate and the individual patient level has implications for the ability to effectively integrate large-scale surveillance systems with traditional case-based and sentinel provider surveillance. For instance, the US Indian Health Service Resource and Patient Management System (RPMS) is an integrated health IT solution in use nationwide within the entire health system for native Americans. The RPMS provides the ability to capture individual patient- specific data at point-of-care that can then be used for public and population health management and surveillance. This allows direct and seamless "drill-down" from population aggregates and the automated linkage of syndromic surveillance with case notification of confirmed cases.

On the other hand, the Australian Department of Health and Ageing (Canberra) utilizes a traditional hybrid approach with multiple systems as data stream sources for their national influenza surveillance system. The case-specific streams include laboratory confirmed notifications from the National Notifiable Diseases Surveillance System (NNDSS), and a national online web-enabled outbreak case reporting system (NetEpi). The de-identified aggregate surveillance systems include a general practitioner sentinel surveillance system, Emergency Department presentations of ILI at sentinel

hospital sites, sentinel community absenteeism, national call centre data [4] and an online self-reporting syndromic influenza surveillance system, FluTracking [5]. The integration of de-identified aggregate data with case-specific data on a national level requires a record linkage algorithm whose ultimate validity is constrained by the levels of de-identification and aggregation.

This variation in the coupling characteristics of the health IT data streams provided an objective constraint against which to design the indicator set for a multi-national pandemic surveillance system. The indicators had to be specific enough to be valid and general enough to be stable and reportable from both tightly-coupled as well as hybrid data streams. For this step, an iterative process was used to identify a set of Influenza-like Illnesses (ILI) and H1N1 indicators that used appropriate standards and which would be reportable across the range of health IT data steams.

The indicators were also chosen to reflect a range of epidemiologically important categories including ILI symptomology, transmissibility/progression, severity, vaccine effectiveness, and healthcare utilization. Indicators considered in the study included both natural language processing (NLP) and formal terminologies such as ICD9 and, ICD10. The group first identified situational awareness indicators that could be monitored for syndromic surveillance of influenza-like-illness (ILI). The indicators identified for pandemic multi-national surveillance of ILI were: (i) fever or temperature of 100°F [37.8°C] or greater, (ii) cough and sore throat for influenza-related complications, (iii) self-report of fever and other ILI symptoms. For transmissibility/progression, indicators were (iv) disposition from outpatient to inpatient when hospitalization occurs with (v) specific indication of hospitalizations for pneumonia. For severity, indicators chosen were (vi) mortality rates associated with H1N1/ILI cases and (vii) ICU admissions for complicated H1N1-related pneumonia. Lastly for utilization and vaccinations, indicators were (viii) health care utilization (number of beds utilized and intensive care units-ICUs), and (ix) adverse events associated with the H1N1 vaccines.

Lastly, a collective cross-walk of these consensus data indicators was carried out against the national health system data streams to assess the feasibility of multi-national pandemic surveillance. Of the set of 27 indicator-data-stream combinations, the three different national health IT systems were able to satisfy 24 reporting streams, for a score of 89% for the eight indicators chosen. Secondly, the data collection and evaluation for the indicator selection resulted in the identification of common data elements and alignment of data sets to candidate disease indicators to foster semantic interoperability for H1N1 electronic multi-national surveillance.

Discussion

One central challenge for the design of national surveillance systems in the medium term is to reconcile (a) the specificity of older, established surveillance data streams based on clinician-diagnosed case reports or sentinel provider syndromic surveillance with (b) large-scale, higher-throughput, timelier but less specific automated surveillance data based on national health IT infrastructure [6].

During a significant epidemic the sensitivity and specificity of these laboratory based and syndromic influenza surveillance systems may need to be optimized. Each type of system has advantages. For example, the timeliness of syndromic surveillance may outweigh its lower specificity than clinical confirmed or laboratory confirmed surveillance systems in certain situations, such as during an emerging outbreak. Once significant clusters are identified during these syndromic systems it then may be necessary to confirm laboratory evidence for each cluster. During a pandemic, it may not be necessary to gather laboratory evidence on every case.

Recognition of differences among international surveillance systems offers the possibility to change the case definition based upon the sensitivity and specificity of early data from countries initially involved in an epidemic situation. Preparation for an epidemic or pandemic from a novel subtype, international cooperation to identify data elements and proposed data monitoring may help increase sentinel awareness and more timely interventions. A further evaluation has begun on refining the indicators to the best level of granularity in terms of case definitions and geographic reporting segments to find the optimal trade-off between specificity and generalizability across the different health IT systems.

Conclusion

This work includes input from participating countries, but is limited to participants from the respective national e-health and surveillance authorities. Future work would benefit from involvement of additional countries. This work also points to the need for integration of public health surveillance within the point of care HIT solutions. Development of meaningful use criteria internationally that encourage the addition of public health functionality within electronic health records may be a critical path for long term improvements in public health surveillance. Similarly, future work such as the development of open-source software components to facilitate the extraction and transformation of identified indicators may promote multinational participation and involvement in pandemic influenza surveillance. This multinational collaboration around surveillance and health IT infrastructure may initiate a more widespread conversation on the critical need for integration of public health programs and health information technology infrastructure development.

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Table 2 - The table summarizes the flu specifications where the empirical data set of influenza indicators are cross walked and validated.

Indicator		Population under surveillance	Common Indicator Definition	Indian Health Service – Integrated Health System	Office of Health Protection, Australian Nat'l Influenza Surveillance Systems	United Kingdom Health Protection Agency
Monitor Transmissibility of Flu	Syndromic	Primary Care	▪ ILI - specific symptomology – fever, throat pain or sore throat, cough	▪ ICD 9 Code definitions: fever 780.6, 780.60, 780.61; pain, throat 784.1, 462; cough 786.2 ▪ 100% of charts reviewed electronically on a daily basis and exported to national epi center each day	▪ GP Sentinel Surveillance, ILI = fever, cough and fatigue	▪ Sentinel Primary Care Surveillance, Royal College of General Practitioners, ILI, pneumonia, acute bronchitis
		Community Based Self Reporting			▪ National Call Ctr Hotline; FluTracking (syndromic survey, self-reported illness); ▪ Sentinel absenteeism data from national employer ▪ Sentinel childcare absenteeism	▪ National Health Service nurse-led call centers, Community Syndromic Surveillance, colds, flu, fever
	Lab Confirmed	Public health notifiable disease surveillance system	▪ Laboratory confirmation of influenza	▪ Laboratory results at point of care in RPMS HIT system	▪ National Notifiable Diseases Surveillance System	▪ First few hundred surveillance system and enhanced surveillance system
		Sentinel School-based syndromic surveillance	▪ILI	▪ ILI with swabs at point of care in reservation based schools using RPMS HT system	▪Not available at national level	▪ Boarding schools in Medical Officers of Schools Association and HPA Scheme
		Primary care	▪ Sentinel primary care surveillance with virilogical monitoring	ILI with swabs when indicated clinically	▪ILI with swabs from a sample of patients in some regional areas	▪ ILI with swabs from a sample of patients
		Hospitals	▪ Disposition from outpatient to inpatient (hospitalizations)	▪ Incidence rate: hospitalizations (as the denominator) and visits coded for pneumonia / influenza (numerator)	▪ Emergency Department sentinel hospital surveillance	▪ All patients admitted to hospital with severe respiratory illness, with virological monitoring
Vaccination	Vaccine effective-		▪ Adverse events - to the H1N1 vaccine	▪ Adverse events instructed by the Food and Drug Administration	▪ Adverse Events Following Immunization Surveillance ▪ Adverse Drug Reactions Reporting	
Severity Measure	Mortality Rates - Virulence	Laboratory surveillance networks	▪ Mortality rates-electronic death reporting ▪ Subtyping, antigenic characterization, sensitivity / susceptibility to anti-virals	▪ Death reporting not utilized due to loss to follow-up. ▪ Delayed monitoring via Death Certificate Data	▪ Deaths data from sentinel hospital surveillance; ▪ ICU admissions and clinical severity; ▪ Drug resistance, antigenic characterization, shift and drift	▪ Death registrations, total respiratory deaths, mortality excess estimation; ▪ HPA Regional Microbiology Network and National Laboratory Reporting Scheme Antiviral Resistance Monitoring and Viral Sequencing
Healthcare Utilization			▪ Utilization of hospital beds, ICUs, and respiratory ventilators	▪ RPMS – Resource and Patient Management System collects this data, but it is not utilized.	▪ Hospital bed capacity, ventilator usage and extracorporeal membrane oxygenators	

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Towards A Multi-Level Game Model for Influenza Epidemics

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Abstract

Although game theory has been first invented to reason with economic scenarios with rational agents, it has since been extended into many other fields including biological and medical sciences. In this paper we propose to model the interactions between virus and human in an influenza epidemic in a two player, adversarial game scenario with multiple levels of abstraction. As conventional game representations are inadequate in this complex problem domain, we propose Object Oriented Multi-Agent Influence Diagrams (OO-MAID), a novel graphical representation for multi-level games, which takes advantage of both organizational information and probabilistic independence in the problem domain. The OO-MAID representation can be readily applied in similar medical situations exhibiting hierarchical and probabilistic independent characteristics. We demonstrate the feasibility of this novel approach with sample models in the domain.

Keywords:

Game theory, Influenza, Knowledge representation

Introduction

Influenza or "flu" is one of the most common diseases found in both developed and developing countries, causing tens of thousands of deaths and huge financial losses each year. The damages are even greater in the case of a flu epidemic, e.g., the recent spread of H1N1 virus. While it is one of the most studied diseases, we have yet to be able to effectively deploy various management strategies to control the spread of seasonal or epidemic influenza.

The current modeling techniques for influenza can be classified into three categories: deterministic dynamics functions [1,2], complex network theory [3,4], and stimulation based on mathematical spreading models and population distribution [5]. Most of these approaches assume fixed virus characteristics, known consequences of policies, and/or unbound resources, which are often unrealistic. In addition, most of the research emphasizes on the epidemiological impact, without details on lower level interactions, such as clinical and microscopic interactions. In this paper, we propose to model the holistic interactions between influenza viruses and human populations in a game theoretic framework.

Game theory provides a mathematical framework for determining what strategies are, according to pre-defined utilities, most beneficial for agents interacting with each other in a partially observed environment. While it was first proposed to analyze rational behavior in economics, its adaptation in the biological domains, i.e., evolutionary game theory [6], enables reasoning with populations under revolutionary pressure, instead of rational agents. In this context, players are individuals in a large population engaging in a series of independent game play. Strategies may be any phenotypic characteristics, such as tail length in certain bird species; or behaviors, such as the instinct of defending territory. Payoffs, or utilities, for the players are additional or reduced "fitness" a player receives after each game play, using some set of strategies. The concept of Nash Equilibrium is replaced by a similar concept of revolutionary stability, and the associated concept Evolutionary Stable Strategies, defined as the set of strategies that, under the current circumstances, cannot be "invaded" by mutant strategies [6].

Modeling Influenza as a Game Scenario

In any game, there are three essential components: players, strategies and payoffs. In addition, there may exist random variables in the problem domain that are beyond the control of the players, who may however observe some of their values. In this section we identify the three components as well as possible random factors in the proposed influenza game scenario, and examine potential challenges and issues in modeling and reasoning in the game.

As the interactions between influenza virus and human society is a complicated process involving a large number of random variables in multiple levels of abstraction, we divide the possible factors and interactions into three levels of different granularities: microscopic, clinical, and epidemiological. In all three levels, the players would be influenza virus and human. The strategies, utilities and other factors, however, may differ.

At the microscopic level, the infection of influenza in a human host is the interactions between influenza virus and human body cells. In general, systematic infection of a host by influenza virus depends on factors [7,8] such as: matching hemagglutinin receptors on the host cell surfaces, availability of protease for virus post-entry cleavage, cleavage properties of virus surface protein precursor (the above three factors facilitate the entry of virus into a host cell, in a process called

endocytosis), suitability of the host cell for viral replication, and release of replicated viruses into bloodstream for further infection, which is related to virus neuraminidase surface protein. The immune system responds to virus infection by two mechanisms: innate response, which respond to infections in general; and adaptive immune response, which keys specifically to some particular virus strain after an infection. The acquired adaptive immune response against a specific influenza virus strain is temporary, waning with time. In response to immune anti-viral mechanisms, influenza virus may evolve to acquire mutant genes that can suppress the immune response [9].

In a game model for the microscopic level, strategies for player virus are characteristics such as HA and NA configurations, while strategies for human player are characteristics such as immune responses. The payoff at this level is the extent of the infections, which can be modeled as average virus count in the infected host.

At the clinical level, we consider medical intervention in influencing infection cases. Treatments for infected cases usually aim for symptom relief and do not directly target viruses, although anti-viral treatments may be necessary in immno-compromised patients. Therefore, for the population at large, the most important step taken during a flu season is prevention. Clinical prevention of influenza can be divided into two categories: vaccination and prophylactic use of anti-viral drugs. Vaccination is highly effective when the vaccine matches with the circulating virus strand. However, the fast mutation of influenza virus means that there is usually a genetic drift of the circulating virus strand. Prophylaxis with anti-viral drugs is less sensitive to genetic drift; still, drug resistance may arise from its usage. We show a sample game models the interaction in Table 1.

Table 1- Sample game model in the clinical level

	Drug-resistant	Non-resistant
Anti-viral	$c\,\beta$	$(1 - \theta)\,\beta$
Vaccination	$c\,(1 - \lambda)\,\beta$	$(1 - \lambda)\,\beta$

Let β be the baseline transmissibility of influenza virus, c be the factor of change in transmissibility after drug-resistant mutation, λ be the efficacy of the vaccine, and θ be the efficacy of prophylaxis. The human player may choose using anti-viral prophylaxis or vaccination. And virus may mutate to become drug-resistant. The four possible scenarios are:

1) Anti-viral prophylaxis is chosen; virus strain mutates to become drug-resistant. In this case, the prophylaxis would be ineffective. However, studies also show that mutated drug-resistant virus strains have lower transmissibility than wild-type virus strains [5]. Therefore, the transmissibility in this case is reduced to $c\,\beta$. c may be as low as 10% [5].

2) Anti-viral prophylaxis is chosen and virus strain does not mutate. In this case the transmissibility is reduced by effective prophylaxis measure. The payoff in terms of transmissibility is $(1 - \theta)\,\beta$. Currently θ (for neuraminidase inhibitors) is around 70% [10].

3) Vaccination is chosen; virus strain mutates to become drug-resistant. The payoff as transmissibility is $c\,(1 - \lambda)\,\beta$.

4) Vaccination is chosen and virus strain does not mutate. The payoff in this case is $(1 - \lambda)\,\beta$.

This simple model may help to explain the low level of emerging drug-resistant strains <1% [11], as strategy "non-resistant" dominates "drug-resistant" for virus player. A complete model would include many more factors and provide a clearer picture of the interactions.

At the epidemiological level, the factors relevant to the extent and severity of an influenza epidemic are well studied. Some of these factors are: transmissibility, a characteristic of the virus strain, which determines how easily the virus can spread in a population; infectious period, the duration that an infected case continues virus shedding (Combined, transmissibility and infectious period can be modeled as a function of infectiousness over time.); regeneration number, which is defined as the number of secondary infections generated from a primary infection case; contact rate, the number of people a person gets into contact in a fixed time unit; quarantine efficacy, which can be defined as either the portion of infected people being quarantined, or the degree that their infectiousness is reduced.

At this level, payoff for the human player may be defined as a cost function consisting of disease management cost and extent of virus infection in the population. For the virus player, the payoff may be a similar function of the extent of infection.

From the proposed modeling approach, we observe that a complete game model consisting of all three levels and all the important factors is a very complex scenario. Therefore, neither of the traditional game representations, including the normal form, which is a table listing payoffs according to different combination of strategies; and the extensive form, which is a game tree with payoffs at the leaf nodes, is feasible. They both suffer from the curse of dimensionality and omit potentially important structural information in the problem domain. A new game representation is needed to address the characteristics in this specific problem domain.

Graphic Representation for Multi-Level Games

A related work that addresses part of the complexity is the Multi-Level Games representation proposed by Hausken [12]. It provides a framework for analyzing game situations where there are different levels of organization. However, at each level, the strategies and payoffs in the sub-game are still represented in either normal or extensive forms. Therefore it is unable to take advantage of any locality features that often exist in complex game domain such as the proposed influenza game scenario.

A representation that does utilize potential probabilistic independencies in the problem domain is the Multi-Agent Influence Diagram (MAID) [13], a probabilistic graphical game representations. It takes advantages of the Influence

Diagrams' ability to represent structural dependencies in the problem domain. However, when dealing with problem domains with multiple levels of organization, the MAID approach requires all hierarchies to be flattened into a single level structure. While this is theoretically possible, it is often inefficient or even intractable when the number of players or levels of organizations are large.

While neither approach alone can satisfy the requirements for the proposed influenza game scenario, a combination of the two addresses both organization and probabilistic independencies issues. Therefore, we propose the Object-oriented Multi-Agent Influence Diagrams (OO-MAID), which is based on the multi-level game concept and the MAID formulation. An OO-MAID is probabilistic graph segment that models an uncertain game situation with multiple levels and multiple agents. Each segment has a set of well defined input and output, which appear as chance nodes in other graphs. In the next section, we formally describe the syntax and semantics of OO-MAID.

Definitions and Semantics

We base our definition of multi-level games on an adaptation of Hausken's work [12]. In this formalism, a multi-level game consists of three components – multi-Level game structure, multi-level game form and finally, multi-level game. All three components are extended in the OO-MAID representation as follows:

Multi-Level game structure, which is a recursively defined directed graph $G = (N, A)$, where N is a set of nodes and A is a set of arcs. Three types of nodes are allowed in set N - chance nodes, decision nodes and utility nodes. We assume that there exists one and only one utility node for each player at each level. The outermost graph (level 0) is labeled G^0, which organizes players. Player A^{L}_{i} at level L plays the game with other players at the same level. In the proposed influenza game scenario, the game structure represents the factors in the whole problem domain, with decision nodes denoting strategies, chance nodes denoting random variables and utility nodes denoting payoffs. The arcs between the nodes share the established semantic meaning in the Influence Diagrams, namely, an arc pointing into a chance node or utility node represents conditional dependence, while an arc point to a decision node represents information availability.

***Multi-Level game form*,** which is a combination of multi-game structure and feasible (pure) strategies S. Therefore, player A^{L}_{i} has strategy domain S^{L}_{i}. This corresponds to the set of possible values for the decision nodes at level L. A decision rule for node D is a function that maps each instantiation pa of Pa(D) (set of parents of D) into a probability distribution. For agent A^{L}_{i} at level L, the assignment of a decision rule to each decision node is called a strategy. In the influenza game scenario, S denotes the possible "strategies" that the virus or the human player may use in the game play in a certain level. Each player may choose to use single strategy or a set of different strategies with different probabilities.

***Multi-Level game*,** which is a multi-game form together with defined payoff structure. In Hausken's definition, each player's (at any arbitrary level) payoff consists of two components: a "within-group" payoff, coming from the sub-game at the player's level, and a fraction of payoff distributed downwards from higher level games. Here, we adopt a simplified case where only "within-group" payoffs are considered. Payoff in the influenza game scenario differs between levels, e.g., for the human player, the payoff in the clinical level may be an individual's well-being after being infected with flu virus, but the in the epidemiological level, the payoff could be a cost function involving the studied population.

With our definition, the basis of modeling a multi-level game starts with building the game structure, which is a directed acyclic graph consisting of basic nodes and complex nodes. There are three types of basic nodes, the chance nodes, decision nodes, and utility nodes, with conditional probabilistic table (CPT), decision rule and utility function, respectively. A complex node is a self-contained OO-MAID segment that models a sub-game in the problem domain and has a set of input nodes and output nodes. Each agent is represented by its corresponding decision nodes in the graph, and may have multiple utility nodes. The overall utility for the agent is simply the summation of all his utility nodes U_{a}^{L} at level L.

An example of a simple multi-level game segment is given in Figure 1, which shows a simplified influenza game model at the clinical level. M denotes the game play in microscopic level, which is an OO-MAID segment contained in the graph. The output of M is observed by both players at the clinical level and has an effect on their utilities. We further define the "output" of

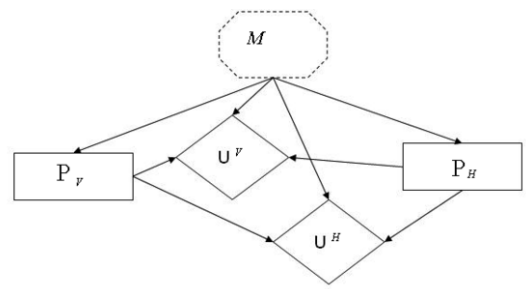

Figure 1- A sample OO-MAID model

an OO-MAID segment below.

We consider an OO-MAID segment to be a stochastic function that converts a set of input to a set of output variables. It is recursively defined as follows: for each complex OO-MAID node X^L at game level L, it consists of

Input: a set of chance nodes or decision nodes in(X^L) defined in X^{L-1}, i.e. for node v in in(X^L), Pa(v) are in graph X^{L-1}. However, they may have children nodes in graph X^L. In addition, v is considered chance nodes in graph X^L.

Output: strategy profile σ, expected payoff EU(X), output chance nodes Out(X^L). The output nodes are defined in X^L, and may be decision nodes or utility nodes in X^L. But they are treated as chance nodes in X^{L-1}.

To map the distribution of input node set to distributions of output nodes, a complex OO-MAID node is itself a complete OO-MAID which may contain basic nodes and complex nodes.

A complex OO-MAID node that contains only basic nodes is simply a MAID. Its correctness is established from the work on Multi-Agent Inference Diagrams. Between levels, we show below that nodes inside a complex are independent of nodes outside, give the input and output nodes set.

Let X^{L-1} be a complex OO-MAID node containing complex node X^L, we prove that node set N^L in X^L are independent of node set $N^{L-1} - N^L$, given the input/output set of X^L.

Proof: First we consider node types in the input/output set of X^L. In the previous section, we have defined the decision rule to be a function that maps each instantiation of D's parents into a probability distribution for node D, therefore it has the same form as a conditional probability distribution. For utility nodes, the utility function also may be considered conditional probability distribution with probabilities of 1 and 0. Therefore, we may treat both decision nodes and utility nodes in similar ways to chance nodes.

Now, consider any path between X^L and $X^{L-1} - X^L$, which contains adjacent nodes n_1 in X^L and n_2 in $X^{L-1} - X^L$. There are two possibilities for the arc direction between n_1 and n_2. If there is an edge from n_1 to n_2, then n_1 is in the output set of X^L. And n_1 does not have converging arrows centered on itself. Applying Baye's Balls rule [15], the path is blocked when conditioning on n_1.

If there is an edge from n_2 to n_1, then n_2 is in the input set of X^L. And n_2 does not have converging arrows. The path is blocked when conditioning on n_2.

With the definition we may now extend the complex node in Figure 1. An example is shown in Figure 2. This is a segment that has one input node and two output nodes.

Computing Nash Equilibrium

The main computation task in any game form is the calculation of the Nash equilibrium. In multi-level games, the definition of the Nash equilibrium can be tricky considering the players and payoffs in all the sub-games. A definition of multilevel Nash Equilibrium is given in [12]. In our proposal, because of the simplification of the "within group" payoff structure and the probabilistic independence proved in previous section, we can use the conventional definition of a single player achieving no benefit from changing strategy, given the strategy of the other players being fixed.

In the single level representation of MAID, the concept of strategy relevance and *s-reachability* is central in the computation of Nash equilibrium [13]. These two concepts both hold for the OO-MAID framework. By definition of the OO-MAID complex node, which maps each instantiated set of pa for Pa(X), the mapping then has the same form of conditional probabilistic distribution. Therefore a complex node can be collapsed into the output node set, with pre-computed distribution function. In addition, as the output nodes are all considered chance nodes in higher level graph, they do not change the topological order of the decision nodes in the higher level.

For games consisting of only basic nodes, e.g., the microscopic level, we may break up the problem domain according to

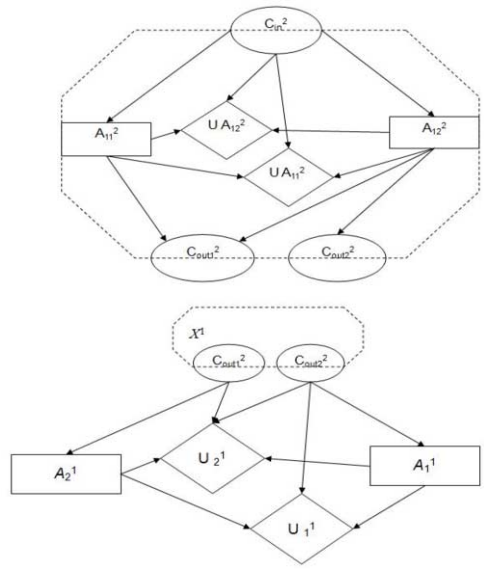

Figure 2- The expanded graph for X' in Figure 1, and an encapsulated X' viewed from the higher level.

strategic relevance, the sub-graph, consisting of decision nodes that are strategically relevant (denoted as a component graph), is then converted to a regular game tree and standard game solver may be applied [13]. As finding a Nash Equilibrium for a game tree is super-linear, this reduces the computational time. A straightforward "divide and conquer" algorithm and an approximate algorithm have been proposed [14].

For games consisting of both basic and complex nodes, we propose a recursive inference algorithm, enabled by probabilistic independence of a complex OO-MAID node given its input and output node set. The algorithm below makes use of the algorithm proposed for MAID [14], denoted as ComputeMAID. An extra step at the end of ComputeMAID is added to return updated probability distribution of the nodes defined in the output node set of a complex OO-MAID node, after applying the strategy profile calculated from ComputeMAID.

Algorithm

```
ComputeOO-MAID (OO-MAID X)
    If X contains only basic nodes
        ComputeMAID (X)
    Else
        For each complex node Xi' in X
            ComputeOO-MAID (Xi')
            Update distributions of output node in Xi'
        // X now contains only basic nodes
        ComputeMAID (X)
```

Comparing OO-MAID with MAID, while both take advantage of the "divide and conquer" concept, the built-in conditional independent complex nodes in OO-MAID simplify the topological ordering process by encapsulating decision nodes from sub-games, and also enables pre-computation.

Towards A Complete Influenza Game Scenario

With the introduction of OO-MAID, each level in the proposed influenza game can be modeled in one or more OO-MAID segments, with the graphical representation at each level able to utilize any structural independencies among the random variables at that level.

A complete model with all three levels and most of the relevant factors is currently in progress. Firstly the three different levels will be constructed separately, each with its own in-level strategy set, random variable set and payoff function. The connection between levels will be made possible with relevant input/output nodes. For example, a "strategy" chosen by the virus in the microscopic level, the extent of mutation, or deviation from prevailing strain, will be reflected as averaged virulence in the general population in the clinical level. Further domain knowledge will be elicited in later stages of the model construction.

Conclusion

In this paper we show the potential and feasibility of modeling an influenza epidemic as a game situation involving influenza virus and human society. As the problem domain is highly complex with multiple levels of granularities and large number of random variables in each level, the conventional game representations are inadequate in this situation. To address both the "multiple levels" and "potential structural independency" nature of the scenario, we propose OO-MAID, a novel probabilistic graphical representation for multi-level games. This framework has the potential of taking advantages of possible conditional independences as well as organizational hierarchies in a problem domain. It is based on single level probabilistic graphical game representations, with extensions to allow modeling of a game scenario in different levels of abstraction. Although it's motivated from the influenza game scenario, it is a general game representation that may be applied to other program domains exhibiting both characteristics.

To complete the proposed game model, further domain knowledge on influenza epidemics must be solicited from healthcare experts.

Future work also includes extension of the payoff definition. Currently we only consider localized payoff (or utility) for each agent within his own game level. While this greatly simplifies computation and probabilistic independence analysis, it is a very restricted assumption that may not be satisfied in many real life complex game scenarios. In the influenza game scenario, for example, an individual's payoff is also associated with the payoff in the general population, as one of the factors, percentage of the population infected, greatly influences an individual's chance of being infected.

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Is population-oriented IT supported preventive care in general practice feasible? A database study

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Abstract

Background: Introducing a clinical decision support system (CDSS) in general practice that provides broad support based on all available guidelines for preventive care might dramatically increase the workload of a general practitioner. Aim: We evaluated the potential effect on workload of a CDSS that aims to support the whole breadth of preventive guidelines currently used in The Netherlands. Methods: We analysed the guidelines of the Dutch college of General Practitioners (DCGP) for preventive activities, developed a CDSS based on the guidelines and studied the behaviour of the system on real patient data. Results: 20 of the 87 DCGP guidelines contained data on preventive activities which was incorporated in the system. Out of 485 793 patients, the system indicated that for 138 885 (28.6%) a preventive action was needed. Conclusion: A CDSS that aims to support the whole breadth of preventive activities in general practice will have a substantial effect on workload. Further tailoring of the support will be needed.

Keywords:

Clinical decision support, Electronic patient records, Prevention.

Introduction

Prevention is often positioned as a disease-oriented activity (prevention of cardiovascular diseases, prevention of diabetes, etc.). Guidelines are disease or risk specific, resulting in overlapping or sometimes even conflicting recommendations. Disease-oriented organizations typically target a limited set of diseases reflecting their own focus. Continuous medical education is often also characterized by disease orientation when preventive care is discussed. In day-to-day care, health-care workers and even the target populations themselves have to integrate (or select between) the separate preventive activities for the different risks or diseases, and, in the context of what is locally feasible, and merge these preventive activities with other activities (such as curative care). Faced with limited resources, a general practitioner, for example, may have to decide whether preventive activities in the context of diabetes should take priority over prevention of cardiovascular diseases.

Research in the past years has shown that Information and Communication Technology (IT) is able to support practitioners and changes physicians' behaviour [1, 2] Already in 1989, the first review paper that also included IT-based interventions suggested that of all known interventions, computer-supported interventions were most effective and costs efficient [3]. In subsequent years, randomized trials studied the impact of IT-based interventions. As a result, most researchers will now accept that IT can play an important role in the implementation of guidelines[4]. IT has also been successfully used to support prevention [1, 4].

The use of IT in the context of prevention has been characterized by a disease-oriented approach. The resulting software modules are aimed at supporting a practitioner in an individual disease domain - resulting in separate, individual software applications. In the Netherlands [5], for example, the general practitioner is confronted with a range of separate modules: a software module for cardiovascular screening, another module for diabetes, yet another for influenza vaccinations, still another for cervical smears, etc.. The general practitioner often decides to focus on just a few diseases (for example, cardiovascular disease), and uses the software available for that disease. That choice for a given domain, however, may have as consequence that another disease or risk will receive less attention. Ideally, the practitioner should tailor, within the constraints of available time and possibilities, preventive activities to the local population. This process of tailoring to the local population needs to be informed by both the total set of possible preventive activities and the specific characteristics of the local population [5]. In a resource-limited setting, allocation of resources should be a careful and explicit decision based on local circumstances. At present, IT tools typically do not aid the practitioner in selecting, from all the possible preventive activities, the most suitable to his or her population. The need to develop an intervention strategy that enables an individual practitioner to tailor preventive activities to his or her local population and local circumstances is often ignored.

Our objective is to assist the practitioner with the whole range of possible preventive activities and subsequently aid him or her in tailoring these activities to his or her own local circum-

stances. The first step in this approach is to confront the practitioner with the consequences of all the available guidelines. That is, not until the physicians has realised what it would mean to actually conduct all these activities will he or she be confronted with the limitations posed by their own environment (e.g. financial constraints, limited time available, or patient compliance). Guidelines are often developed as individual guidelines, but the consequences of a collection of guidelines with the resulting possibly exponential growth of activities are typically not studied. In order to gauge the consequences of implementing a collection of guidelines, we need to gain insight in the actions that will need to be performed once the IT intervention is implemented.

Various authors have described critical success factors when introducing any computerized decision support system (CDSS) into daily practice[1, 6]. These include integration of the software with the electronic patient record, performance and enabling general practitioner workflow. It is, however, interesting to observe that the consequences of a CDSS on workload are often not addressed. The fact that the introduction of decision support carefully tailored to workflow might have as a consequence a prohibitive increase in workload is of ten not considered.

In this paper we evaluate the potential effect on workload of a CDSS that aims to support the whole breadth of preventive guidelines currently used in The Netherlands.

To understand the consequences of a CDSS supporting all the available preventive actions in guidelines, we first need to analyse the guidelines, secondly need to develop a system based on the guidelines, and, finally, based on actual medical records, study the behaviour of that system based on real patient data.

The objective of this study is to understand the practical consequences the CDSS would entail if physicians would introduce the system in daily care.

Materials and Methods

Design overview

Our study analyzed the guidelines of the Dutch College of General Practitioners (DCGP) on preventative activities, formalized the recommendations into a CDSS framework, and studied the recommendations of the CDSS based on the electronic patient records of general practitioners.

CDSS knowledge base

In the Netherlands the DCGP publish and maintain evidence based guidelines for use in the Dutch setting [7]. The guidelines have a high acceptance and penetration amongst Dutch general practitioners. The guidelines advise on actions that a GP should undertake in the presence of a trigger factor. A trigger factor can be previous diagnosis, physical exam results, measurement values, or more difficult, a combination of any of the above.

If a trigger factor is present, the guideline suggests any of a number of actions to perform; Table 1 lists the possible actions.

Table 1- Definition of activities needed in prevention

Type of action	Definition of action
Diagnosis	Capture a specific diagnosis in the presence of absolute values
Medical History	Capture a value needed to complete a risk profile or set a diagnosis
Physical exam	Capture a value related to the physical examination a of a patient
Laboratory investigation	Request a laboratory investigation
Medicine	Prescribe or change medication
Referral	Refer the patient to a specialist
Patient action	Advise patient on actions that can be objectively measured

A limiting factor of electronic patient records is that not all patient data will be available in a coded, structured format. Data, for example, may be available only in free text. That is, a guideline might refer to a medical condition that can only be recorded in text. In order to integrate the CDSS with the commercially available electronic patient records and existing workflows, we focus on data that is available in a coded (e.g., diagnosis, laboratory values or prescriptions) or structured (e.g., system-specific defined coding schemes) fashion. That is, we did not include free text analysis to mine for data not available in a coded or structured fashion. As a result, sections of guidelines that refer to data not available in a coded fashion were ignored.

Patient data, setting

To study the consequences of the CDSS, we conducted a retrospective cohort study in the Integrated Primary Care Information (IPCI) database. IPCI is a longitudinal GP research database, which contains information from computer-based patient records of GPs in The Netherlands. Within The Netherlands, patients are registered at single GP and the record for each individual patient contains all medical information on that patient [8, 9]. The database contains information on approximately 500,000 patients.

The computer records contain information on patient demographics, symptoms (including free text), diagnoses (using the International Classification for Primary Care (ICPC)), episodes, referrals, laboratory values, measurements (e.g. BP, cholesterol levels), drug prescriptions with their ICPC-coded indications, and hospitalizations [10, 11]. Summaries of the hospital discharge letters or information from specialists are available in a free text format. To maximize completeness of the data, GPs who participate in the IPCI project are not allowed to use paper-based records. The system complies with

European Union guidelines on the use of medical data for medical research and has been proven valid for research [12].

Participants

The sample date in IPCI was July 1st 2008. The source population comprised all living patients, with at least one year of valid history (that is, the patient had to be alive on July 1st 2008, and registered in that practice prior to July 1st 2007). All subjects were evaluated from the earliest of the following dates: one year of valid history, or birth.

Outcome measure: Recommended Preventative actions

Data from IPCI were submitted to the CDSS. We established whether any patient in our cohort had any of the identified trigger values available that should lead to a preventative action by a GP. When a trigger value was present we evaluated if the action had been performed. We thus counted the total number of actions needed as an indicator of the clinical workload needed to perform preventative activities recommended by the guidelines.

RESULTS

Knowledge Base

We analyzed all of the guidelines of the DCGP up to 31 March 2007 [7]. Of the 87 guidelines, 20 contained trigger factors and related recommendations relevant to preventative activities that could be determined based on coded or structured data. The recommendations in the guidelines could not be translated to coded or structured data were ignored. For example, the guideline on asthma for adults contains a reference to the patient feeling a shortness of breath over the last month. This information, however, cannot be captured in a coded or structured fashion in the available Dutch systems. As a result, such instances in guideline were not included.

Preventative Activities

The electronic patient records of 103 GP practices with a total valid population of 485 793 patients (females 247 557, males 238 087) were submitted to the CDSS.

Of these 485 793 patients, the CDSS generated for 138 885 patients (28.6%) recommendations to perform one or more preventive action(s). Of the 247 557 females, the CDSS generated for 71 944 patients (29.1%) one or more recommendations. Of the 238 087 males, the CDSS generated for 66 941 one or more recommendation (28.1%).

For an individual patient, the CDSS could recommend a range of preventive action to be taken (see Table 1). Table 2 shows the number of patients requiring actions recommended by the CDSS.

As shown in Table 2, a total of 1092 patients had sufficient information in the electronic patient record to assign a diagnosis whereas 138 885 required the inclusion of the results of a physical examination. It is interesting to observe that in total 40 113 patient needed some form of modification of the drug prescription, whereas 64 006 needed laboratory tests.

Discussion

We built a CDSS that support preventive care in general practice, and we studied the potential impact on the workload by submitting electronic patient record to that CDSS.

We observe that approximately one third of all registered patient in the GP practices required some form of preventive actions to be undertaken. The percentage of preventive actions to be undertaken varied slightly between males and female (28.1% versus 29.1%). Our first conclusion is that if a GP was to use the CDSS it would have a significant impact on the workload that that physician. We would argue that our finding that so many patients would be eligible for additional preventive care highlights the need to tailor the workload the locally available resources.

In the design of the CDSS we limited ourselves to those recommendations that could be firmly concluded based on coded or structured information. That is, we ignored a number of recommendations that could not be reliably concluded from the data available in the medical record. As a result, our estimate of the workload might be an underestimate; if we were to include the currently ignored section of the guidelines, a further increase in workload would ensue.

It is important to underscore that our finding that the workload to GP increases significantly does not constitute a value judgement on the medical content of those guidelines. We merely argue that the designer of a CDSS faces the issue of the practical consequences of implementing of a collection of guidelines when these guidelines were never considered as a whole. The collective impact of the different guidelines may result in a situation that the CDSS is destined to fail because the consequences of translating the guidelines into actions cannot be dealt with within in the constraints of day-to-day care. We also propose that designers of CDSS should include in their endeavours to introduce decisions support in daily care some form of impact analysis that would aid in gauging the practical consequences of their system without having to decide on the medical content of the guidelines involved.

Limitations

Our study suffers from a number of fundamental limitations that need to be stressed in order to avoid misinterpretation.

Firstly, the general practitioner is not the sole provider of care. It is quite possible that some of the preventive care is proved by secondary or tertiary care providers. That is, the absence of a preventive action in the GP record does not necessarily mean that the action has not been conducted. It is important to stress, however, that if the CDSS would be introduced in the GP practice, the recommendation would be given to the GP. Although the actions might be supervised by some else, the GP would be confronted with the need to determine whether the activity had been performed. Secondly, although the CDSS requires coded or structured data, the GP might have recorded data in free text. If the GP records data in free text, we will not have identified that data. As a result, we could have overestimated the workload proposed by the system.

Table 2- The number and type of actions identified by the CDSS by gender

	Male		Female		Total	
	n	(%)	n	(%)	n	(%)
Total number of patients with actions	66941		71944		138885	
Actions by type						
Diagnosis	532	(0.8)	560	(0.8)	1092	(0.8)
History	43017	(64.3)	45919	(63.8)	88936	(64.0)
Physical Exam	66941	(100.0)	71944	(100.0)	138885	(100.0)
Laboratory investigation	31509	(47.1)	32497	(45.2)	64006	(46.1)
Medicine	21552	(32.2)	18561	(25.8)	40113	(28.9)
Referral	1137	(1.7)	1092	(1.5)	2229	(1.6)
Patient action	7046	(10.5)	5969	(8.3)	13015	(9.4)

Conclusion

We believe that out study is the first that address workload that will result from implementing a set of guidelines focusing on preventive activities in general practice. The workload that will result from the preventive activities, even in the most optimistic scenario, is substantial. We propose that further tailoring is needed in the activities, for example by disease profile. We aim to pursue this tailoring in the SUNRISE trial.

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Exploring new directions in disease surveillance for people with diabetes: Lessons learned and future plans

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Abstract

The main objective of this paper is to report our achievements in investigating new directions in the disease surveillance field. Targeting the vulnerable group of people with diabetes, we explored the possibility of early detection of infections using an electronic disease surveillance system (eDSS); this system could collect data for certain physiology indicators, e.g. blood glucose and white blood cell count, by incorporating specific point-of-care (POC) devices. We performed an analysis using the data of two large-scale clinical studies that involved people with type-1 and type-2 diabetes correspondingly; also, we conducted a feasibility study to examine the available POC technology. Even though the analyses provided us with some evidence for further investigation, the available technological solutions appeared to have significant limitations, mainly in terms of usability. Based on our first-hand findings we defined the next steps of our research, i.e. the data collection in a controlled study and the subsequent development of the eDSS. Furthermore, the lessons learned in our project could facilitate the related research for other vulnerable population groups.

Keywords:

Infection, Surveillance, Diabetes, Point-of-care systems

Introduction

The utilization of reliable and accurate means for the timely detection of infections may prevent contagious disease outbreaks or even pandemics. Biological threats still exist, such as the avian influenza that, according to World Health Organization (WHO) reports, has caused almost 60% deaths among the total number of cases reported from 2003 to September 2009 [1]. The recent influenza virus threat (H1N1 – swine flu), has alerted the health authorities and governments over the globe, and increased the pandemic fear. Such pathogens can spread over and affect the general population but, primarily, the most vulnerable individuals.

The 2005 International Health Regulations articulated surveillance as 'the systematic ongoing collection and analysis of data for public health purposes and the timely dissemination of public health information for assessment and public health response as necessary' [2]. The existing disease surveillance systems collect data after the onset of the first symptoms and eliminate the incubation period[1] from their processes; thus, a significant delay from the actual onset of the infection threat occurs. Beyond that, they mainly target the general population and work less on vulnerable groups, such as people suffering from chronic diseases (diabetes, chronic heart failure etc.) and elderly; these groups are likely to be at heightened risk even in non-outbreak settings, such as in the case of cryptosporidiosis and other waterborne diseases [3]. Indicatively, the National Center for Chronic Disease Prevention and Health Promotion (Atlanta, GA, U.S.A.) has recently announced special guidelines for H1N1 flu and diabetes [4].

To address these needs we explored some new directions in the field of disease surveillance under the umbrella of an ongoing project, which investigates the automatic detection of infections; this project is supported by the Tromsø Telemedicine Laboratory (TTL). The core of our approach is the identification of an infection before people even know, through the onset of the symptoms, that they have been infected; specific physiology indicators and other personal health data could be used for that. Also, we are particularly interested in investigating this idea in people with diabetes and, furthermore, in exploring the possibility of building a dedicated electronic Disease Surveillance System (eDSS) for them.

The starting point for our study was based on the hypothesis that blood glucose (BG) and white blood cell (WBC) count could be the potential indicators for the early detection of infections in people with diabetes: BG may increase at a very early stage of infestation, immediately after the infection manifestation [5]; also, WBCs play a key role in the body's defense against infections and in most of the cases their count is increased at the early stages of incubation period [6]. Hypothetically, an eDSS could collect the appropriate data for these parameters incorporating monitoring devices and, subsequently, process this input in combination with other personal data; early indications for infection threats, i.e. quite before the onset of the symptoms, could be the system output.

[1] The subjects have no symptoms during the incubation period but have already been infected and become contagious.

In order to investigate these assumptions we defined the specific study objectives and attempted to meet them following a certain plan, which is presented below. This plan has been implemented over a period of 3 years (March 2007 – March 2010) and most of our findings have been already published (references are provided accordingly). The current paper attempts to give an overview of our efforts to explore novel approaches in the disease surveillance of people with diabetes, the main tasks that we have accomplished and the lessons that we have learned. Based on our experience we further discuss the potential future directions in the field.

Materials and Methods

In the beginning of our study the potential use of the suggested physiology indicators for disease surveillance purposes was investigated. This was highly prioritized considering that there are no solid findings for the BG elevation during the incubation period as well as for the exact timing of this alteration. The technological aspects had to be examined as well; for example, even though there are various BG monitors available that could be used as part of the eDSS, it is questionable whether similar devices for WBC count can be found in the market.

External Data Sources

In order to study the physiology response to infections for people with diabetes, we should either run a clinical study to collect the appropriate data for thorough analysis and model development or use external data sources to further investigate our ideas. The latter option was explored considering that diabetes is a condition that has been studied extensively in randomized controlled trials (RCTs); thus, we assumed that the huge data collection in a RCT might contain information both for infection incidents and continuous blood glucose monitoring. Subsequently, we gained access to the data collection of two RCTs:

- *Diabetes Control and Complications Trial (DCCT)*. DCCT was a full-scale multi-centre clinical trial, which recruited 1441 people with type-1 diabetes and was conducted by the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) [7]. The participants were randomized into two arms (conventional vs. intensive therapy arm) and data was collected every three months, i.e. during the follow-up visit. Among the numerous parameters of this study, glycosylated haemoglobin (HBA_{1c}) and disease-related parameters were further assessed. Adult males and females were studied separately. The null hypothesis that the diseased HBA_{1c} values were equal to the non-diseased values was tested for both sexes and arms [8].
- *Informatics for Diabetes Education and Telemedicine (IDEATel)*. The population of IDEATel study consisted of 1665 people with type-2 diabetes who were enrolled through the primary care practices in the New York City [9]. With the enrolment hub at the NewYork-Presbyterian Hospital/Columbia University Medical Centre (NYP/CUMC), the study participants either received a set of telemedicine services (intervention group) or remained under the usual care of their primary care providers (control group). The intervention group measured and uploaded their BG values into the NYP/CUMC Clinical Information System Repository and used the inpatient and outpatient health services in the same hospital as well. Consequently, it was possible to access and analyze inpatient and outpatient healthcare data (related to infection incidents) as well as glycemic control data (BG and time of measurement) for a certain number of people with diabetes.

Electronic Disease Surveillance System – Feasibility study

In order to incorporate a set of physiology indicators into a disease surveillance system and support patients' monitoring, it should be primarily checked whether the existing technology could support the development of this system. For example, our approach to use WBC count required the existence of a point-of-care (POC) device that could accurately measure this parameter at the user's location and not at the healthcare facility; even though such a device existed, it had to be examined whether it fitted our purposes. Furthermore, the cost-effect relationship could not be otherwise evaluated but in the context of a feasibility study. This study was performed in the city of Tromsø, using four POC devices that could monitor temperature, blood pressure, blood glucose level and certain hematological variables. It should be also mentioned that we selected validated and approved devices, which were shown to produce results equivalent to laboratory equipment [10].

Results

Table 1 shows the results of the DCCT data processing. Paired comparisons of diseased HBA_{1c} values (during the infection incident) vs. average HBA_{1c} values (before or after the infection incident) were performed using t-test statistics; the values for the intensively treated females were normalized to correct the skew and normalize the distribution. In almost all cases (excluding the intensively treated females case) HBA_{1c} values rose after infection despite the tight BG control held in the DCCT study, and returned to the non-diseased levels when the initial infection cause ceased; the complete analysis and results have already been published and presented at MIE 2008 conference (Göteborg, Sweden) [8].

Regarding the processing of IDEATel data we could briefly mention that glycemic control (blood glucose values and time of measurement) was shown to be altered when a person with type-2 diabetes was exposed to a pathogen. The complete analysis and results are fully presented in another paper, which is still under review; thus, it is not possible to discuss the findings of this work here.

Table 1- The results of testing the null hypothesis using the DCCT data; the mean paired difference (Mean), the standard deviation of the difference (SDev), the 95% confidence interval of the difference (95% CI) and the p-values of the t-test statistics [8].

		HBA_{1c}	Mean	SDev	95% CI		P
Conventional Arm	Female	Diseased – Average Before	0.288	0.719	0.163	0.412	<0.001
		Diseased – Average After	0.273	0.851	0.126	0.421	<0.001
	Male	Diseased – Average Before	0.267	0.722	0.151	0.384	<0.001
		Diseased – Average After	0.225	0.681	0.115	0.335	<0.001
Intensive Arm	Female *	Diseased – Average Before	0.007	0.081	-0.009	0.023	0.342
		Diseased – Average After	0.016	0.076	0.001	0.031	0.021
	Male	Diseased – Average Before	0.169	0.450	0.077	0.261	<0.001
		Diseased – Average After	0.115	0.563	0.001	0.230	0.049

* normalized values

The findings of the feasibility study suggested that it is not possible to use the available devices for our purposes, even if they are really promising. Particularly, the POC device measuring certain hematological variables appeared to be the most problematic due to the repeated failures during the feasibility study; moreover, the thermometer accuracy was questioned as well as the blood pressure measurements. The blood glucose monitor operation was quite acceptable; however, it caused dissatisfaction among the users because it required manual quality control. An overall limitation factor was the excessive time needed for the measurements (prepare consumables, perform tests, wait for results), with the average time for performing all measurements being 20 minutes. It should be also mentioned that the total cost of the four devices per subject was approximately $5,200, while the appropriate consumable costs were approximately $350 per subject for performing daily measurements in a one month period. These costs were further split per subject, device and daily measurement (Table 2).

Table 2- Equipment costs; all prices are calculated in USD (no taxes included) [10]

Devices	Price	Consumables*	Accessories**
Haematologic Analyzer	4,000.00	8.00	500.00
Blood Glucose Monitor	400.00	3.50	40.00
Blood pressure Monitor	167.00	N/A	25.00
Thermometer	55.00	0.40	N/A

*N/A: Not Applicable, * Cost per measurement, ** Cables, software, printer*

Specific details for the devices (vendors, trade names etc.) as well as the complete results of the feasibility study can be found in the manuscript that has been already published [10].

Discussion

The main scope of this project was to work on new directions in the disease surveillance field targeting the early detection of infections. Particularly, in the context of the existing disease surveillance systems that have been studying mainly the general population [11-13], our disease surveillance approach for vulnerable population groups with special physical needs is novel. For completeness, we should refer to Mohtashemi et al. [14] who described a system for the early (still after the onset of the symptoms) detection of tuberculosis outbreaks among the San Francisco homeless population; however, homeless individuals should be considered vulnerable mainly due to social and not physiology reasons. As a first approach to our idea we considered that diabetes could be the ideal research area since:

- People with diabetes are highly motivated to monitor their infection status;
- Diabetes is a condition that has been extensively studied before and, thus, we expected to:
  - get access to external data sources with numerous variables and complete data,
  - attract the interest of other researchers in the field, and
  - disseminate our ideas rapidly;
- The diabetes monitoring technology has advanced more than the technology in other chronic conditions;
- Our team has years of experience in the field [15-16].

One of our primary mid-term goals was to build the theoretical background of our approach. Thus, it was necessary to investigate our claims regarding the early detection of infections and, mainly, the possibility of using certain physiology indicators for accomplishing this task. Normally, a dedicated clinical study is required to fulfill this demanding task. However, it is often risky to allocate a considerable amount of resources before examining the solidity of a novel idea. In this context, the solution of getting access to external data sources was the most appropriate.

Subsequently, we have managed to access the archives of two large-scale RCTs, the DCCT and the IDEATel studies that involved people with type-1 and type-2 diabetes correspondingly [7, 9]. This allowed not only the processing of two large data sets but also the investigation of our approach in both types of diabetes condition. The idea of blood glucose elevation and the alteration of glycemic control during the incubation period were supported by the results of the analyses in both cases [8]. It was not possible though to investigate either the contribution of other parameters (e.g. WBC count, insulin intake) or the detailed physiology mechanisms.

Unambiguously, the methodology that was followed in the first phase of our project had some limitations. First of all, both studies were not specific for our purposes and, thus, it could be argued that the results are inadequate to base any further research. Nevertheless, it should be mentioned that our main intention was to seek for evidence and reserve our resources for a dedicated clinical study. The same strategy was followed in the feasibility study where approved devices were tested in a low-budget schema.

Additionally, the study of devices that measure symptomatic (i.e. temperature) and non-infection-related (i.e. blood pressure) parameters could be considered as irrelevant to our purposes. However, our disease surveillance approach should be viewed as an effort towards personalized medicine; otherwise users might not see the potential benefits and be skeptical on such systems. Subsequently, the examination of other 'pieces of the puzzle' is important; this is further discussed below.

Considering that the end point of our project was the development of an eDSS that would incorporate specific devices for the continuous monitoring of physiology parameters, it was important to test the available technology. As aforementioned this was the reason for conducting the feasibility study, which showed that technology is still immature both in terms of accuracy and usability [10]. On the other hand, a successful eDSS requires the collection of accurate data in order to fulfill its purposes. Consequently, the idea of performing continuous monitoring for multiple physiology indicators should be abandoned, especially in the case of diabetes where only blood glucose can be measured in a reliable manner.

Based on our up to date progress, we are able to define our next step that is the conduction of a dedicated clinical study to collect the appropriate data. Taking into account the results of the feasibility study and, particularly, the high cost of the POC equipment, the main characteristics of the proposed study should mainly include:

- A cohort of 100 people with diabetes, either type-1 or type-2;
- Continuous data collection (BG values, insulin, physical activity, food intake, infection-related data, temperature, diagnosis of infections);
- A study period of one year to be able to accurately define the participants' profile and maximize the possibility of observing infection incidents.

The tools that should be used in this study are also important; the selection should be based both on the conclusions drawn from the feasibility study and on the characteristics of the existing equipment solutions. Keeping in mind that users' involvement is critical for the success of any system (before, during and after system development), the following criteria should be considered:

- A simple device for continuous BG monitoring is definitely more usable and should be part of the clinical study; however, more accurate devices should be used as part of the final eDSS. The BG monitor that was used in the feasibility study was comparable to laboratory equipment in terms of accuracy and should be examined prior to building the final product [17];
- A mobile device carrying a dedicated software for data input should be used, like the one that has been developed by Arsand et al [16];
- The secure communication infrastructure should support the data collection in a central repository for further processing;
- An important component of the eDSS is the mathematical model that will process the incoming data, send feedback to people with diabetes/physicians and trigger alarms if necessary. The potential modeling approach should be examined before the initiation of the clinical study and then adjust its parameters at predefined time points.

Our approach could also empower the development of personalized health care systems that involve portable devices, sensors and wireless networks [18]. In this context a personalized eDSS could adjust its parameters to support each subject, e.g. by alerting them for an infection threat in a region. Systems of the kind could also interoperate with Electronic Health Record (EHR) systems and provide health care professionals with adequate information to take the necessary actions and support the information sharing between vulnerable individuals. For example, a threat raised by monitoring one person with diabetes could be used in evaluating the relevant threats for the community of people with diabetes living in the same area. This would also consist an excellent opportunity to build a social network with special interest and a huge impact on the infection control.

The project objectives were decided upon but not limited to the initial selection of people with diabetes; our approach is broader and we aim to study other vulnerable populations, too. Among our intentions was to form the basis for a further exploitation of our findings in the general population or otherwise healthy groups that are very interested in getting early

alerts for their condition, such high-competition athletes. The related research might initially target individual surveillance and then move up to the population level (bottom-up approach). Beyond the study that is required to determine the exact physiology alterations after infection, the role of medical informatics regarding the eDSS conceptual, organizational, architectural and technological aspects is crucial.

Conclusion

The development of strategies for the detection of infections before the onset of the symptoms is critical, especially given the limitations of the current disease surveillance systems that are based only on people's awareness of their health status. This is particularly important for vulnerable population groups, such as people with diabetes, that their health status is altered significantly when they are infected. Here, we highlighted the lessons learned in our project, the difficulties of this approach as well as our future plans. We hope that this work will provoke the thoughts for new directions within the disease surveillance field.

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A 3-step eHealth approach to transfer knowledge on HIV and sexual violence in developing countries

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Abstract

This paper discusses an innovative 3-step eHealth approach to translate research for target audiences' knowledge uptake in developing countries. The first step uses a knowledge transfer model for the identification and packaging of health content as well as the selection of appropriate Information and Communication Technologies (ICT) platforms; followed by consumer health informatics studies to evaluate the efficacy of addressing health consumers' information needs; and the final step recommends forming of strategic partnerships to strengthen and support knowledge transfer and sharing. The 3-step eHealth approach is based on a convergence of ICTs, and application of the practices and principles of informatics and knowledge management. It was refined during the development of AfroAIDSinfo, an AIDS information portal of the SA Medical Research Council (MRC). The approach was evaluated during the forming of a strategic partnership between the AfroAIDSinfo project of the MRC's Web and Media Technologies Platform and the Sexual Violence Research Initiative. The successful outcome of the eHealth approach served to collect evidence for good practice in informatics and knowledge management.

Keywords:

Consumer health informatics, Knowledge management, Knowledge transfer, eHealth, Research translation, Information needs, Informatics, Web, HIV, Acquired Immunodeficiency Syndrome, Sexual violence.

Introduction

The developing world and Africa in particular is facing the dual epidemic of sexual violence and HIV. In the AIDS Epidemic Update for sub-Saharan Africa [1] South Africa is still singled out as the country in this region where an estimated 1.8 million people have died of AIDS-related disease since the epidemic began.

The linkages between HIV and Sexual Violence are well established [2]. With a rate of reported rapes at 194 per 100,000 women, South Africa is said to be the "rape capital" of the world [3]. Education has been highlighted as fundamental to overcoming both HIV/AIDS and sexual violence in the sixth millennium development goals [4].

In response to the AIDS epidemic, the high prevalence rate of HIV in sub-Saharan Africa, and the call for education interventions, AfroAIDSinfo™ was launched in 2001 on World AIDS Day. Developed by the Web and Media Technologies Platform (WMTP) of the SA Medical Research Council (MRC), it is an online HIV and AIDS project[1] supported by community outreach programmes.

AfroAIDSinfo aims to provide reliable information on HIV and AIDS to its consumer groups, with emphasis on the needs of sub-Saharan Africa. The AfroAIDSinfo consumer groups are researchers, health professionals, educators, policy makers and the public.

Using portal technology and community based educational interventions AfroAIDinfo meets its objectives by:

- **educating** its audiences on HIV;
- **updating** audiences on current issues and developments;
- **facilitating** decision-making;
- **improving** peer interaction, and;
- **stimulating** innovative knowledge transfer, with the latter focusing on innovative online as well as community outreach projects.

Sexual violence is the least understood and researched form of violence against women. Research is critical in highlighting the extent of the problem, and strengthening public health services and prevention programmes dealing with this problem. Lack of evidence hampers the development of good quality, evidenced based policies, services and programmes for women and girl survivors of sexual violence [5]. To address this gap, the Sexual Violence Research Initiative (SVRI)[2] was established in 2002, with the support of the World Health Organisation as an initiative of the Global Forum for Health research and is currently hosted by the Gender and Health Research Unit, Medical Research Council of South Africa.

The SVRI consists of a network of experienced researchers, policy-makers, activists, donors and others committed to the promotion of research on sexual violence and to generating empirical data to ensure that sexual violence is recognised as a priority public health issue.

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[1] AfroAIDSinfo is available online at www.afroaidsinfo.org

[2] SVRI is available online at www.svri.org

Against the background of the WMTP's work in eHealth to address HIV through a Web portal and its partnership with the SVRI to address sexual violence, this paper discusses an approach to address public health problems in the developing world.

The WMTP implements eHealth solutions in the context described by the World Health Organisation that refers to it as "*The cost-effective and secure use of information and communication technologies (ICTs) in support of health and health-related fields, including health-care services, health surveillance, health literature and health education, knowledge and research* [6].

The aim with this approach is to collect evidence for good practice eHealth approaches in public health interventions in developing countries. Good practice in eHealth is interpreted as those sets of processes and activities that are consistent with eHealth values, theories and models, understanding of the environment, and are most likely to achieve eHealth goals. Using a Consumer Health Informatics theoretical framework proposed by Lewis & Friedman [7], the health consumer is placed at the centre. Information technology becomes a mode to transfer health information to the consumer, as well as acting as a feedback catalyst. Health consumers' interaction with health providers empowers them to make healthy lifestyle decisions.

Based on this theoretical framework, this paper outlines a 3-step informatics and knowledge management approach with the following objectives:

- To implement a knowledge transfer (KT) model for the initial identification of consumer groups' information needs and selection of suitable Information and Communication Technologies (ICTs) platforms;
- To conduct Consumer Health Informatics (CHI) studies evaluating the extent to which consumer groups' information needs and format preferences have been met, addressed and integrated into the ICT platforms and
- To form strategic alliances between two developing country initiatives to address their public health problems.

The objectives of the 3-step eHealth approach aims to strengthen and support the effective translation of research into practice.

Materials and methods

A Web to Public Knowledge Transfer Model (WPKTM) was developed as an intended standard for Web development at the MRC. It was applied for the development of the AfroAIDSinfo AIDS information Web portal. Over time this model was extended into a 3-step eHealth approach to address specific areas of public health in developing countries.

Step 1 of the eHealth approach

This step consists of two phases, where the WPKTM's generic principles were applied during the first phase of development to establish the information needs of the AfroAIDSInfo consumer groups.

The generic principles included processes to:

- *Identify the target audiences;*
- *Ascertain whether the knowledge intended for the audience is required by them;*
- *Classify content according to the health literacy of the audience;*
- *Show the relevance of new knowledge;*
- *Avoid an information overload;*
- *Strive for utilisation of knowledge by the audience;*
- *Address the issues relevant to the audience.*

The WPKTM is further put into practice according to Snowden's [8] definition of knowledge management as "*the identification, optimisation and active management of intellectual assets, in the form of explicit knowledge either held in artefacts or as tacit knowledge possessed by individuals or communities. The optimisation of explicit knowledge is achieved by the consolidating and making available of artefacts. The optimisation of tacit knowledge is achieved through the creation of communities to hold, share, and grow the tacit knowledge. The active management of intellectual assets is the creation of management processes and infrastructure to bring together artefacts and communities in a common ecology that will sustain the creation, utilisation and retention of intellectual capital*."

With this definition in mind, health information was transformed into technology based on good practices for knowledge transfer on the Web. These practices formed the second phase of the WPKTM and included:

- *Selection of appropriate push and pull technologies to transfer and share knowledge;*
- *Packaging content with cultural understanding;*
- *Classifying content for different audiences;*
- *Packaging content according to Web Accessibility standards;*
- *Applying a convergence of ICTs to address the information needs of consumers;*
- *Implementing methodologies to measure health consumers' knowledge levels and packaging content accordingly;*
- *Implementing content to prevent an information overload;*
- *Implementing intuitive and easy navigation;*
- *Implementing quality assurance methodologies such as the HON principles[3], workflow processes, and an editorial process;*
- *Implementing policies, terms of reference for use, explanations and assistance.*

ICTs that further facilitated the knowledge sharing process for the AfroAIDSinfo consumer groups included a Discussion Forum along with technology to distribute a monthly eNewsletter to registered members. In the monthly eNewsletter; and at the end of articles specific questions are

[3] The Health On the Net Foundation (HON) developed an ethical Code of Conduct to guide consumers on the Web to reliable health information.

posed to each consumer group to be discussed in the forum in order to stimulate discussions among its members. The main purpose of the discussion forum is to capture tacit knowledge of members' expertise in a format that could benefit all the consumer groups.

Step 2 of the eHealth approach

The next step is underpinned by Consumer Health Informatics as described by Eysenbach [9]: "*the branch of health informatics that analyses consumers' needs for information, studies and implements methods of making information accessible to consumers and models and integrates consumers' preferences into health information systems.*"

Cognisant of the theoretical framework, regular CHI eSurveys are conducted among AfroAIDSinfo consumer groups to investigate if the deployed ICTs were successful in transferring research knowledge to consumer groups. It would imply effectively responding to information needs and identifying new requirements, based on the CHI model referred to earlier.

As an example, the AfroAIDSinfo CHI study revealed a need by the health profession and public consumer groups for more information on women and HIV. As part of an overall strategy to address this information request, the AfroAIDSinfo entered into a partnership with the Sexual Violence Research Initiative (SVRI).

Step 3 of the eHealth approach

The notion to form partnerships is seen as a strategy for improved public understanding of health and science [10]. Both the SVRI and AfroAIDSinfo view partnership as a key strategy to advance innovation and to extend their reach. The partnership included technology development for the SVRI; collaborative content development and CHI studies to evaluate the deployed ICTs to translate research and knowledge effectively to benefit health consumers.

The Sexual Violence Research Initiative has been providing materials and resources on sexual violence to its members since 2003. Based on the successful 3-step eHealth approach followed for the development of AfroAIDSinfo, the same approach was pursued for the expansion of the SVRI ICTs.

Through this partnership, members of both networks were able to share knowledge and insights into HIV and Sexual Violence; and to learn more about the increasing feminisation of the HIV epidemic and the complex interactions between rape and HIV. Examples of the outputs of this partnership were the collaborative development of a fact sheet on the link between HIV and sexual violence. News items based on the linkages between these areas are exchanged and disseminated to each initiative's consumer groups.

Two years after the partnership between the SVRI and AfroAIDSinfo was formed, the WMTP and the SVRI undertook a CHI study to evaluate whether the core ICTs as implemented for the SVRI were successful in addressing the information and research needs of the SVRI members.

Results

AfroAIDSinfo CHI study results

At the time of this study, the AfroAIDSinfo Web portal was recently re-engineered and registered users requested to resubmit subscriptions. Of the 491 new subscribers, the AfroAIDSinfo eSurvey received 124 (25%) responses where the majority of consumers registered in the *scientist* group 74.19% (n=92) followed by *public* 11.29% (n=14), *health professionals* 6.45% (n=8), *educators* 5.65% (n=7) and *policy makers* 2.42% (n=3). As previously alluded to, efforts were focused on providing reliable and useful information on HIV and AIDS to the AfroAIDSinfo consumer groups. Figure 1 is a summary of the collective feedback from respondents in the main areas on which all audiences were questioned.

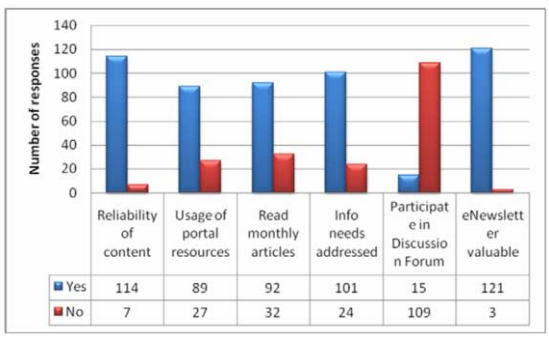

Figure 1- High level summary of eSurvey responses

These results showed that the aim of AfroAIDSinfo to be a reliable resource on HIV information was achieved as its members rated reliability of content at 91.94% (n=114).

Linked to the above, 71.77% (n=89) of the respondents indicated that they used the resources on AfroAIDSinfo. A respondent from the public category said he/she considered the AfroAIDSinfo content reliable and thus felt confident in using it in community events. 74.19% (n=92) of the respondents read the monthly articles. The value of the eNewsletter to transfer HIV knowledge was rated at 97.58% (n=121). This result was very encouraging as the eNewsletter acts as a pull technology, including links to the latest articles on the AfroAIDSinfo portal. On the other hand, only 11.29% (n=15) usage was reported for the Discussion Forum.

Finally, 81.45% (n=101) of the respondents indicated that their information needs were addressed as described in the first step of the eHealth approach. They were further given the opportunity to identify "new" topics and areas on which they needed information and resources. A community worker in the public category requested "*case studies in handling a community project*" and "*basic HIV information in indigenous languages*"; while a health professional required guidance on "*Different forms of support - for the patient as well as the family*." Results of the CHI eSurvey were communicated to the AfroAIDSinfo members through the monthly eNewsletter. In the months following the CHI eSurvey, articles addressing these identified topics were highlighted in the eNewsletter.

The same 3-step eHealth approach was implemented for the partnership between the WMTP's AfroAIDSinfo project and SVRI to develop their ICT platforms (step 1) and was later followed by a CHI study (step 2) to evaluate the SVRI members' perceptions how their information and research needs were addressed.

SVRI CHI study results

The SVRI originally set various objectives to be met with information distributed to their members via the Web site and listserv[4]. Respondents overwhelmingly indicated that their expectations were mostly met or were exceeded. As shown in Figure 2, the objective to *Promote informed research practices* was *Mostly met* receiving the highest rating (n=80) followed by *Bridging research and practice* (n=73). The objective that exceeded expectations was *Promoting reliable, valuable information* (n=56), followed closely by *Raising awareness of SV as a public health priority* (n=53).

New information needs were addressed, for example a number of key changes to the SVRI ICT platform have been made. The SVRI initiated a number of region-specific activities to increase its membership and interest in work on sexual violence in the Latin American and the Caribbean regions. Taking the feedback forward and using the technology available, the SVRI plans to create a policy portal to promote research based policy analysis and expert commentary in the field of sexual violence, with emphasis on research from developing countries. Through the proposed SVRI Policy Portal the SVRI will endeavour to raise the level of debate by providing a space for researchers to draw out the policy implications of their research, and to make their work more accessible to professionals working in the field.

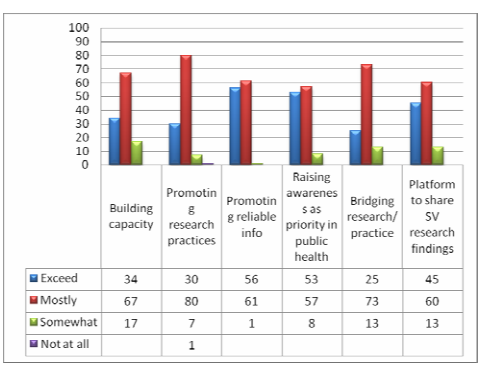

Figure 2- Information needs of SVRI member met

Discussion

As the results indicated, each of the three steps proved to be beneficial to the respective initiatives and their consumer groups. The eHealth approach assisted both AfroAIDSinfo and the SVRI from inception, to become aware of the specific information needs of their consumer groups.

Following the eHealth approach enabled both partners to select the most appropriate ICTs and to develop the appropriate resources to address the information needs of their specific consumers. Examples include the additional portal desktops integrated into AfroAIDSinfo with basic information on HIV in two indigenous languages.

Both sites have been reviewed and carry HON accreditation as reliable sources of health information on the Web. These actions were specifically taken during the first step to meet the aim of the approach – to translate research into a practice.

The CHI studies conducted during the second step was used to further inform both AfroAIDSinfo and the SVRI of extent to successfully implement the Web to Public Knowledge Transfer Model. It also gave the consumer groups an opportunity to highlight new information needs that subsequently arose, initiating interaction with communities as advised by the CHI theoretical framework.

The high rate of satisfaction reported by both CHI surveys indicated the importance of unpacking research into different formats according to the information needs of those who seek it.

The CHI studies further highlighted areas for improvement, such as the low participation rate in the AfroAIDSinfo discussion forum.

Robertson [11] believes that a *clear purpose* should exist for people to use online collaborating ICTs, i.e. they should see that their contributions make a direct impact on their group or they should see tangible effects from their contribution. He further suggested that an online collaborating ICT should draw upon *a common sense of community*. A success criterion is thus that there should be an existing community or network.

Although the "community" does exist in AfroAIDSinfo in the form of its five consumer groups, it does not mean that the consumers have a sense of being a community and therefore make time to participate with "strangers" in the forum. This calls for innovative approaches to unlock experts' knowledge. If this could be achieved, the spiral effect of learning predicted by Nonaka [12] would take place. He suggests that knowledge sharing leads to knowledge uptake which in turn leads to production of new knowledge practices, and beneficial usage.

In communicating the results of the CHI studies to consumer groups the gap between knowledge provider and consumer was decreased. It laid the foundation for future responsive relationships as both sites received increased member registrations and interaction in their collaborative ICTs.

The final step of the eHealth approach, to develop a strategic partnership, acted as a catalyst for a strategic alliance between two eHealth initiatives. It opened up opportunities for consumer groups to share in knowledge across both platforms, meeting the objectives of each step of the eHealth approach.

Conclusion

The successful implementation of the 3-step eHealth approach has provided knowledge for good practice in informatics and knowledge management. Moving forward, the SVRI and

[4] Listserv is an application that maintains lists of e-mail addresses in order that users can participate in an electronic discussion or conference.

AfroAIDSinfo will continue with regular CHI studies to collect evidence ensuring that the aims and objectives of both partners are met. Continuous adaption of efforts and activities will promote the use of best evidence in the prevention and responses to sexual violence and HIV. From a public health perspective, the 3-step eHealth approach is presented for replication in other fields of health.

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Using a File Audit to Evaluate Retention in Care and Patient Outcomes in a Programme to Decentralise Antiretroviral Treatment to Primary Health Care Facilities in a High Prevalence Setting in KwaZulu-Natal, South Africa

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Abstract

HIV care and antiretroviral treatment (ART) provision is largely hospital-based with an over-reliance on doctors. Existing ART sites are reaching capacity and are increasingly unable to initiate new patients and also see follow up patients. In response, the Reproductive Health and HIV Research Unit (RHRU), has supported the KwaZulu-Natal provincial Department of Health with developing a model to decentralise services to primary health care (PHC) level. The programme has been in operation since 2006, and currently nine ART initiation sites down refer stable patients to 24 PHC clinics. Data on patient numbers, treatment outcomes and patient retention rates were collected through a file audit of 2071 adult patient files and analyzed. Results indicate that a file audit is a feasible mechanism to provide this data and can be used to identify gaps and improve quality of care. PHC sites in resource-constrained settings are able to manage stable patients on ART; however, sites need support with monitoring and evaluation and with tracking patients that have been down referred. In terms of quality of care, PHC sites need to ensure that clients receive CD4 count tests and viral load monitoring at six monthly intervals to ensure that treatment failure does not go undetected. Patients suspected of experiencing adverse events or treatment failure appear to be managed according to standard operating procedures, but there is a need to ensure that adverse events are clearly documented in patient files.

Keywords:

Antiretroviral treatment, Primary health care, Retention.

Introduction

eThekwini district in KwaZulu-Natal has an estimated 1.5 million individuals infected with HIV; 12-15% of whom require antiretroviral treatment (ART). HIV care and ART provision is largely hospital-based with an over-reliance on doctors. Existing ARV sites are reaching capacity and are increasingly unable to initiate new patients and also see follow up patients. In response, the Reproductive Health and HIV Research Unit (RHRU), has supported the KwaZulu-Natal provincial Department of Health with developing a model to decentralise services to primary health care (PHC) level. The rationale for shifting the care of stable patients to PHC level is two fold. Firstly, it will allow for stable patients to access care closer to their homes saving them time and resources and ensure that waiting times for services are minimized. Secondly, it would allow more new patients to be initiated on ART, reduce waiting times for treatment initiation and result in more efficient use of human resources if doctors are freed up to focus on new patients and follow up patients are managed by nurses. This approach has been used in countries such as Malawi [1], Rwanda [2] and Lesotho [3, 4] and is promoted by the World Health Organisation [5]. The HIV and AIDS and STI Strategic Plan for South Africa 2007-2011 mandates decentralised care and nurse-driven services [6] and there is widespread recognition for the need for decentralised care and task shifting/sharing in the South African context [7, 8].

RHRU has developed a comprehensive model for decentralising care. The model starts at PHC level, where clients are prepared for ART (all services prior to ART initiation are conducted at PHC level) and then referred for ART. Once clients are stable on ART (at least 6 months), they are down referred to be managed at PHC level. In order to support implementation, RHRU has developed standard operating procedures for the up and down referral process [9]. This includes documenting the procedures for up referral of adults (including pregnant women) and children; management of patients at initiating sites; down referral of stable patients; dispensing ARVs to PHC; and the management of side effects. Standardized data collection forms and a two-way referral form were developed in consultation with the provincial department of health to track patients up and down referred. RHRU conducts a three day training programme for nurses and provides follow-up mentoring & coaching on-site in order to implement the model. RHRU has implemented the programme since 2006. However, no formal assessment of the programme has been conducted. In order to assess patient retention in care and how well patients, who are down referred are being managed, RHRU conducted a file audit of patients down referred to RHRU supported PHC sites. Currently nine ART initiation sites down refer patients to 24 PHC clinics.

Research Objectives

The objectives of this study were to:

1. Collect information on the numbers of patients currently accessing care at PHC level
2. Collect information on treatment outcomes and inconsistencies in patient management to inform improvements in quality of care
3. Identify areas requiring follow-up interventions, quality improvement projects and to improve the quality of routine data collected.

Methods

RHRU has developed a file audit process for the collection of valid and reliable data in hospitals and clinics using paper-based record keeping systems. The file audit methodology allows for the collection of valid and reliable data in a way that keeps disruption of normal clinic operations to a minimum and makes use of all available clinic staff at various levels of training and expertise. The process has been found to be useful to establish the need for specific follow-up interventions, such as introducing staff for defaulter-tracing and identifying improvements to existing data collection systems. RHRU has used this method in numerous facilities in KwaZulu-Natal, Gauteng and North West Province [10].

RHRU has subsequently adapted the tool to collect similar data on patients who have been down referred to primary health care facilities. Two audit tools designed by RHRU were utilized in this study, a Client File Audit Form and a Clinic Register Audit Form. The tools allow for data collection on the following variables:

- patient demographics;
- CD4 count & viral load at time of down referral and during the course of treatment;
- ART regimens used;
- Incidence and timing of side effects and adverse events;
- numbers of patients falling pregnant on treatment;
- prevalence of co-morbidities;
- number of patients and timing of defaulting including patients not reaching down referral sites and those defaulting after down referral;
- number of patients up-referred to ART sites;
- number and timing of deaths.

A total of 14 individuals were trained on the tools and participated in the audit including 11 of RHRU's monitoring and evaluation team and three visiting students. The team visited 9 initiation sites and 24 primary health clinics over a one month period in October 2008 and reviewed a total of 2071 files. Data on the above variables were extracted from patient files, registers, two-way referral forms and other sources of data at each site and entered on a file audit form for each patient. Data were captured in EpiData and analyzed with SPSS Version 17.

Results

A total of 2071 adult patients were identified as down referred from files opened at PHC sites. The nine initiating sites referred patients to a number of PHC clinics. Table 1 below illustrates the sites and numbers of patients down referred. The number of patients down referred by initiating sites ranged from one to 275, with the average number of patients being 122. As a result of several sites with small numbers of patients and several with large numbers, the median is likely to be a more accurate reflection, at 45 patients per PHC.

Table 1- Number of patients down referred by site

Site Name	Number (n)	Proportion (%)
Prince Mshiyeni Memorial Hospital		
Umbumbulo	15	
Danganye	5	
U21	58	
Folweni	67	
K Clinic	24	
Magabheni	1	
Kwa Makutha	35	
Total	**205**	**10%**
Charles James		
Umbumbulo	19	
Danganye	45	
U21	21	
Folweni	61	
Umnini	45	
Magabheni	37	
Kwa Makutha	104	
Total	**332**	**16%**
R K Khan Hospital		
Shallcross	26	
Unit 6	31	
Total	**57**	**3%**
Addington Hospital		
Addington Gateway	217	
Beatrice Street	176	
Newlands East	116	
Newlands West	50	
Redhill	75	
Total	**634**	**31%**
Kwa Mashu Community Health Centre		
Lindelani	63	
Goodwins	36	
Ntuzuma	64	
Total	**163**	**8%**

Table 1 (continued)

Wentworth		
Cato Manor	62	
Lamontville	13	
Merebank	7	
Total	**82**	**4%**
Don McKenzie Hospital		
KwaNgcolosi	47	
Clermont	7	
Halley Stott	144	
Molweni	86	
Total	**284**	**14%**
Kwa Dabeka Community Health Centre		
Clermont	274	
Total	**274**	**13%**
Clairwood		
Lamontville	38	
Total	**38**	**2%**
Missing	2	

Table 2 presents demographic and patient information for the down referred patients. 72% of the down referred patients were female. Data on gender were missing for 2% of patients. Most patients were on regimen 1A or 1B (94%), while this information was missing for 1% of patients. Most patients (56%) had been down referred for a period of 0-5 months, the primary reason being that the programme has rapidly expanded in recent months. Only 4% of patients had been down referred for 12 months or more. Poor record keeping and the non- completion of the two-way referral form meant that the date of down referral was not available for 20% of the files. At the time of down referral 99.6% of patients had undetectable viral loads and the median CD4 count was 264. Three patients were down referred with detectable viral loads. This is not in line with the standard operating procedures for down referral, but may reflect a transcription error of the results. 164 patients (8%) had no information on CD4 count at down referral in their files, while 37% of patients had no viral load documented.

As shown in Table 3, of the 2071 patients identified as down referred, PHC sites received 78% of these patients, 3% did not ever arrive at the PHC site and there was no data on any visit available for 18% of the patients. One possible reason for the lack of data in the files is that some sites reported preparing patient files in advance before patients arrive and therefore may reflect patients yet to arrive at the site. As a result of this finding, measures to prevent this will be implemented on site.

Table 2- Demographic Data

Patients down referred	**Number (n)**	**Proportion (%)**
Number of patients down referred	2071	100
Period down referred	**Number (n)**	**Proportion (%)**
0-5 months	1154	56
6-11 months	424	21
12+ months	77	4
Missing	416	20
Gender	**Number (n)**	**Proportion (%)**
Male	547	26
Female	1488	72
Unknown	36	2
Age	**Years**	
Median Age	37	
CD4	**Number (n)**	**Median**
Median CD4	1922	296
Viral Load (VL)	**Number (n)**	**%**
% VL undetectable	1298	99.6
Regimen	**Number (n)**	**Proportion (%)**
1A	1508	73
1B	433	21
2	7	0
Alternate	103	5
Missing	20	1

Table 3- Number of Patients Received at PHC Sites

Number of patients received at down referral clinic	**Number (n=)**	**Proportion (%)**
Received	1624	78
Not received	65	3
No data available	382	18

Patients showed increasing CD4 counts at 6, 12 and 24 months indicating that management at PHC level is effective. However, of concern is that not all patients were receiving regular follow up CD4 counts at PHC or these were not being documented in their files. Most patients continued to have undetectable viral loads at 6 and 12 months after down referral, with 90% and 97% of patients having undetectable viral loads respectively. As for CD4 counts, few patients had these test results documented in their files, which may hamper the effective monitoring of treatment.

Table 4- CD4 & Viral Load Results

Median CD4	**Number of individuals (n)**	**CD4**
@ down referral	1922	264
6 months	223	339
12 months	49	395
% of patients with undetectable VL	**Number of individuals (n)**	**%**
Baseline	1298	99.6
6 months	224	97
12 months	43	93

Files were also reviewed to identify patients lost to follow up after being received at PHC sites. The review found 13% of patients received on site were lost to follow up (13%). Data on 4% of patients were missing or there was no information on last appointment attended in the file. As only stable patients are down referred, the retention rates at PHC level should be higher than at initiating sites [11]. Without a more sophisticated patient information system, it is not possible to identify whether the patients lost to follow up have returned to the initiating site or another site for treatment. Data on patient deaths were not found in any patient files.

Table 5- Loss to follow up

Patients lost to follow up after down referral	**Number (n)**	**Proportion (%)**
Lost to follow up	263	13
Active patients	1737	84
Not documented	38	2
Missing	33	2

The file review also collected data on patient outcomes. In total only 3% of client files indicated adverse events (AE) and 3% opportunistic infections (OI). This data is presented in table 6. Most common OIs were flu, shingles and other minor ailments. In terms of AE, peripheral neuropathy, lipodystrophy and fungal infections were most common.

Table 6- Adverse Events

Numbers of clients who presented with Adverse events	**Number (n)**	**Proportion (%)**
Clients with adverse events	59	3
Clients with opportunistic infections	68	3

Table 7 shows the number of patients and the reason for up referral. Only 1% of patients were up referred back to the initiating site. Reasons for up referral included pregnancy (16%), medication not being available (12%), side effects (12%) and patients wanting to return to the initiating site (8%). Logistics for the delivery of medication may need to be strengthened at some sites. In 40% of the cases, no reason was documented on file. Without accurate and complete documentation, it is difficult to assess the outcomes of programmes. Sites will need to be supported to improve record keeping if that data are to be used for evaluation purposes. Also of concern is the up referral of pregnant women to secondary level care. Pregnant women should be managed at PHC level and not up referred.

Table 7- Patients Up Referred

Clients Up Referred	**Number (n)**	**Proportion (%)**
Number of clients	25	1
Reasons for Up Referral	**Number (n)**	**Proportion (%)**
No reason stated	10	40
Medication out of stock/not available	3	12
Pregnant	4	16
Lactate levels raised	1	4
Side effects	4	16
Non adherence	1	4
Missing prescription card	1	4
Returned to initiating site	2	8

Conclusions & Recommendations

While PHC sites report that down referral programmes are feasible and effective, programmes may lack accurate data on key variables such as patient numbers, treatment outcomes and patient retention rates. A file audit is a feasible mechanism to provide this data and can be used to identify gaps and improve quality of care. The results of the file audit indicate that PHC sites in resource-constrained settings are able to manage stable patients on ART. However, sites need support with monitoring and evaluation and both the initiating and PHC site should track patients down referred and accessing services to prevent loss to follow up. Systems to track patients not attending appointments need to be introduced at PHC sites. This includes the need to ensure accurate and updated contact details are recorded for patients at each visit. On-going mentoring and support for monitoring and evaluation is required at PHC level and RHRU has introduced regular audits and data quality reviews at PHC to address these gaps. Other gaps identified during the audit included two way referral forms not being completed and no standardised tools being used at PHC sites. The planned introduction of a new ART register should go some way to address this concern. In terms of quality of care, PHC sites need to ensure that clients receive their CD4 count tests and viral load monitoring at six monthly intervals to ensure that treatment failure does not go undetected. Patients suspected of experiencing adverse events or treatment failure appear to be managed according to standard operating procedures, but there is a need that this management is clearly documented in patient files.

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CEMARA an information system for rare diseases

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Abstract

Rare diseases cover a group of conditions characterized by a low prevalence, affecting less than 1 in 2,000 people; 5000 to 7000 rare diseases have been currently identified in Europe. Most diseases do not have any curative treatment. They represent thus an important public health concern. CEMARA is based on a n-tier architecture. Its main objective is to collect continuous and complete records of patients with rare diseases, and their follow-up through a web-based Information System, and to analyse the epidemiological patterns. In France, 41 out of 131 labelled Reference Centres (RC) are sharing CEMARA. Presently 56,593 cases have been registered by more than 850 health care professionals belonging to 171 clinical sites. The national demand of care was explored in relation with the offer of care in order to reach an improved match. Within 2 years, CEMARA stimulated sharing a common platform, a common ontology with Orphanet and initiating new cohorts of rare diseases for improving patient care and research.

Keywords:

Rare diseases, Information system, Ontology, Public health, Thesaurus.

Introduction

Rare diseases cover a group of conditions characterized by a low prevalence, affecting less than 1 in 2,000 people. According to this criterion, 5000 to 7000 rare diseases have been currently identified. Three to 4% of children and 6% of the population in Europe are affected. Rare diseases are often chronic, progressive, degenerative, life-threatening and disabling. It is thus a true public health concern since most diseases do not have any curative treatment. In France, the Ministry of Health has initiated in 2004 a National Rare Diseases Plan; 131 Reference Centres (RCs) were then labelled for a given disease or group of diseases. Among their missions, the RCs lead the management networks and are involved in the epidemiological monitoring of pathologies they are in charge of, in order to better assess the distribution of rare conditions on the territory, as well as their social, educational and familial repercussions. To support RCs networking, an information system named CEMARA (CEntres MAladies RAres), was developed.

The main objective of CEMARA is to contribute to the missions of the RCs regarding the registration and description of their activities, collecting continuous and complete records of all patients presenting with a rare disease in France and their follow-up, coordinating the network of correspondents, and analyzing the epidemiological patterns.

Material and Methods

Professional network

Thirty three centres are presently active members of the CEMARA network in France (Figure 1) and 16 additional centres joined CEMARA in 2009. Each centre is composed of one or more clinical units, managed by a coordinator. The RCs have been described elsewhere [1].

Ontology for rare diseases: Orphanet classification

Orphanet[1] [2] is member of the European Rare Disease Task Force[2] and in charge of the topical advisory group for rare diseases for the World Health Organization. Orphanet database provides an ontological support to experts for each field of CEMARA. Thus, specific thesauri were designed. The specificity of our collaboration provided a shared ontology for each thesaurus of CEMARA. A grammatical and lexical uniqueness for labelling each disease includes the management of synonyms and eponyms. The associated nosography helps health professionals to share common terms.

[1] Orphanet : http://www.orpha.net
[2] Rare Disease Task Force : http://www.rdtf.org/

Regarding gene mutations we use GENATLAS[3], which contains relevant information with respect to gene mapping and genetic diseases. A specific link was also developed with this database. OMIM codes are also provided.

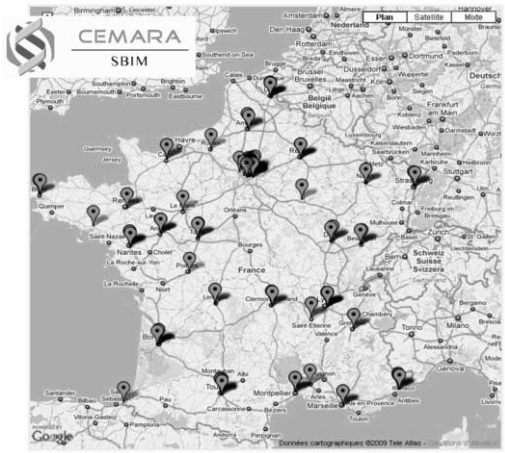

Figure 1- CEMARA network of the first 33 centres for rare diseases

Information System (IS): Design and Implementation

The IS of CEMARA has been described elsewhere [1]. Briefly, it collates in a standardized representation a minimal patient record. CEMARA IS has been based on a n-tier architecture. At the client side, CEMARA relies on existing local Internet networking facilities and on a widely spread computer configuration in medical settings. Via a web browser, the client tier connects to the middle tier, which is connected to several databases: the production database, the geographical dictionary database, and the thesaurus database. The data warehouse and the geographical information system are not yet connected [3]. Their framework is close to an already available application for end-stage renal disease [4]. The middle tier supports client services through Web containers and business logic services through component containers. Business logic components in the middle ware support transactions toward the databases.

CEMARA fulfils several requirements: scalability, portability, reliability, accessibility and cost effectiveness oriented toward non-proprietary software [1].

Maintenance and evolutions are made centrally, which reduce deployment costs and delays. The structure of the production database was built according to a "beehive-like" structure.

The implementation began as of May 2007, initiated by fifteen centres. Coordinators were trained and on-site trainings were also provided for the rare diseases professionals. A technical assistance was also available.

Data entry sheets

All centres share a common core data set. It comprises identification data for the index case and family members, diagnosis, context and medical activity. According to the European Directives and French protection Act, permission was obtained from the "Commission Nationale de l'Informatique et des Libertés"[4] to identify patients on the basis of: name, surname, birth date, date of death, place of birth and municipality of residence. The respect of privacy, confidentiality and security [5] was ensured. An identification module warrants identity doubles using a double-entry prevention function [6].

Figure 2- CEMARA data entry sheet: patient identification.

Medical activities and mode of recruitment are recorded. Optional information is related to antenatal or neonatal data. Diagnosis is recorded using Orphanet classification cited above, as well as the circumstances of the diagnosis. A description of chromosomal abnormalities is also possible. Additional keywords are available for describing atypical signs and symptoms, or for patients presenting with a still unknown diagnosis. Several diagnoses may be provided for a given patient, if need be. Complementary information for specific diseases are described in the so called "petals", attached to the core data set, and focused on specific data collection. Petals are dedicated to follow-up specific diseases such as ichthyosis, nephronophtisis, nephrotic syndromes, cystinosis, juvenile chronic arthritis, rhombencephalosynapsis, rare congenital deafness, Turner syndrome, or neonatal diabetes.

Results

Demand of care

As of September 23rd 2009, the data set included 56.593 records comprising 29,241 male patients (1,605 foetuses) and 25,900 females (1,431 foetuses). Gender was indeterminate in 1452 foetuses. Median age of patients born alive was 9.2 years, (range: from birth to 87 years). Patients were mainly

[3] GENATLAS http://www.dsi.univ-paris5.fr/genatlas/

[4] CNIL : http://www.cnil.fr/english/the-cnil/

enrolled via outpatient clinics (39,402) or hospital wards (3,460). They were predominantly referred to CRs by paediatricians (20,646) and medical specialists (13,084). For foetuses, their mothers were mainly referred by gynaecologists (3,074) and by centres for prenatal diagnosis (1,012). Foetal cases were described during pregnancy (3,162), or after spontaneous miscarriage or termination of pregnancy (1,619). Figure 3 shows the heterogeneous distribution of patients with rare diseases according to departments per 10^5 inhabitants; in mean, 86 patients / 10^5.

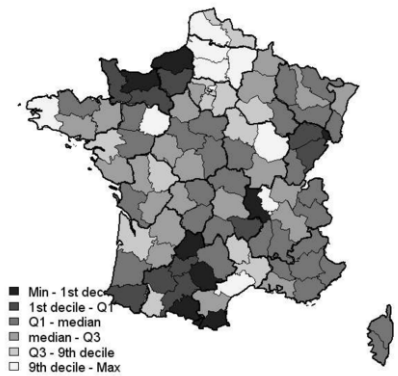

Figure 3- Distribution of patients with rare diseases according to French departments per 100,000 inhabitants

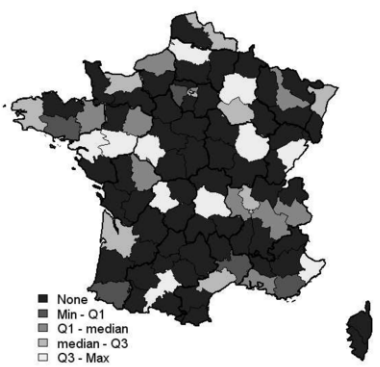

Figure 4- Distribution of CEMARA clinical sites in the French departments, according to departments'population

Table 1 and table 2 summarize the 10 most frequent diagnoses for the 4 centres of rare renal diseases (5,789 patients) and the 8 centres of rare developmental defects during embryogenesis (3,938 foetuses and 28,636 patients), respectively. They cover a broad spectrum of developmental anomalies[5].

[5] http://www.feclad.org/anomalies.html

Offer of care

Close to 850 members are presently registered in 171 clinical units of the 33 active registered RCs. All gave their consent and signed the confidentiality charter of the network. Figure 4 represents the distribution of CEMARA RCs offer of care. The offer of care is present in 35 departments out of 95. A median of 2 clinical units by region cater for patients except in Paris where there are 50 clinical units.

Table 1 – Ten most currently registered diagnoses by the 4 centres for rare renal diseases (879 unknown diagnoses).

Diagnoses *(n)*
Nephrotic syndrome, steroid-sensitive (*534*)
Polycystic kidney disease, autosomal dominant (*306*)
Posterior urethral valve (*285*)
Renal agenesis, unilateral (*244*)
Renal dysplasia, multicystic, unilateral (*228*)
Renal hypoplasia, bilateral (*208*)
Berger disease (*172*)
Renal dysplasia (*152*)
Hydronephrosis congenital (*138*)
Henoch-Schoenlein purpura (*135*)

Table 2 – Ten most currently registered diagnoses by the 8 centres for rare developmental defects during embryogenesis (1,552 "unknown diagnoses" for foetuses and 6,582 for patients).

Diagnoses *(n)*
For foetuses
Trisomy 21 (*153*)
Spina bifida (*84*)
Trisomy 18 (*80*)
Anencephaly (*44*)
Turner syndrome (*42*)
Osteogenesis imperfecta (*40*)
Holoprosencephaly (*36*)
Isolated corpus callosum agenesis (*36*)
Trisomy 13 (*35*)
Cleft lip with or without cleft palate (*30*)
For patients
Neurofibromatosis type 1 (*575*)
Marfan syndrome (*509*)
Trisomy 21 (*444*)
Noonan syndrome (*416*)
Osteogenesis imperfecta (*373*)
Intellectual deficiency with developmental anomaly, rare (*336*)
Fragile X syndrome (*307*)
Steinert myotonic dystrophy (*203*)
Beckwith-Wiedemann syndrome (*200*)
Cleft lip with or without cleft palate (*200*)

Institutional collaborations were developed with the Ministry of Health, the National Institute for Health Surveillance for epidemiological survey, with the French National Authority for Health[6] and the National Health Insurance Fund concerning the design of national protocols for diagnoses, treatment and follow-up, as well as for cost analyses, with associations of patients, university hospitals, for the coordination and networking of clinical correspondents.

Discussion

As of June 9, 2009, a recommendation of the European Council called for concerted action at EU and national levels in order to:

- Ensure that rare diseases are adequately coded and classified;
- Enhance research in the field of rare diseases;
- Identify Centres of Expertise by the end of 2013 and foster their participation into European Reference Networks;
- Support the pooling of expertise at European level;
- Share assessments on the clinical added value of orphan drugs;
- Foster patient empowerment by involving patients and their representatives at all stages of the decision-making process;
- Ensure the sustainability of infrastructures developed for rare diseases.

This recommendation was welcome since many patients with rare disease continue to advocate their need to overcome common obstacles.

An important challenge is thus to collect pertinent information on rare diseases in order to better assess the demand of care and adapt the offer of care.

CEMARA: networking rare disease reference centres

In this perspective, CEMARA offers a secured web-based information system via Internet for rare diseases dedicated to professionals of RCs. The platform is shared by 33 rare diseases centres in France, and recently 16 added centres joined the network in 2009. It helped networking 850 health care professionals belonging to 171 clinical sites who recorded 56,593 cases since 2 years. During this period, it stimulated sharing a common platform, a common ontology with Orphanet and initiating new cohorts of rare diseases for improving patient care and research. We developed a simple core data set to enable registering easily all patients presenting with a rare disease. A pattern of the demand of care could thus be initiated.

As expected, the number of patients per diagnosis is limited, even for the most prevalent diagnoses (tables 1 and 2). Moreover, for rare developmental defects during embryogenesis, nearly 1 out of 4 records are classified as “unknown diagnosis”. It means that no diagnosis has been reached, which is a common occurrence for patients with multiple malformations, whose syndrome do not fit with currently delineated entities. It is less frequent for rare renal diseases where 1 out of 6 records remained however with a not yet identified diagnosis.

Other networks for rare diseases have been proposed. For instance, the European Society for ImmunoDeficiencies (ESID[7]) promotes research on causes, mechanisms and treatment of primary immunodeficiencies (PID) [7]. ESID developed an Online Database network for PID. The French National Immunodeficiency Centre, CEREDIH[8], belongs to this network.

RAMEDIS [8] enables reporting cases of rare metabolic diseases. It is a platform independent, web-based information system. Developed in close cooperation with clinical partners, it allows collecting symptoms, laboratory findings, therapy and molecular data. Comparing and analyzing data was made possible by the use of standardized medical terms and conditions.

The British Paediatric Orphan Lung Disease[9] (BPOLD) [9] was dedicated to nine rare lung diseases in children in the UK. This registry is oriented toward describing epidemiological data, prevalence and incidence of these rare lung diseases. It also informs on research projects in order to improve treatment strategies.

The Tumori Rari in Età Pediatrica (TREP) project [10] was launched in 2000. It is an Italian cooperative project focusing on rare pediatric tumors. It is oriented towards improving clinical management, networking professionals and stimulating basic research on very rare solid malignancies in childhood (annual incidence < 2/million). Though an electronic web-based data management system is not yet available, in the near future it will support this multidisciplinary experience, a network of professionals sharing a common structured framework including practical management schemes and research project.

Demand of care for rare diseases: patients’ expectations

The demand of care is multiple and complex as illustrated by two recent EurordisCare surveys which investigated patients’ experiences and expectations regarding access to diagnosis and to health services [11]. The results of Eurordis Care2 showed that much remains to be done. For instance, 1 patient out of 4 reported a delay of 5 to 30 years to a confirmatory diagnosis of their disease from the time of first symptoms; misdiagnosis was reported in 4 out of 10 cases; 1 out of 4 of patients had to travel to a different region to obtain a diagnosis. Genetic counselling was provided in only 50% of cases which is low since most rare diseases are of genetic origin.

Over the two-year period preceding EurordisCare3, in mean, a patient required more than nine different medical services (from 4 to 12, according to the disease). One patient out of 4 reported difficult or even impossible access to services. The greatest barrier in accessing essential medical services was a lack of referral. Three out of 10 respondents required the assistance of a social worker in the 12 months preceding the survey. More than one-third experienced difficulty or even failed

[6] http://www.has-sante.fr/portail/jcms/c_5443/english?cid=c_5443

[7] http://www.esid.org/

[8] http://www.ceredih.fr/

[9] http://www.bpold.co.uk/

to find such assistance. Twenty-nine percent of respondents reported a patient in their family had to reduce or stop professional activity as a result of their disease and an additional 30% of respondents reported one member in the family had to reduce or stop professional activities to take care of a relative with a rare disease. The majority of patients reported a reluctance of professionals to treat them due to the complexity of their disease.

Federating Reference centres

These two studies confirmed that a lot remained to be done. The offer of care has to be organized in order to match the demand. CEMARA faced this major goal. It appeared as an efficient platform to gather useful information to aid promoting a better identification of the demand of care, a necessary step to better adapting the offer of care. To date, the offer of care described by CEMARA shows that it covers 1 out of 3 departments for a demand for care which covers the whole French territory. Thus, much remains to be done to allow each patient to have an appropriate access to care.

Federating RCs in France is also an important challenge for reinforcing European Reference Networks. The Rare Disease Task Force[10] (RDTF) at the European level contributes to networking professionals through its two main goals:

- advise and assist the European Commission Public Health Directorate in promoting the optimal prevention, diagnosis and treatment of rare diseases in Europe, in recognition of the unique added value to be gained for rare diseases through European co-ordination,
- provide a forum for discussion and exchange of views and experience on all issues related to rare diseases.

The Alliance Maladies Rares[11], the Association Française contre les Myopathies[12] (AFM) or EURORDIS[13] strongly stimulate a better knowledge for rare diseases and attaining the most appropriate offer of care.

Conclusion

An information system shared by professionals appeared a valuable support to better matching the offer of care to the demand. In this perspective, CEMARA proposed a secured information system via Internet for rare diseases centres. The platform is now shared by 49 rare diseases centres in France. It helped networking health care professionals. They share a web-based secured beehive-like platform and a common ontology with Orphanet. It also helped initiating new cohorts of rare diseases for improving patient care and research.

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The coordinators of the 49 centres who chose CEMARA for their information support are warmly acknowledged for their participation to the program as well as the members of all the centres. This work was granted by Paris Descartes University.

[10] http://www.rdtf.org/testor/cgi-bin/OTmain.php
[11] http://www.alliance-maladies-rares.org/
[12] http://www.afm-france.org/ewb_pages/l/la_une.php
[13] http://www.eurordis.org/secteur.php3?id_rubrique=1

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IMPACT: A generalisable system for simulating public health interventions

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Abstract

Populations are under-served by local health policies and management of resources, partly because of a lack of realistically complex models to enable a wide range of potential options to be appraised. Rising computing power coupled with advances in machine learning and healthcare information now enables such models to be constructed and executed. However, such models are not generally accessible to public health practitioners because they do not have the requisite technical knowledge or skills. This paper presents a system for creating, executing and analyzing the results of simulated public health and healthcare policy interventions, which is more accessible and usable by modellers and policy-makers alike.

Keywords:

Computer simulation, Graphical models, Epidemiology, Medical economics, Public health, Decision modelling

Introduction

Long-term conditions, such as Coronary Heart Disease (CHD), consume the largest proportion of healthcare budgets, and are a major target for public health initiatives. Moving interventions up-stream to earlier stages of the natural histories of diseases would delay or prevent subsequent events, thereby reducing the amount of suffering over the average lifetime, and saving money. Health policy-makers and those planning and managing local health services are poorly served by over-simple estimates of the potential public health impacts of making changes to the pathways of care or taking preventive public health measures. These estimates are often unreliable [1], because the models do not adequately represent the complexity of the disease, population or care over time.

Population health impact estimation is usually done by a small group of analysts synthesizing evidence and producing a report for a decision-making team. For example, how should the balance be struck between investments in statins vs. smoking cessation vs. physical activity promotion in respect of health impact for a defined population over five years? There are three problems with this approach: a) there are not enough analysts to support current decision-making needs, yet the available data and literature to consider is increasing - it is unlikely that health systems could afford to employ more analysts, and furthermore they are in short supply; b) a static report does not enable 'what if' scenario planning, so the options that are appraised are inflexible; c) most healthcare commissioning groups do not have the skills or time to build realistically complex models which take all reasonable factors into consideration, so decisions may be biased by where a narrowly defined model focuses –this may reflect the interests of service providers more than the needs of the population served. It is possible to construct graphical models of disease and healthcare pathways, and to use the resulting probabilistic networks to simulate outcomes for populations. Such a simulation system would enable the user to compare different intervention scenarios, with the ability to modify both clinical and public health interventions, and measure both the effectiveness based on clinical outcomes and costs. Such a system could bring together public health professionals, clinicians and service commissioners in interactive scenario planning activities to inform policy decisions. The ideal system would enable users to construct and share models around 'what if scenarios' easily; to execute individual simulations quickly; and to interpret simulation results collectively. Larger simulations, in terms of the population size, provide greater accuracy but consume more computational resources. The construction of models requires collaboration between health economists, epidemiologists, biostatisticians and typical decision-makers/leaders (public health professionals, healthcare managers, and clinicians).

In this paper we report on the IMPACT system that has been designed to enable this approach, by bringing together model builders, model users and computational resources to participate in shared decision-making.

Background

CHD is one of the most extensively modelled diseases, so we chose it as the focus for designing a generic system for modelling health impacts in defined populations.

A recent systematic review [2] of cardiovascular disease policy models concluded that models vary widely in their depth, breadth, quality utility and versatility, with few models ade-

quately validated or replicated in different settings. Moreover, few were available for inspection or transparent enough to fully understand model methods and assumptions. As such, the strengths and limitations of most models could not properly be defined, therefore few were acceptable for use in policy making. Most recently, a model published by the English Department of Health to support cardiovascular screening is both over-simple and not transparent [3]. Out of 70 modelling attempts identified in this area fewer than 10% published a paper and almost none have survived for a decade or more.

The first IMPACT model [4], typical of those used in Health Economics, was based on simple Markov propagation and implemented in a spreadsheet with over 44,000 cells – it required extensive training of users and was difficult to deconstruct for validation. Here we report a new approach to IMPACT, separating the generic modelling challenge from its application to CHD. Furthermore we separate the computation of the model from interaction with users, and address the generic problem of simulating public health impact.

Research Aim & Objectives

The mathematical methods and computing technologies required to unify model building, and use are available [5]. The aim of this work was to harness the unified modelling methods for health policy making. The main objectives were: to develop a versatile, flexible, valid and credible quantitative system for executing population disease models; to provide a single framework for domain experts to collaborate on model design and validation; and to provide a decision support capability that enables health professionals to interact with the models.

Method

System Requirements and Analysis

Taylor-Robinson et al conducted a consultation exercise with policy-makers on their attitudes to modelling and simulation [6]. The findings of that research were used to inform our requirements for the system.

Versatile and flexible

Our principal objective is to provide a generic system for simulating public health interventions, enabling users to to ask, find and reuse 'what-if' questions about options for preventive and clinical interventions in a population's health. This can be contrasted with the prevailing use of bespoke models often implemented with spreadsheet applications. Consequently, the system must contain a generic execution engine, that can instantiate a given *model* and perform the simulation. To create models, a model design tool is required that guides the end user through model creation and ensures valid models are created. What constitutes a valid model is intrinsically linked to the design and implementation of the model execution engine. The model alone cannot be executed; it must be configured with additional parameters that define a *simulation*. Thus a simulation is the combination of the model and the data that characterises the population, the environment, and the interventions being considered. Therefore the system must provide a tool that enables users to define simulations for a given model. We must also consider what the system will be used for. The IMPACT system is intended for answering five types of question:

- How will the burden of disease change over time?
- What will be the impact of specific treatment interventions/technologies?
- What will be the impact of population level/public health interventions?
- In terms of life expectancy is prevention more effective than treatment?
- Are interventions targeted at high-risk groups more effective than whole population level interventions?

The system must provide a tool that enables the results of a simulation to be analysed and visualised, and for comparisons to be made between simulations.

Transparent

Transparency was identified as a key requirement for users to be able to trust and subsequently act on the result of simulations. By transparency we mean that the system must be open to inspection at all levels. Consequently:

- The system software must be open source. We have chosen the Artistic Licence 2.0. The source code must have companion documentation that describes its architecture, algorithms and implementation that is accessible from the system.
- The mathematics underpinning the models and their execution must be formally documented and accessible.
- For each model, the model builders are required to supply descriptive meta-data that describes the risk factors and disease groups; data sources and main assumptions; the relative risk reductions of interventions; the uptake (availability and adherence) of interventions; the nodes of the graphical model; the edges of the graphical model, defining transition probabilities between health states; the observable outputs of the model; and terminology.
- For each simulation, the system must enable users to inspect the configuration that defines the population & environment, and the interventions.

Accessible

To achieve wide spread adoption, access to the system must be as easy as possible for the end user. Thus we are delivering the IMPACT model as a web application that requires no end user installation, configuration or maintenance.

The user interface must be simple and intuitive to use. In order to achieve this different classes of user are defined in terms of their intended use of the system, such that the functions and features available in each user class provides a different view of the system. This enables the complexity of the system to be hidden from the user interface if it is not required. Basic users can execute simulations, compare simulations, and edit simulations (restricted to modifying population demographics and

interventions). In addition, intermediate users can create new simulations. In further addition, advanced users can edit models.

Usable for collaborative model creation and decision making

The development and validation of models requires collaboration between statisticians/modellers, epidemiologists and health economists. Health policy-making is also a multi-disciplinary process. Web-based social computing technologies are widely deployed and used across many different disciplines [7] for collaborative working. This again favours a web application such that a shared workspace can be created and technologies for storage, retrieval and search of work products can be leveraged. In essence the system must bring people, data and methods together if it is to meet our objectives.

Model and Execution Engine

In the IMPACT system a population is modelled and simulated through the use of a number of graphical models. A population model is used to generate incident patients from the general population; the patients are then consumed by the patient model that models the life course in the presence of specific disease(s) and treatments. The priorities for the population and patient side models are different, so different types of model are used. As the patient side is concerned with the healthy life years gained from treatment vs. cost, and as clinical trials study treatments in isolation from one another, strong emphasis is placed on modelling the combined effects of different treatments.

The population model employs a Bayesian network [8] and is restricted to categorical variables for tractability of computation. There is a single node for the general health state, reflecting different levels of health, and one for each of the disease states considered. There is a time period associated with these states, producing a probability distribution over the health state of an individual at a given time point.

The posterior distribution over the general health and the various disease state variables in the patient model, together with the population size, are used to sample incident cases for the subsequent time period. Any variables relevant to the disease course are included in the generated cases.

Interventions are added as variables. In the simplest case they will have just two states, 'yes' and 'no', indicating compliance (or not). The associated probability mass function will describe the probability of compliance. But as they are variables like any other, they can also be made children of variables, which are believed to influence compliance. Children of interventions need to have their conditional mass functions updated to reflect the presence of the intervention. In the simple case this means retaining the existing probabilities for the 'no' state of the intervention, and specifying a corresponding set of probabilities for the 'yes' state. It is a very flexible approach, with the graph structure implying exactly what information needs to be supplied with an added intervention. More importantly, the effects of multiple interventions are handled naturally by the causal structure, with no need to resort to simplifying assumptions.

The patient model is governed by another graph where nodes represent variables. Generally, there should be a node for each variable where a change in state will influence the likelihood of a change in state of another modelled variable. Thus it will generally contain a node for general health, and a node for each possible intervention. Interventions will generally have some influence on disease progression.

It is possible to adjust the parameters of the models to reflect external factors such as changes in the population (migration) or in prescribing/availability of treatments. Migration can be modelled by adjusting the population size of a model at, say, annual intervals, and/or by adjusting ancillary variables such as ethnicity. Non-prescription/unavailability of an intervention can be accommodated by making a suitable adjustment to the relevant survival densities for a simulated case (such that a transition from 'yes' to 'no' is made immediately, or a transition from 'no' to 'yes' is scheduled for some time well beyond death). Thus the various components can be part of a larger simulation environment. New interventions can be added easily, and the structures of the models dictate what accompanying information is required.

System Architecture

The system was designed around a number of architectural principles. In the interests of transparency open source technologies were used and the IMPACT system has Service Oriented Architecture to provide a clean separation between components with a view to minimizing the impact of future development and to enable scaling through flexible deployment across a range of hardware platforms.

The system architecture is composed of four components that work together to provide the capability to create and edit models, to create, store and retrieve simulations, to execute simulations and to analyze results. The presentation layer is a web application that provides the interface for users to interact with the system. Views are provided for model editing and for configuring individual simulations through intervention editors, adherence and availability editors, region editors and cohort simulation type that specifies whether the simulation is limited by population size or epoch over which the simulation should run. Users can therefore select an existing simulation to run, modify an existing simulation by changing its parameters, modify and existing model. User accounts and role-based access control is managed through the presentation layer component. Because the user interface requires a high degree of graphical interaction, the lack of consistent support for a common standard in web browsers resulted in both VML and SVG implementations to ensure the system works across the full range of modern web browsers. The *data management* component provides storage and retrieval services for models, simulations and results. The system domain model is defined via entities, each of which provides the definition of a domain object and, where applicable, mapping attributes that specify how it will be persisted within the database; therefore providing an abstraction of the logical data model from the physical one. The Hibernate framework is used to perform the object-relational mapping. Users can therefore select an existing simulation to run or modify an existing simulation by changing

its parameters or modify an existing model by retrieving them from the data management component.

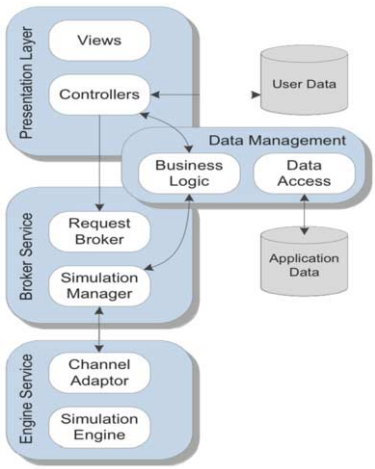

Figure 1-The IMPACT system architecture

The presentation layer interacts with the Request Broker Service (RBS) to execute a simulation. It uses the Data Management component to retrieve information required to configure simulations and to persist the results. The RBS is a client of the Engine Service, which it uses to set-up simulations, start execution and retrieve the results. The RBS is a web service and each RBS client is required to identify itself using an X509 certificate, which is validated by comparing it to existing client certificates held on the host. The use of X509 certificates enables the RBS to guarantee the integrity of the transferred data by including a digital signature in the request message. The Engine Service component is another web service that executes simulations and returns the results under the direction of the RBS. The engine service is composed of two sub-components. The Simulation Engine actually performs the simulation. Given a simulation configuration it instantiates and configures the model according to the simulation definition that it is passed. Once execution is complete, it returns the results. The simulation was developed primarily in Python with some mathematical functions written in FORTRAN. As the other components are developed in C# on Microsoft .NET technology this led to the decision to allow the Engine Service to execute on a different server from the Request Broker Service; it was therefore necessary to be able to configure a simulation and obtain results across a network. To support this, a *channel adapter* was developed for the Simulation Engine that exposes a web service interface to support both the configuration of a simulation, execution and the return of results based on the exchange of SOAP messages over HTTP. This architecture allows multiple Engine Services to be deployed to execute simulations, ensuring the future scalability of the system to many concurrent simulations and improving the tolerance of the software to problems such as hardware failures and network faults.

Results

The IMPACT simulator is deployed and available on the Internet at http://www.impactsimulator.org.uk.

Validation

The system has been tested by using it to implement and validate the IMPACT model of coronary heart disease.

The validation process is an integral part of model development. It helps in identifying issues with model implementation, data and assumptions. More important, it is a key element towards increasing the model value for policy makers. However, this aspect of model development has been frequently overlooked in cardiovascular disease modelling [2].

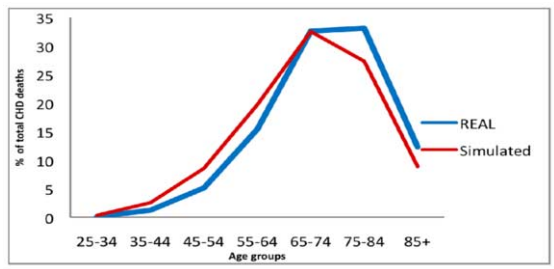

Figure 2 -Distribution of CHD deaths by age, simulated vs real

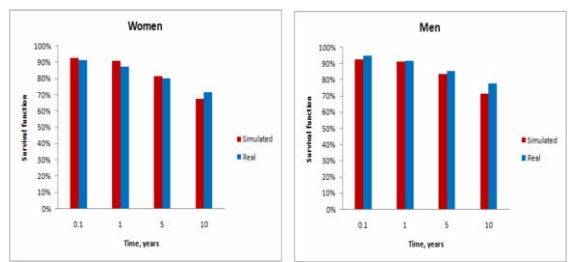

Figure 3 -Comparison of simulated and real survival functions at selected time in years, men and women.

We validated the model by simulating the SLIDE cohort, a cohort of survivors of acute coronary syndromes in Scotland [9]. Our aim was to reproduce with the model CHD mortality experience of the acute myocardial infarction sub-cohort. (n=80241). For this, we simulated a population with the same age and gender structure of the real sub-cohort, and enabling the simulation to take into account historically plausible treatments effects.

The model produces an age distribution of CHD deaths that resembles the real cohort (Figure 2), although it tends to overestimate the absolute number of events. This is probably related to the fact that the model cannot replicate the actual censoring that happened in the real cohort. Mortality calibration issues related to this particular population might be also relevant, as well as an underestimation of treatment effects, due to

lack of Scottish specific treatment uptake data for the period. The Kaplan-Meier survival functions generated by the model were similar to the observed ones (Figure 3). These preliminary results are encouraging. They demonstrate that the system is usable for model creation and execution and that the predictions of such models match observations. More validation work is needed, specifically regarding comparisons with different cohorts and populations. In addition, the validation process will offer valuable insights towards improving the model ability to produce more accurate estimates of the number of CHD deaths, data visualization and model functionality.

Figures 2 and 3 show close concordance between death rates simulated by IMPACT and those observed in a well-studied case cohort.

Discussion and Conclusion

The next phase in the evaluation will be to return to the community of planners and policy makers [6] to assess the usability, accessibility and utility of the system and the IMPACT CHD model. The usage and uptake of the system will be monitored, as this will be the key measure of success.

Future work is planned to parallelise the simulation engine to take advantage of multi-core and cluster computing. This will dramatically reduce the simulation run-time making the system more usable for complex models and large populations. The modular nature of the architecture enables the use of cloud computing infrastructure in the future.

The IMPACT simulator will be integrated into the nascent e-Lab population health information system [10]. This will leverage electronic health record data to refine, extend and localise models. The e-Lab platform provides the Work Object mechanism as a way of exchanging knowledge between federated e-Labs in different localities. The IMPACT Simulator already has the capability to export IMPACT Simulation Work Objects (ISWO) for a specific simulation, including information used to configure the simulation and the outputs from the simulation. As each simulation is configured based on evidence gathered from range of sources (including clinical trials and literary reviews) and makes use of specific statistical methods, the outcomes of each simulation can only be fully understood in the context of these methods and evidence. The ISWO provides a semantically unambiguous way to explicitly relate components of a simulation together along with statistical methods, decisions and evidence.

Unified modelling frameworks such as IMPACT may encourage epidemiologists, health economists and public health practitioners to contribute to open, accessible policy models rather than creating a blizzard of niche models.

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A full-text information retrieval system for an epidemiological registry

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Abstract

Case finding for epidemiologic registries still relies mainly on a manual process. In this paper, we show that retrieval information tools could be a complementary way to identify cases for a pediatric malformation registry. We developed a full-text and metadata search engine plugged to a clinical documents repository and used it to identify Epi/Hypospadia and Spina bifida cases. The queries were enriched with Snomed terminologies. We compared the performances of this prototype versus the hospital DRG database (classical method). The best precisions of prototype for identification of Spina bifida and Epi/Hypospadia were respectively 73% and 87%. The prototype overlap with the DRG system was 83% and 97%. Compared to DRG, 13 new not referenced and 2 miscoded cases were detected. This free full-text retrieval system prototype allows efficiently reusing clinical documents for case finding for an epidemiologic purpose.

Keywords:
Registries, Epidemiology, Information Storage and Retrieval

Introduction

The conventional method of case finding used by many institutions to feed an epidemiologic registry is still largely to manually scan and read printed reports or manuscript notes generated during the health care process. These documents are most of the time archived in the paper patient record. This task aims to identify cases in a comprehensive way. It is a painstaking, time consuming and costly work [1]. With the development of Electronic Medical Records (EMR), patient data are more accessible as ever, however these data remain widely coded as free text. Clinicians either dictate or type relevant patient data into the EMR without formal structure or a controlled medical vocabulary.

Coding information is difficult and the reasons why clinicians are so reluctant to do it are well identified [2]. So, clinicians still code little information, either because it's mandatory (e.g. for the billing process), or because they derive a direct benefit (e.g. in term of scientific research or patient safety). Hence, electronic free text medical reports are a mine of information for the registry feeding or cohort enabling, but they are also difficult to exploit. Numerous works have been carried out to develop NLP methods for automatically extracting information from patient data but they are still rarely applied outside of the laboratory [3]. An alternative way to achieve this goal is to provide to clinicians, information retrieval tools (that rely on methods of indexing, searching, and recalling data, particularly text or other unstructured forms). These tools, derived from the web technologies are today broadly used for searching accurate information amongst terabytes of data for personal information management as well as on the Internet (e.g. Google Desktop or Apache Lucene). Hence, "Finding a needle in a haystack" becomes a reality.

For example Schulz & al. [4] have developed a retrieval system to support search across patient discharge letters. They used a linguistic transformation method to deal with the morpho-semantic wealth of German language. They have shown the very good acceptance among the physicians of a WWW-like querying. Few works using these technologies have been carried out in the epidemiologic field. For example, Hanauer & al [5] have defined a custom-made list of terms, phrases and Snomed codes intended to build free text query. Their system was designed to populate a cancer registry database.

Rosier & al [6] applied regular expressions to extract relevant information from surgical reports in order to populate a cardiologic registry.

In this paper, we describe an information retrieval platform combining a searching engine "plugged" to a clinical documents repository automatically fed by our Hospital Information System (HIS). We study the performance of this retrieval system in order to identify cases for an epidemiological pediatric registry. We compare our searching method using free-text clinical documents and their related metadata versus a classical query method, based on the DRG (Diagnosis related group) coded database. We study also the interest in our system of using SNOMED (versions 3.5 and CT) terminologies for a semantic enrichment of the full text queries. As the coverage of the DRG coded database is structurally lower than our EMR repository (as it concerns only inpatients) we measure the added value of our system to identify cases that are not reachable through the DRG coded system.

Materials and Methods

The pathologies studied:

This work fits within a broader feasibility study for the future neonatal malformations registry of Brittany (France). This study focuses on Epi/Hypospadia, Spina bifida malformations.

According to the MeSH definitions, Epi and hypospadia *are* birth defects due to malformation of the urethra in which the urethral opening is below its normal location. Spina bifida is a congenital defect of closure of one or more vertebral arches, which may be associated with other malformations.

Population of interest:

We searched cases amongst children aged 1 year old or lower, born between 11/1/2006 and 11/1/2008, and who had a contact with the University Hospital of Rennes until March 1rd 2009.

System design:

We developed a repository containing the medical reports corpus extracted from our HIS (see Figure 1). The repository is automatically fed by an Extract Transform and Load (ETL) process. ETL is a process in database usage and especially in data warehousing that involves: Extracting data from outside sources; transforming it to fit operational needs (which can include quality levels); loading it into the end target. Each document extracted from the EMR is associated with a XML notice containing all the relevant metadata available from the EMR such as patient information (birth date, sex, weight) or administrative information (such as ward id, dates of admission and discharge). Then the documents and the XML notices have been indexed. We used Apache Lucene [7] as the indexing and search engine tool.

Lucene is an open-source, high-performance, full-featured text search engine library written entirely in Java. It relies on the tri-grams indexing method, allowing phrases, wildcard and proximity queries and returns ranked search results. All the developments were based on web 2.0 technologies (PHP, Ajax). The system provides statistical analysis: e.g. occurrence of expression present in each document, and in the whole corpus. Accessing the document is immediate, and the searched expressions are highlighted in the text to make the reading easier (see Figure 2).

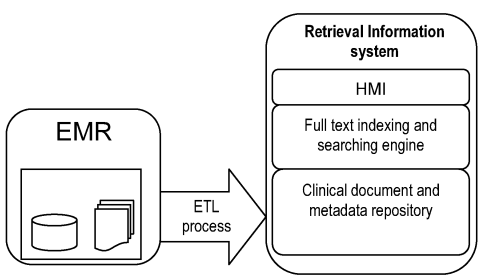

Figure 1-System design

Free Text queries building:

For each pathology, we asked 2 experts (a pediatric surgeon, and a pediatric physician) to provide ten of the most meaningful literal expressions usually employed in clinical notes and that characterize these pathologies. In order to avoid a too high level of noise, a third expert split these expressions in two sets:

The "Major set" consists in expressions relative to the diagnosis and a procedure used in these pathologies (e.g. "neural tube defect" or "myelomeningocel" for *spina bifida* malformation).

The "Context set" corresponds to expressions not directly explicit, but used often with one or more major expressions: for example the anatomical term "penis" or "prepucial" for *Hypospadia* malformation.

As a registry is supposed to be exhaustive, we tried to semantically enrich the expressions given by the experts, by building the "extended major set" containing expressions with synonym and subsumed terms found both in Snomed (version 3.5 and CT). Amongst these candidate terms, we selected only those containing any redundant terms (regarding to the other expressions) e.g: for *spina bifida,* [76916001:Spina bifida occulta] was ruled out, [61819007:Rachischisis] was ruled in.

Then, for the two pathologies, we built 6 queries, combining with Boolean expressions the expressions from respectively the Major set, Context set, and Extended Major Set.

In order to avoid searching in the narrative text different morpho-syntactical forms of a same expression, we transformed them in morphemes. Below is an example of full text query for *spina bifida*. The contextual expressions are underlined.

Expert expressions : *Spina bifida, myéloméningocèle, méningocèle, Fermeture du tube neural, syndrome d'Arnorld Chiari, paraplégie, agrandissement de vessie, cystosomie continente, intervention de Mitranoff, intervention de Malone, sphincter artificial.*

"Major set" query :*(spina) (bifida) (myelomeningocele*) (+fermeture +tube +neural)(meningocele*)*

"Context_set" query:*(+Arnold +chiari) (paraplegie)(+agrandissement +vessie)(cystostomie continente) (mittranoff)(malone)(+sphincter +artificiel)*

"Extended set" query: *(spina) (bifida) (myelomeningocele*) (+fermeture +tube +neural)) (meningocele*) (+rachischisis +aperta) (syringomyelocele*) (meningocele*) (meningomyelocele*) (myelocystocele*) (hydromeningomyelocele*) (+hydromeningocele* +spinal) (+spina +fissure*) (hemimyelocele*) (lipomeningocele*) (rachischisis) (holorachischisis*) (myelocele*) (hydromyelocele*).*

Assessment:

We compared the outcomes of the full text method with the information available in the DRG system (called the PMSI in France). The PMSI aims to provide medico-economic statistics for the hospital budget.

As the PMSI information is supposed to be exhaustive, we used it as a gold standard. It contains the entire coded discharge summaries for all inpatients. Each summary is coded

with ICD10 diagnosis and CCAM procedure classifications. In French hospitals, this coding concerns only inpatients. In our hospital, this coding is centralized and manual. We searched all the patients having a coded discharge report in the DRG System, with ICD10 codes relative to one or more of both pathologies studied.

DRG query building:

For each pathology, a DRG expert selected the codes from ICD10. Two medical experts reviewed these codes. Then we queried the DRG database, using SQL language. For example, the query for spina bifida concerned all the codes starting by *Q05*, which includes of course *spina bifida*, but also codes detailing specific anatomical types e.g : *Q05.1:Thoracic spina bifida with hydrocephalus, etc.*

Comparison method

Two authors reviewed manually each case found by the two searching methods. We searched for the wrongly coded cases and looked at the pertinence of the expressions found with the search engine. For example, for the free text, if the expressions were used with negation, or written in the list of familial histories, the case was considered as False Positive (FP).

For the DRG coded query method, we checked if the DRG were in adequation wih the content of the medical record.

We tried to figure out the reason of non-agreement between the both methods: if for example a case was found by the ICD10 method and there was no track of information of this diagnosis in the medical record, then we considered the case as being "wrongly coded" and false positive.

We also characterized the contributions of the extended set. For each query, we calculated the percentage of added cases owed to the Snomed enrichment.

In France, the coverage of the DRG system only concerns the inpatients. As our clinical documents repository gathers inpatient and out patient's medical reports, it represents a source of information broader than the DRG, and contains potentially precious information about newborns who have been seen only in consultation. Therefore, we measures the number of cases we spotted with our system and amongst them, the number of cases that are true and false positive.

Results

Information sources features:

The clinical reports repository contained 787.000 documents such as surgery reports, clinical notes, or discharge summaries. A subset of these documents, corresponding to the period of study was selected thanks to the "birth" metadata extracted from the HIS. This subset contained 16.512 documents . The full text queries have been applied on this corpus. The run time to queries never exceed 6 seconds.

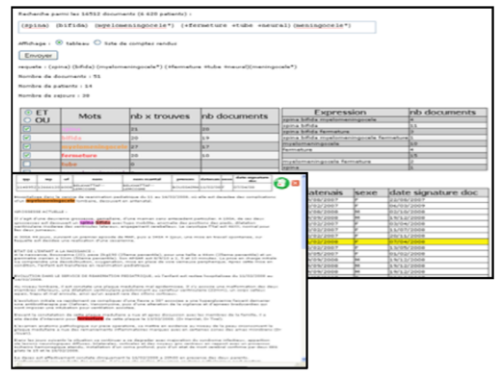

Figure 2-Screenshot of the Retrieval Information System

Cases found with the full-text queries

For the *spina bifida*,
With the "Major set" query, using only the expression given by the two experts, we found 51 documents related to 14 different children and corresponding to 38 contacts in the hospital (in and outpatients). Among them, after checking each document, it turned out that 11 cases were true positives (precision = 73%) i.e. patients for whom there was one or several reports containing an explicit reference to spina bifida. 3 cases have been considered as false positives (FP) and corresponded to the use of related terms in the familial history section of the documents.

The "extended set" query contained 14 supplementary expressions derived from the Snomed terminology but none of these expressions has been found in the reports. So the cases found with the "extended set" query were strictly the same as for the "Major query".

The "context set" query which contained "major" and "contextual" expressions, returned 65 documents related to 20 patients for 47 hospital contacts . Obviously, these results included the cases of the "major set" query. The six new cases were actually five false positive, so the precision was 55%: for example , documents for three cases containing the expression "Malone" which is both the name of a surgery procedure, and the first name of the three patients; one case related to a paraplegia thought it was not caused by a spina bifida. One case corresponded to the maternal familial history, another case was considered by the physicians as a possible spina (a MRI was ordered to confirm the diagnosis), but we didn't consider this case as true positive.

For the epi/hypospadia, with the "Major query", we found 318 documents related to 116 different children and corresponding to 274 contacts in the hospital (in and outpatients). Among them, after checking each document, it turned out that 102 cases were true positives (precision= 87%). 14 cases have been considered as false positives (FP). In 4 cases, we found a negation associated to the expression (e.g : "*no argument for an hypospadia*"), 6 cases were related to an abnormality of the penis with close similarity with an hypospadia (e.g : chordee is a condition strongly associated with hypospadia) but, eventually, the surgeon or the pediatrist did not consider that this

was an actual case of hypospadia. Two cases were related to a penis surgery, but for another problem. Two case contained "hypospadia" in the familial history section. Let's note that we only found one case of epispadia (this pathology is very rare).

The "Context set" query has brought out 45 FP cases, 95 % concerned another diagnosis, 5% a normal clinical exam.

The "Extended set "query (with Snomed) for this pathology was exactly the same as the expert's one. Indeed, after having applied the non-redundancy rule (defined in the method), no new expression was found.

So, for both pathologies, the method using the Major set query (i.e. using only the expressions given by the experts) turned out to be the best one.

The "Extended set" queries gave the same results either because the added expressions were not present in the clinical reports, or because, according to our method of semantic extension, no new expressions were added in the query.

Concerning the "context set" query, for both pathologies, the new generated cases were only FP that is noise.

Comparison with the DRG system

We compare here the best method (i.e. "the major set" using only the expression provided by the experts) versus the DRG query method.

In order to analyze comparable populations, we only consider the hospitalized patients (inpatients).
We calculated the number of patients corresponding to the following sets (Figure 3 illustrates the relationships between these subsets):
Set A =C+D: cases retrieved by the full-text method amongst the inpatients
Set B =C+E: cases retrieved by the DRG methods
Set C: cases retrieved by both DRG and full-text methods
Set D: cases retrieved amongst the inpatients and only by full-text but not by DRG method
Set E: cases retrieved only by the DRG method
Ratio C/B: % of coverage of full-text / DRG method

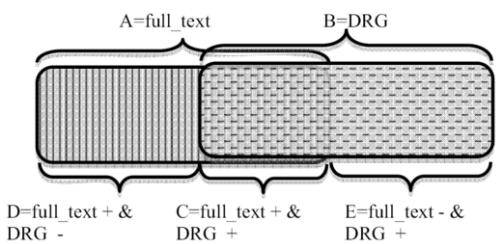

Figure 3-Set definition

The results (in number of patient terms) are presented in the following table for each pathology. The number of true positives and false positives are given for the discordant sets (sets D and E)

Table 1 -Comparison of full text vs DRG searching methods for spina bifida and hypospadia.

Sets	Spina bifida	Hypospadia
A	10	98
B	6	88
C	5	85
D	5 (3TP and 2 FP)	13 (9 TP and 4 FP)
E	1 (1 FP)	3 (2TP and 1FP)
C/B	83%	96,5 %

Concerning the set D *(full text + and DRG -)* and for both pathologies, our system found 12 new true positive cases. These cases weren't retrieved in the DRG database, because they were either not coded, or the DRG summaries didn't contain any code relative to the malformations.
Inversely, our system found 6 false positive cases. The reason was the same as the one quoted above (e.g.: expressions associated with a negation, or found in the familial history, etc).

Concerning the set E *(DRG + and full text -)* and for both pathologies, the DRG method found 2 True Positive cases. It turned out that these cases were coded from manuscript notes, or from the paper-based medical record, so no electronic clinical document about these children was present in the hospital information system.

Inversely, 2 cases were false positives and where clearly due to miscoding.

Added value of the full text method:

Compared to the DRG system, which is focused only on inpatients population, our system, gives in addition access to the outpatient population. The new cases found from this population are summarized in the following Table 2.

Table 2-New cases found with the Full text method from the outpatient population.

	Cases found from outpatients population	TP	FP
Spina bifida	2	2	0
Hypospadia	19	13	6
Total	21	15 (68%)	6 (27%)

Discussion

Our system aims to help researchers retrieve relevant information amongst a huge number of documents. The results are quite good according to the very good overlap between the full-text and the DRG coded sources (83% to 96,5%).

As we dealt with very rare pathologies, we were not able to calculate classical measures of the search engine efficiency (especially recall, Fall-out or F-measure). Indeed, this would have supposed to check a documents sample large enough for containing a significant number of cases, i.e. probably an enormous sample. For this study, we used the same methodology as Li and al. [8] who had carried out a similar study for searching eligible patients for clinical trials.

As the related previous study carried out by Moskovitch and al [9], our outcome tends to show clearly that a combined strategy, using both full text and structured methods, can improve the search of clinical cases for epidemiologic registries. Indeed, the use of the "birth date" metadata for selecting a subset of the clinical reports has clearly helped us to define a context (newborns aged =< 1 year old). This first selection allowed avoiding the adult cases. We plan to include in our system more metadata or structured information in order to reinforce this mechanism.

The noise is the main problem of the full-text searching method. We got a low noise level, probably because the expressions used in the queries were very specific and because we had started by selecting a subset of documents, using the metadata extracted from the HIS.

We assumed that the semantic enrichment of the queries could improve the search of news cases. It seems here that is not the case. The expressions given by the experts were sufficiently comprehensive and specific. Despite this, a terminological system could be useful to help users for designing queries, especially if the user is not a domain expert.

Unlike Moskovitch [9] we didn't find better performance by adding contextual expressions to the queries. On the contrary, these expressions have caused noise.

We were rarely confronted with lexical variations, even if the step of morphemes transforming was manual. Our system could certainly be improved by reusing methods [4] of automatically transforming natural expressions into "sub words" (or lexical units) straightly useable by the search engine.

Finally, from a technical point of view, we were careful to take into account the usability of the system. The system was developed with the Web Ajax technology and so allowed to improve the system accessibility while keeping good ergonomics, as it has been already shown [10].

For example, users could instantly open the reports and check their pertinence at a glance (the keywords were highlighted like Google cached pages [11]). Statistics were also very useful to assess if the query or a document was relevant.

We designed the system in order to be integrated to the HIS but we deliberately chose to build an independent data repository for several reasons.

First, querying such a huge set of documents would be overloading the HIS if the search engine was directly connected to it. This would compromise the health care process in an inacceptable way.

Second, we wanted to control the ETL process, which is a critical step in data warehouse building. Indeed, some information has to be cleaned or corrected before loading (e.g.: outliers, birth date, missing data, incoherent identities).

Third, we can consider extending the repository to other data sources (such as biologic tests or genomic data) and for other purposes such as searching patients eligible for a study.

Conclusion

This prototype allows to efficiently reuse clinical documents for case finding for epidemiologic purposes. As a perspective, we plan to create a regional repository that gathers information from different HIS.

Acknowledgments

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Obesity Atlas and Methodbox: Towards an Open Framework for Sharing Public Health Intelligence Workflows

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Abstract

The large growth in data sources relevant to public health has not been matched by a growth in human resource for producing intelligence to support decisions or generate new insights. There is a need to bring scarce public health expertise into closer alignment with data and data processing methods to support timely public health analysis. The difficulties of developing and sharing this expertise in large organisations such as the UK's National Health Service have long been recognised. We report findings in this area across two projects Obesity Atlas and Methodbox, which are developing and sharing best practice between Public Health Analysts in England, and we address the relevant generic knowledge management problems in the Public Health community.

Keywords:

Public health intelligence, Workflow, e-Lab, Knowledge management

Introduction

Most public health analysis in England takes place in Primary Care Trusts (PCTs), which are responsible for commissioning health services for populations of around 300,000 people. Each PCT employs analysts who collect and analyse local and national health-related data to support local decision-making. Analysts from the different PCTs belong to informal public health intelligence networks which meet regularly to exchange ideas and share expertise. They also communicate by frequent ad hoc telephone and email conversations.

Despite regular communications within and between PCTs' analysts, we identified substantial difficulties in finding information for particular analyses in a timely manner. For example, analysts reported issues such as the difficulty of locating an email sent a year ago which discussed the calculation of an annual statistic, or uncertainty around deciding how and when to apply different versions of a method. All of these difficulties can be characterised as knowledge management problems. The term 'knowledge management' refers to a broad group of activities around the creation, sharing and adoption of expertise and understanding. Knowledge management looks beyond the sharing of information (e.g. the definition of a statistical method) and considers the experience and tacit knowledge required to make use of the information, such as how and when to apply the method, or who is the relevant local expert. Such knowledge, often tacit to individuals or teams, can be difficult to transfer to new staff and is easily lost to an organisation when people move to new jobs. This folk knowledge (making connections, shared learning through problem solving) is often highly contextual and held only in people's minds or reflected in e-mails or informal communication channels such as forums or instant messaging – ideal for supporting the processes of knowledge exchange and problem solving, but poor long term repositories, which cannot be searched and cannot generally provide reliable, accessible context data.

Bate and Robert's review of knowledge management practices in the UK National Health Service (NHS) [1] compared the relative maturity of private sector companies with what they describe as a 'naïveté' around knowledge management within the NHS. In particular, they observed a policy of 'top down' imposition of networks intended to support the sharing of best practice and expertise which was considered unlikely to be successful or self sustaining, and contrast this with a recent change of approach within the private sector to support more organic, grass-roots knowledge sharing activities and naturally-occurring networks

Previous reviews of knowledge management practices in the NHS identified successful approaches as well as pitfalls. The CHAIN (Contact, Help, Advice and Information Networks) project [2] succeeded in fostering the development of a community, and helping users find people with particular areas of expertise. This study highlighted the importance of the social dimensions of knowledge management – whilst there was a technical element (the development of a messaging system), the success of the project depended on vigorous facilitation by an email list administrator, who created new connections between pre-existing groups.

Studies of knowledge management have tended to focus on technologies for storing knowledge [1]; there have been few in-depth case-studies of the human factors and the wider processes of managing knowledge. Storey [3] observes that often, there can be too much focus on the technology, a sense that if only the right technology is in place, people will be able to make use of it, but this has repeatedly been shown not to be the case – successful knowledge management projects build on existing networks. Consequently, we report the engineering of

two pieces of knowledge management software as extensions of a user community, involving users from inception.

Obesity Atlas

Like many western countries, for more than half a century, the UK has recorded the heights and weights of children in order to monitor their growth [4]. More recently these data have been used to produce public health reports for obesity surveillance and local planning [5]. The Obesity Atlas project aimed to develop software to automate the cleaning and analysis of these data.

We identified a number of knowledge management requirements. First and foremost was the need to support a disparate group of Public Health Analysts, from different organisations and backgrounds, to converge on a single workflow for data cleaning & analysis and interpretation of the resulting child obesity profiles for their localities. The analysts work independently in separate geographic areas and are used to determining their preferred analysis approach in isolation. Whilst there were aspects of the workflow on which it was easy to reach a consensus (e.g. which summary statistics to use), other steps were more ambiguous (e.g. handling missing and possibly erroneous data – some analysts may choose to exclude records with any missing data, other analysts may decide to keep those records depending on exactly which fields are missing, or alternatively may choose to go back to the data supplier for clarification). Therefore agreeing a shared workflow for such decisions requires the analysts to negotiate and share their tacit knowledge. In other circumstances, rather than working with the analysts to agree a common workflow, the system has been built to provide some flexibility, for example providing obesity profiles based on different definitions of child obesity.

We used a variety of requirements-gathering techniques to facilitate this negotiation process, including group discussions and meetings, one-to-one formal meetings, informal telephone conversations, and workshops allowing users to interact with prototypes. The use of prototypes was particularly successful, users were able to respond to and interact with simple prototype versions of the software. This interaction encouraged and inspired participants to discuss additional functionality that was incorporated into the system.

The analysts identified two workflow types, data pre-processing and data querying. The data pre-processing workflow included data categorisation, cleaning, standardisation and integration. Once uploaded and pre-processed, the dataset is ready to be queried. There were four functional types of data query: statistical analysis; thematic mapping, charting, and locality profiling. The latter is a context-specific superset of the former three.

The most sophisticated query was the locality profiling in the context of creating a consistent PCT-level profile of child obesity. A profile is a document resulting from a series of data queries. The profiles summarised child obesity statistics for the PCT in a standard format that could be compared with other PCTs. It also compared obesity prevalence by socio-demographic groups and geographical areas within the PCT. Thematic maps showed the spatial distribution of obesity; and charts and accompanying statistical modelling results reflected relations (or not) of obesity with deprivation, ethnicity, or other groups specified by the user. The profile is produced automatically following the upload of a dataset, saving each analyst several days of work, and provided to the user as a downloadable document of approximately 30 A4 pages. Again, the content and format of the document was designed in consultation with the PCT analysts. The document was designed such that components can be extracted and reused in official public health reports. An example component (a thematic map) showing the relative levels of child obesity within Bury PCT sub-regions is shown in Figure 1.

Obesity Atlas V1.0 has been released and is being used by public health decision makers and data analysts across the 10 Greater Manchester PCTs; it is informing their decisions on local public health policy to monitor and reduce childhood obesity[6, 7]. Early feedback is very positive and ongoing improvements and support will be delivered by the Northwest e-Health programme[8], which is set up to sustain health informatics innovations as reliable services for the NHS.

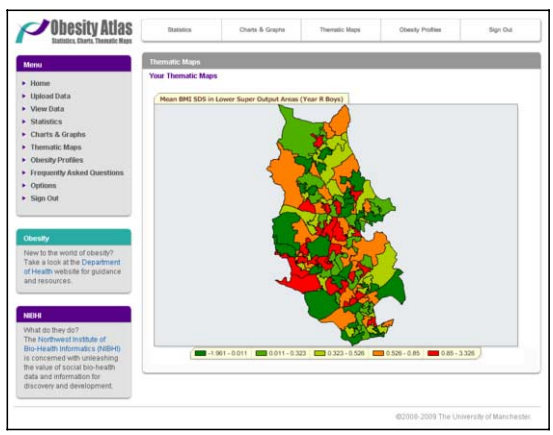

Figure 1- Thematic mapping in Obesity Atlas

The Obesity Atlas project is an example of combining the expertise and knowledge of many public health analysts to converge on an agreed workflow and produce a piece of software that dramatically reduces the burden of analysis on the PCT staff. From a knowledge management viewpoint, the process has enabled a group of experts to work together, sharing their tacit expertise to agree on a set of best practices for this analysis process, which have then been automated. This expertise has now been captured, holding it within the organisation, so that if any of the analysts involved in the project were to leave, the relevant organisational memory would persist.

Methodbox

Our team is now working on a project which takes a wider view of analysts' working practices. Rather than focussing on one single workflow, the Methodbox project [9] looks at supporting PCT analysts and academic researchers in sharing

analysis expertise and methods – applied in the first instance to large health surveys. Methodbox draws on the experience of managing knowledge in e-Science settings, particularly on sharing workflows and using social networking technologies to share expertise [10]. The initial motivation for the project was the recognition that understanding the obesity epidemic at the population level requires expertise from disparate disciplines including medicine, biology and the social sciences, as well as the involvement of academic and NHS researchers – experts who are interested in learning from other disciplines but who find accessing another field challenging for numerous reasons including language, methods, tacit assumptions and background to the work.

The first stage of our project was to interview NHS analysts and academic researchers who either currently use or have expressed an interest in using Health Survey for England (HSE) [11] in order to understand current working practices and barriers to use of the survey. HSE is the largest scale annual health survey in the UK and is intended for both health policy and scientific purposes. Its datasets, although freely available, are complex and perceived to be under-used. We held two workshop sessions at regular meetings of North West England Public Health Analysts, followed by longer interviews with three volunteers. We also interviewed five academic users of HSE, three epidemiologists and two social scientists.

Many of their concerns relate to problems accessing expertise and knowledge about the specifics of how to work with HSE. The most frequently cited reasons for not using existing data were methodological concerns over how to go about using the data, for example understanding the circumstances in which to apply weightings to a survey – tacit expertise that is not easily codified into clear-cut rules. Interviewees also reported being overwhelmed at the size of the dataset, difficulties working with the documentation and a lack of worked examples. Similarly, whilst the expert academic users we interviewed had developed coping strategies for many of these problems, novice academic users also felt the lack of examples and found the size and complexity of the survey and metadata problematic. They were equally unsure of how to access expertise.

These concerns have informed the design of Methodbox. Methodbox provides tools to support the individual in working with HSE data, including improved metadata searching and the ability to download selected slices of a survey rather than entire datasets, but also provides support for collaboration and networking in order to address many of the knowledge management concerns expressed by the analysts. Methodbox allows users to share their expertise with other analysts, whether that be a comment about a variable, a script demonstrating how to harmonise educational variables across several years or a publication they have used, but it does this in a rich context specific way, creating links between the data, for example:

- An analyst's comment about a variable is associated with that variable, so that any search returning the variable will also display the comment to other users. A second user can react to the comment, adding their experiences or suggestions.
- When uploading a harmonisation script the user can link the script to all the survey variables used within that script, providing a rich example for other users. Another analyst who refines the script can upload a new version, linking back to the original script and adding comments to develop the discussion.
- A user can upload details of a publication, perhaps providing evidence in support of a method they have chosen to use, or uploading their own publication, and associating it with a script and a set of variables, used in generating the published results.

Thus Methodbox allows users to interact with each other, in an environment that supports richly contextual information sharing, and allows the searching and indexing of content.

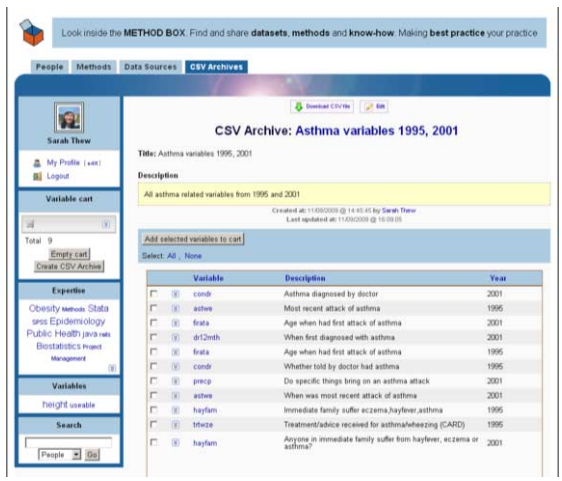

Figure 2- Methodbox Prototype showing a selection of asthma related variables collated by a user from Health Survey for England 1995 and 2001

A prototype system has been developed which is being tested with academic public health researchers and NHS analysts. Based on the experiences of other relevant knowledge management projects we are focusing on building existing communities [12] by working alongside NHS Action Learning groups, PhD supervisors & students, and topic-specific research groups. We believe the system will encourage wider sharing and improved communication between different communities. Whilst a social scientist and an epidemiologist, both interested in public health issues around obesity, may superficially appear to have much common ground, the methods, language and tacit assumptions underlying their analyses can be quite different. Methodbox aims to bridge the division of knowledge that results from this specialisation by providing rich, worked examples of analyses from different disciplines.

e-Labs and Work/Research Objects

The Obesity Atlas and Methodbox activities feed into the general e-Labs initiative, focused on healthcare by NorthWest

e-Health [8]. An e-Lab is a set of integrated components that, used together, form a distributed and collaborative space, enabling in-silico investigations. An e-Lab brings together data, methods and people sharing a currency of Work Objects (digital resources encapsulating the inputs, processes and outputs of an exploration or problem-solving activity). In the e-Science context a Work Object (WO) is known as a Research Object. A WO is an entity that an e-Lab: creates, stores, accesses and manages; exchanges with other e-Labs; publishes to external sites, deposits in external resources; and displays through work- benches. The motivation behind WOs (and the associated services that produce and consume them) is to improve the curation, accessibility and repeatability of research and business intelligence processes. A WO might be:

- A template equity audit containing a collection of workflows with instructions, examples with default input data, a tutorial and links to external learning resources on the methodology;
- A reproducible research article with the workflows and data required to reproduce the results described in the article.
- A reproducible and easily repurposed annual public health report containing: the report and supporting files such as slides, spreadsheets and graphics; commentary around the report such as copies of emails and press releases/articles; pointers to data sources and extracts used in analyses; data extraction, cleaning, derivation and statistical analysis workflows behind the analyses; bibliography; project management resources.

From a knowledge management perspective, WOs address the concerns that: knowledge is heavily context dependent; and knowledge-transfer relies on common ground.

Research/experimental/business intelligence knowledge depends on context, making it's codification and exchange difficult [12]. Some redundancy of knowledge between two parties is necessary for knowledge transfer to take place [13], without any overlap it is almost impossible for anything but the most basic information to be transferred. WOs can provide the rich context and common ground necessary to take, for example, a method beyond a flat set of instructions, to provide worked, interactive, re-playable examples – the learner can interact with the research object, changing parameters, supplying new raw data, and learning by doing.

A case study by Quintas [12] observed that rigid formal reporting and recording of progress, without a social dimension is not an effective way to transfer knowledge. There is a requirement for joint activities - "working together and gaining shared experiential knowledge", WOs provide an alternative way to support collaborative working and, longer term can provide rich examples for teaching.

Conclusion

Obesity Atlas demonstrated the need for combining related public health intelligence tasks into workflows that result in near-complete reports. Methodbox demonstrated the need for a generic framework for finding, sharing and reusing public health intelligence workflows – with an initial focus on the under use of large-scale, general health surveys. The UK NHS is using the NorthWest e-Health programme to harness e-Science activities such as these into a generic framework, e-Lab, for combining data, methods and people more effectively – to produce more health intelligence from the same number of analysts.

WOs and e-Labs, however, are not familiar concepts to most public health analysts. Adoption will require technical and cultural change; change to working practices, as well as assumptions about what it is preferable to share or keep confidential. Obesity Atlas and Methodbox provide steps towards public health e-Labs. Obesity Atlas provides an example of a single packaged reusable workflow, and Methodbox encourages the sharing of methods and expertise.

The next steps include developing knowledge management practices alongside the e-Lab software by embedding e-Lab development in the continuing professional development of public health practice and science. For example, action learning groups in healthcare organisations can produce and use WOs as learning materials as well as operational tools. Continuing professional development credits could be earned by users transforming WOs in ways that demonstrate key competences. The provenance and audit services of e-Labs are easily harnessed for this purpose. These services are essential for the information governance required by healthcare organisations. As WOs contain rich contextual metadata, an e-Lab is a context-specific alternative to (or extension of) a conventional file store – in this respect organisational memory is increased by keeping work as WOs rather than separate files.

e-Lab could also be used to engineer the reward environment for working across organisations and disciplines. For example, a Social Scientist could demonstrate the impact of his/her method for measuring material deprivation by showing the consumption of a WO they produced as a template for this methodology. Given that such environments are increasingly global, e-Lab could be a step towards international interoperability of public health intelligence. Given also that future healthcare is likely to be more model-rich [14], clinical decision-support and public health intelligence may need to interoperate in a similar way.

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Spatiotemporal Antibiotic Resistance Pattern Monitoring using Geographical Information System based Hierarchical Cluster Analysis

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Abstract

Bacterial antimicrobial resistance in both the medical and agricultural fields has become a serious problem worldwide. Antibiotic resistant strains of bacteria are an increasing threat to human health, with resistance mechanisms having been described to all known antimicrobials currently available for clinical use. Monitoring the geotemporal variations of antibiotic resistance pattern is crucial factor in planning a successful therapeutic guidelines preventing further emergence of antibiotic resistance. This study is based on the retrospective spatiotemporal analysis of laboratory results of Antibiotic Sensitivity Tests, time stamped with the date and time of the microbiological specimen dispatched to the laboratory. Geographic location of the isolated bacterial colony is specified with the latitude and the longitude of the patient's location. Agglomerative Hierarchical Clustering was performed on antimicrobial resistance findings based on the geographic locations generating series of Heatmaps to visualize the extent of the resistance pattern. Sequential Hierarchical cluster analysis was proven to be effective in visualization of antibiotic resistance using Heatmaps demonstrating the temporal variations of the antibiotic resistance patterns.

Keywords:

Antibiotic sensitivity test, Antibiotic resistance, Spatiotemporal pattern, Cluster analysis, Agglomerative hierarchical clustering, Geographic information system, Heatmap.

Introduction

The emergence of antimicrobial resistance is neither an unexpected nor a new phenomenon. It is, however, an increasingly problematic situation due to the frequency with which new emerging resistance phenotypes are occurring among many bacterial pathogens.

Over the past 6 decades, the introduction of new classes or modifications of older classes of antimicrobials has been matched slowly but surely by the development of new bacterial resistance mechanisms, [1].

Antibiotic Sensitivity Test is the investigation carried out to determine which antibiotic will be most successful in treating a bacterial infection in vivo. Testing for antibiotic sensitivity is often done by the Kirby-Bauer method, [2] where small wafers containing antibiotics are placed onto a plate upon which bacteria are growing. If the bacteria are sensitive to the antibiotic, a clear ring, or zone of inhibition, is seen around the wafer indicating a poor growth.

Numerous retrospective and prospective studies have demonstrated that increases in antimicrobial resistance occur among both pathogenic and commensal bacteria after introduction of an antimicrobial agent, [3]. Infections caused by resistant bacteria have been shown to be more frequently associated with increased morbidity and mortality than those caused by susceptible pathogens. The emergence and dissemination of bacterial antimicrobial resistance is the result of numerous complex interactions among antimicrobials, microorganisms, and the surrounding environment including geographical location and population dynamics.

There are considerable variations in the antibiotic susceptibility of clinically important bacterial strains based on the geographical distribution of hosts, [4, 5] and exposure to environmental factors over a period of time, [6].

Geographic information systems (GIS) and analysis based on GIS has become widespread and well accepted tool in the field of medicine as well. Geographic information systems are an important way in which to better illuminate how humans interact with their environment to create or deter health, [7]. Recent advancements in the analysis of disease maps have been influenced by and benefited from the adoption of new practices for georeferencing health data and new ways of linking such data geographically to potential sources of environmental exposures, the locations of health resources and the geodemographic characteristics of populations, [8].

It was shown in relation to some bacterial strains that the geographic maps of antibiotic resistance can be used to guide physician antibiotic selection before culture results are available. This has significant implications for the health care provider in proper antibiotic selection within the community minimizing the treatment failures and emergence of new, drug resistant bacterial strains, [9].

Methods

Antibiotic Sensitivity Test results extracted from a retrospective laboratory based study was the key data set concerned in this analysis. When an Antibiotic Sensitivity Test is performed, type of the specimen, the name of the bacterial species isolated and the resistance or the sensitivity of the bacteria towards a set of selected antimicrobial agents along with the personal information of the patient from whom the specimen was collected are recorded in all microbiological laboratories. Number of antibiotics a bacterial colony is tested for ranges from 8 to 12 depending on the laboratory where the Antibiotic Sensitivity Test was performed. The types of antimicrobial agents used for the Antibiotic Sensitivity Tests are also laboratory dependent unless a request is made by the physician to include a specific antibiotic based on the clinical condition and suspected pathogen.

Out of the above mentioned information available in microbiological laboratories, type of the specimen, date and time when the specimen was dispatched to the laboratory, the bacterial species isolated, resistance or sensitivity to each antimicrobial agents and the location of the patient were fed in to a MySQL based relational database using web based interface developed with scripting languages *PHP*: Hypertext Preprocessor, JavaScript and Python. Location of the patient for each test result was linked to a look up table in order to match location from where the microbiological sample was collected to its nearest possible latitude and longitude.

The interface developed has the capacity to filter the antibiotic sensitivity and resistance counts for each spatial location based on latitude and longitude and the type of antimicrobial agent. Several pre-formatted queries are provided through the interface to find counts based on bacterial strains, antimicrobial agent and time period.

Google Maps, [10] was used as the primary GIS layer as shown in Figure 1. Google Maps provides a Java Script based API which includes calls to add markers on the map for various data points.

However a supportive API, Gheat, [11] has to be employed to assist Google Maps layer, since the study manipulates vast number of data points and mapping those antibiotic resistance counts is beyond the capacity of Google Maps alone. An additional tile set was created with the aid of Gheat and which was layered on top of the base map tile set to visualize clustered antibiotic resistance counts of each antimicrobial agent based on the latitude and longitude as a Heatmap.

Similar to the Google Maps API, Gheat creates the final tile layer using multiple 256x256 pixel tiles knitting them together. Since the data points are time stamped, it is possible to generate these tile sets based on the time stamp of the individual Antibiotic Sensitivity Test result in a serial manner to analyze the periodical distribution of the resistance counts.

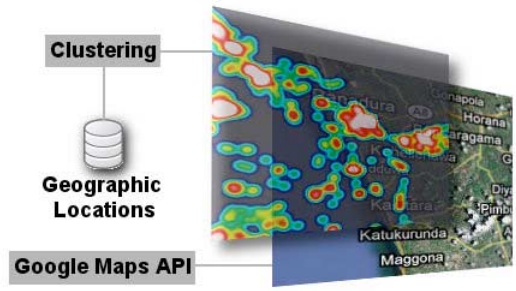

Figure 1 – Use of Google Maps API and Clustering geographic locations of test results

While frequency of occurrence are being calculated for each geographical point, those locations have to be grouped to different hierarchical layers based on the frequency of the occurrence of resistance or sensitivity reported for each cluster. In order to do this the interface accepts the individual occurrence of resistance from the database and cluster the data points, based on Agglomerative Hierarchical Clustering, [12] algorithm. The frequency clustering is possible as a cross sectional study with a single observation or as a longitudinal study with sequence of observations. In clustering antibiotic resistance results, Euclidean distance, between two data points is considered the preferred Metric as in Equation (1) to decide dissimilarity between sets of observations.

$$\|a-b\|_2 = \sqrt{\sum_i (a_i - b_i)^2} \qquad (1)$$

The selected Linkage Criteria to decide the distance between sets of observations is Single Linkage (Nearest Neighborhood) where pair wise distance between observations is used as shown in Equation (2).

$$min\{d(x,y): x \in A, y \in B\} \qquad (2)$$

The distance between two clusters is calculated as the distance between the two closest elements in each cluster. Linkage function – the distance $d(x,y)$ between cluster A and cluster B is described by, $d(A,B) = min(d(x,y))$ where,

- $d(x,y)$ is the distance between element $x \in A$ *and* $y \in B$;
- A and B are two sets of clusters within the same hierarchy

The maximum positional accuracy of storing the values for the latitude and longitude values are to the $1/1000000^{th}$ of a degree. So 0.000001 degrees of latitude or the longitude would be the closest distance for any two elements to be identified as two different clusters, as specified by the $d(x,y)$ in Equation (2) above.

Gheat color scheme consists of four channels of colors (red, green, blue, and alpha). Each channel ranges from 0 to 256. When the data is being clustered alpha channel is used to draw the base template of the Heatmap as shown in Figure 2. Then

each cluster will be colorized using appropriate combination of red, green and blue channels according to the color scheme. Once the color scheme is applied, each cluster of the Heatmap will have a unique color combination as shown in Figure 2.

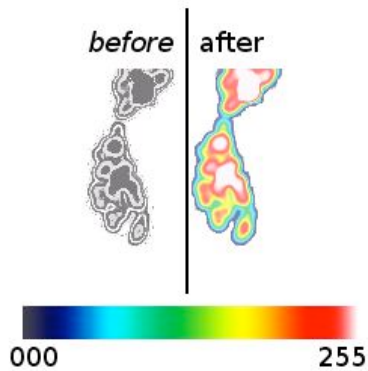

Figure 2 – Before and after colorizing clusters creating a Heatmap

This approach allows agglomerative positioning of clusters where each observation starts in its own cluster and pairs of clusters are merged as the process moves up the hierarchy. In these hierarchies of clusters, least dense clusters would occupy the bottom layers where as high density clusters would occupy the top layers. A color scale can be defined shown in Figure 2 to colorize the each layer in the Heatmap.

Results

Heatmap based on clustered antibiotic resistance counts for each bacteria. Cases were mapped with reference to the latitude and longitude of the specimens collected as shown in Figure 3.

Figure 3 – Antibiotic resistance cased mapped to the respective GIS positions

Data extracted from the Antibiotic Sensitivity Test result was fed in to the GIS system and the interface was able to generate

Similarly, cases resistant to a selected antimicrobial agent can be filtered by time stamp and Heatmap can be generated sequentially. In this approach spatial distribution of the antibiotic resistance cases can be visualized periodically as shown in Figure 4.

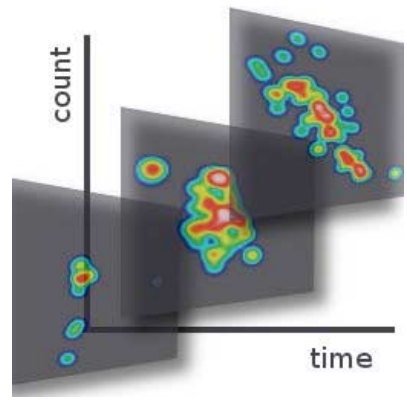

Figure 4 – Sequential Heatmap highlighting the changes of the resistance counts against time

Discussion

The serial Heatmaps generated by the interface are useful in cross sectional studies of the database, providing visual clues on the extent of the distribution of antibiotic resistant cases at any given time.

With the use of Heatmaps, large number of values can be visually presented compares to conventional map markers used with the Google Map API.

There are numbers of clinically significant statistical analysis can be performed with the help of pre-formatted database queries.

- Comparison of resistance or sensitivity of a bacteria to an antibiotic in different points in time as a longitudinal study
- Comparison of resistance or sensitivity of a antibiotic to one or more bacteria as a cross sectional study
- Comparison of resistance or sensitivity of a antibiotic to one or more bacteria as a longitudinal study
- Comparison of resistance or sensitivity of a bacteria to one or more antibiotic as a cross sectional study
- Comparison of resistance or sensitivity of a bacteria to one or more antibiotic as a longitudinal study

Conclusion

The study was able to demonstrate the ability to incorporate Geographical Information Systems with clinical and laboratory based data. Cross sectional as well as longitudinal analysis is possible with the use of cluster mapping.

Heatmaps are easy to interpret than numerical data or charts in representing pattern of distribution of antibiotic resistance cases over a geographical location.

It was also shown that, in longitudinal sampling of frequencies, a temporal analysis of the antibiotic resistance or sensitivity pattern is possible with sequential Heatmaps.

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Traffic Accidents in Crete (1996-2006): the Role of the Emergency Coordination Center

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Abstract

The general decline in traffic accidents throughout Europe is not the case for Crete, a favorite holiday destination. The extent of problem and reflections on the significant impact of the interplay of organizational, educational, & technological interventions by the Emergency Coordination Center of Crete (ECC-Crete) are presented. 10-year data from 1996-2006 have been analyzed revealing demographic, topological, and qualitative issues of traffic accidents in Grete. Primary source of data is 315000 emergency calls answered by ECC-Crete. Over this 10 year period, ECC-Crete gradually employed advanced medical technologies and electronic protocol-based handling in all phases of an emergency episode contributing to its timely and effective management. GIS/GPS technology and telemetry for biosignals in ambulances, up-to-date triage protocols combined with incidence analysis provide vital information for continuous process improvement. In 2000-2006, process improvement due to technological and organizational changes has led to increased efficiency. The mean reduction was ~75% in dispatch time, ~50% in the time at accident scene for metropolitan areas, and ~75% in time at the emergency ward, mainly due to medical interventions on site.

Keywords:

Emergency management, Road accidents, eHealth Infrastructures, Technology assessment

Introduction

Traffic accidents, one the gravest problems of our times, is projected as one of the leading causes of death in 2030 by WHO [1]. Whereas all over Europe the number of traffic accidents is declining [2], in the island of Crete the problem escalates year after year. Crete is the largest island of Greece located in the center-east part of the Mediterranean. It is a popular tourist destination with a permanent population of 750,000 people rising to 1,250,000 during the 8-month long tourist season. All health-related emergency calls (166) are handled by the National Center of Emergency Response (ECC-Crete).

In the period 1995-2006, the number of vehicles using essentially the same aging road infrastructure has more than doubled. In 2005-06, 420000 motor vehicles (30% owned by rental agencies) were on the roads of Crete [3-6]. While various traffic-accident indicators for Greece decrease, this is not the case for Crete: 1248 persons lost their lives and 18901 were seriously injured in the last decade (1996-2006).

In the period 1996 to 2001, advanced Information and Communication Technologies (ICT) were gradually introduced to the day to day operation of ECC-Crete driven by organizational changes supported by systematic educational and hands-on training activities.

In the backdrop of a comprehensive analysis of the problem of traffic accidents in Crete, this paper presents elements of the operational plan of ECC-Crete, assessing the effect of the Integrated Emergency Management Information System (iEMIS) and reflecting on the interplay of organizational, educational, and technological developments.

The next section (Materials and Methods) presents elements of the operational plan of ECC-Crete and the data sources and methodology employed in this assessment. The Results section presents quantitative and qualitative results of the traffic accidents in Crete 1996-2006 focusing on quantitative evidence for their demographics and geographic locality, and qualitative evidence on the role of ICT in the effective management of emergency episodes and traffic accidents, in particular. Discussion-Recommendation outlines further interventions to contain the problem of traffic accidents that claims the life of people in their most productive age. Finally, Conclusions summarize the contribution of this work, outlining future challenges for ICT in emergency management.

Materials and Methods

Integrated Emergency Management Information System

Since 1996, iEMIS has been gradually introduced in the day to day operation of ECC-Crete to serve its primary objective, namely to improve the health outcome of those injured in emergencies including traffic accidents, through timely and effective intervention of emergency response teams. In this context, the role of ICT is central in collecting and managing relevant information providing decision support for individual emergency episodes, but also for resource planning.

iEMIS [7,8] at ECC-Crete aims to serve as the key to effective health emergency management employing state-of-the-art ICT. The basic capabilities of the iEMIS include: (a) online archive of all emergency calls and associated information; (b) geographical tracking of ambulances and mobile ICU units using Global Position System (GPS) and a Geographical Information System (GIS); (c) decision support on optimal use of the available resources; (d) acquisition, transmission, analysis, and storage of vital signs on the ambulance allowing patient telemonitoring on the way to the hospital; (e) continuous training & education of paramedics, rescuers, health professionals, and the public.

Lifecycle of an emergency episode

Every incoming emergency call at ECC-Crete is recorded on an electronic "incidence card". The incident card employs the minimal Hector data set, which was the result of consensus among many European countries in the Hector project [9]. Operator/dispatchers at ECC-Crete are responsible for initial protocol-based triage of emergency calls, dispatching of ambulances, and their follow-up. Two screens provide access to iEMIS, i.e. on-line triage protocols, GIS, and the emergency incidence database.

Once a call for a traffic accident is received by ECC-Crete, the episode is automatically geo-located on the GIS. Thus, the operator/dispatcher may promptly identify the origin of the call and the ambulances closer to the scene of the emergency. On the incident card, the operator enters all the details as provided on the phone and assigns a color code to the episode based on its severity as assessed by triage protocols: Red, Orange, Yellow, and Green. The severity of the emergency call is dictated by this color-coding with Red being that of the highest urgency. A suitable ambulance is dispatched to provide first aid and necessary medical interventions on site and transfer the victims to an appropriate medical facility. When an episode is characterized as Red, a mobile ICU manned with an emergency doctor is urgently dispatched. In Orange episodes, an Advanced Life Support (ALS) ambulance equipped with a defibrillator is dispatched, while in Yellow episodes a Basic Life Support (BLS) ambulance is dispatched. Green episodes can be scheduled with some flexibility.

Upon arrival at the scene of the accident, the medical doctor, if present, and the paramedics use radio communication and telemonitoring of the patient's vital signs and ECGs. The incidence card remains "open" until the emergency episode is received by the Emergency Ward of the medical facility.

BLS ambulances as well as mobile ICU units (ALS-MICU) have been equipped with state of the art equipment extraction, immobilization multi-trauma patients (long spine boards, «scoop stretcher», vacuum mattress, vest KED). They are also equipped with medical devices for vital signs monitors for first aid therapeutic interventions such as defibrillator, oximeter, electronic blood pressure monitors, devices for warming of liquids, intubation set, ventilators etc.

Thus, the doctor on duty at ECC-Crete can receive real-time patient tele-monitoring of the patient's vital signs and ECGs as transmitted from the ambulance. The doctor may record in the "Clinical evaluation" section of the "Incidence Card" patient condition and immediate actions. Special effort has been focused on designing this service to require minimal intervention by paramedics. In this way, the crew of the ambulance can concentrate fully on the management of emergency and the doctor receives timely information in a transparent and efficient way.

Resource management

The resource management component of iEMIS of ECC-Crete facilitates continuous evaluation of emergency services, conveying valuable insights on the management of resources and the organization of sectors (areas where ambulances are proactively deployed). Intelligent incident data analysis provides decision support at the administrative level regarding the creation of new sectors and the positioning of ambulances to improve response times. Simulation programs apply advanced data analysis methods to the contents of the emergency archive to support administrative decisions with regards to staff performance, training and scheduling, as well as the need for special equipment.

Continuing Education and Training

The personnel of ECC-Crete undergo regular training to maintain high levels of readiness and aptitude in emergency response [10]. In 2000-2006, the educational center of ECC-Crete, offered paramedics and health personnel more than 2800 hours of training certified by the Hellenic Organization of Professional Training. BLS-AED training takes place regularly based on the protocols of European Resuscitation Council (ERC). All personnel are retrained on a yearly basis on trauma management based on the principles of Advanced Trauma Life support (ATLS) and the protocols of emergency management as customized by ECC-Crete. Since 2008, a Prehospital Health Trauma Life Support (PHTLS) Center extends training to health professionals, rescuers, and citizens alike. Moreover, ECC-Crete participates in a variety of tele-training programs to train health professionals and the public in Crete and the surrounding islands.

Data Sources and Evaluation Approach

Complementary data sources have been used to assess the effect of these interventions on the management of emergencies. In particular, the following sources of data have been used in this work:

- mortality data associated with traffic accidents referring to the whole island, which were collected with support from the Police and the Forensic Medicine Department of the University of Crete
- detailed outcome data on traffic accidents with severely injured only from eastern Crete (2/3 of the population), where assistance from ECC-Crete was requested
- emergency calls to which ECC-Crete responded in the period 1996-2006, all of which were recorded in the iEMIS i.e. 315000 emergency episodes.

Based on these data sources, the results section reports quantitative evidence on traffic accidents and their severity: (a) number of fatally and severely injured in traffic accidents; (b) age distribution and gender of the victims; (c) geographic lo-

cation of traffic accidents; (d) main causes of accidents: nationalities, alcohol, tourism.

Then, in an effort to assess the role and prospects of information technology in emergency management: (a) we evaluate protocol-based triage by comparing severity of the episodes as evaluated by ECC-Crete, with assessment by the paramedics on the scene, and doctors at the Emergency Ward of the hospital; (b) we measure average times in the management of emergency episodes over time to reflect on organizational, educational, and technological interventions.

Protocol-based triage of emergency Calls - trauma scores

As already mentioned, protocol-based triage of each episode begins at the time of the emergency call with the color-coding of its priority from the operator/dispatcher of ECC-Crete. The Revised Trauma Score (RTS) and the Hector Emergency Scale (HES) rate the severity of the episode at the scene of the accident and upon arrival to Emergency Ward.

RTS is a physiological scoring system, with high inter-rater reliability. It is scored from the first set of data obtained on the patient, and consists of Glasgow Coma Scale (GCS), Systolic Blood Pressure (SBP) and Respiratory Rate (RR). RTS is heavily weighted towards the GCS to compensate for major head injury without multisystem injury or major physiological changes. HES attempts to leverage vital signs information acquired through monitoring in the ambulance and transmit it to the ECC-Crete, to be visualized at the doctor's workstation. In HES, GCS and a set of four vital signs are used for the calculation of a score that expresses the current status of the patient under care. HES scores result from the addition of the severity scores (1-4) for each of the five vital signs that appear in Table 1. Note that a total score of 14 or lower indicates a critical condition. The primary treatment goal is to achieve HES Score of at least 15 as soon as possible. The HES & RTS scores are routinely compared to the initial color-coding to assess the effectiveness of protocol-based triage.

Table 1- HECTOR Emergency Score (HES)

Severity	GCS	NISBP	HR	RR	SpO_2
4	13-15	101-180	50-100	10-30	> 94
3	9-12	76-100	101-120	> 30	92-94
2	6-8	50-75 or 181-220	121-140	6-9	90-91
1	4-5	1-49 or >220	<50 or >140	1-5	85-89
0	3	0	0	0	< 85

Results

Quantitative evidence: traffic accidents and their severity

From 1996 to 2006, ECC-Crete was called to provide assistance in 18901 traffic accidents that involved one or more injured persons. Figure 1 shows that the number of heavily injured in road accidents in 1996 was 730. Since then, with the exception of 2001 (1453) and 2003-2004 (1619, 1713) the number of injured persons is steadily rising. In 2005, the number of injured is 2869 (7.8 injured per day) and 3315 in 2006. The total number of injured is higher than the population of major cities such as St. Nikolas, or Sitia in Crete. The rising trend on the number of deaths, particularly after 2004 (shown in Figure 1), is also alarming. After a short drop in 2003 (98 deaths), we reached 148 deaths in 2005.

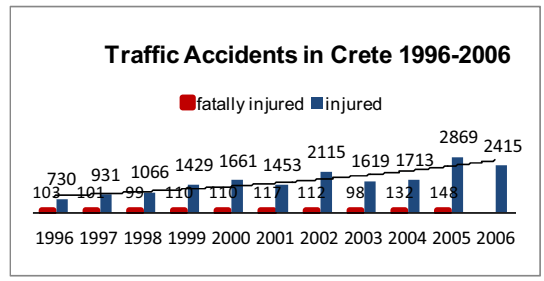

Figure 1- A rising trend in the number of fatally or heavily injured in traffic accidents. (9.4 seriously injured per day).

On the roads of Crete traffic accidents claim the lives of the young: 41% of the injured and 30% of dead are persons 17-30 years old. Moreover, 71% of the injured and 60% of the dead belong to the creative and productive ages between 20 and 50. 72% of the victims and 80% of those injured are men, compared with 28% and 20% of women, with children ranging 2-5%. Surprisingly, the number of Greeks involved in road accidents is higher than that of other nationals among fatally (85%) and heavily injured (79%). However, the tourist season pays a heavy toll in terms severely and fatally injured in traffic accidents (data not shown).

Figure 2- Location of accidents on Northern National Road.

Geographic Distribution

The largest number accidents for which ECC-Crete received an emergency call are located near the urban centers. In particular, 40% of the traffic accidents involving serious or fatal injuries were within the urban areas of Heraklion, St. Nikolas, Ierapetra, Hersonissos, and Malia. Furthermore, the number and severity of traffic accidents along the Northern National Road of Crete (NNR) and minor roads leading to the south in the Heraklion prefecture are high (20%), with the main intersections in Heraklion, claiming 10% of the total (Figure *2*).

Main causes of traffic accidents

The main causes of traffic accidents involving Greeks and other nationals differ considerably. As shown in Table 2, the most frequent cause of accidents among Greeks is violation of

traffic rules. Violation of traffic lights, high speed, and violation of priority are the top causes for severe traffic accidents involving Greeks (51%). For other nationals, the same causes of accidents account for 31%, while alcohol abuse is at the top (22%/52% for fatally injured). For Greeks, just 13% of the accidents involve alcohol abuse. Driving conditions (e.g. road conditions, light conditions) cause significant percentage of accidents to Greeks (31%) and other nationals (42%). Other nationalities are likely to drive a rented car (p=0.02) and come from countries driving on the left (p=0.02) when involved in a traffic accident. It is also worth noting the significant increase in cerebral injuries (CCS<8) among injured motorcycle drivers who did not wear a helmet (from 31 in 2000 to 195 in 2005).

Table 2- Main causes of accidents for different nationalities.

Cause of Accident	Greek	Other nationalities
Violation of traffic rules	54%	31%
Alcohol abuse	13%	22%
Alcohol abuse (among fatally injured)	35%	52%
Use of illegal substances	2%	5%
Road Conditions	31%	42%

Qualitative evidence: the role of information technology

As already noted, the aim of ECC-Crete is to improve the health outcomes of those involved traffic accidents: (a) by reducing the mean time in the different phases of handling an emergency: dispatch, access, time on site, transfer time, time in the emergency ward and (b) by employing appropriate interventions on site and en-route to the hospital to improve the RTS and HES and thus improve prospects of the emergency.

The following sections provide qualitative evidence on the effectiveness of the interplay of organizational, educational and technological interventions. iEMIS plays a central role in effectively employing technology to achieve these objectives.

Efficient handling of emergencies

Despite the increasing number of traffic accidents noted in the previous section, effective use of technology has led to a drastic reduction in the time spent at the different stages of managing an emergency episode:

- *mean dispatch time* has been reduced from 5′, 6′ in 2000 and 2001, to 1′ in 2005 and 2006 (>75%).
- *mean time to the scene* of the accident has been reduced from 10′, 12′ in 2000 and 2001 to 5′ within urban centers and in distances less than 20km (50%)
- *mean time at the emergency ward* of the hospital was reduced from 18′ in 2000 to 4′ in 2006 (>75%)

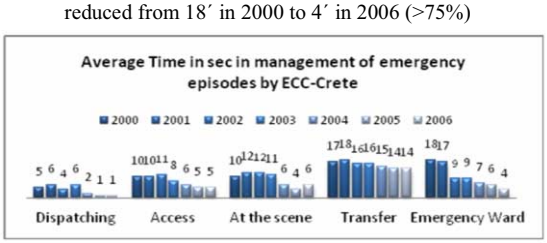

Figure 3- Response Times (sec) in emergency management

The sharp reduction in dispatch time can be attributed to iEMIS as it facilitates immediate (re)allocation of emergency resources. iEMIS provides expert assistance to operators by assessing the proximity of resources to incidents supplying scheduling data, expected times of resource availability, and accurate categorization of incident severity. The significant reduction in the mean access time can be attributed to new local sectors. ECC-Crete evaluates sector effectiveness using data mining of geolocalized incidents. New sectors were formed within the limits of urban centers and locations presenting high frequency of traffic accidents in the tourist season. Furthermore, a Special Unit of Disaster Medicine was created initially with 32 paramedics-rescuers and 4 doctors. Thus, combination of information technology, resource allocation, and training, has visible impact on the reduction of the time at the scene of the accident.

The reduction in the time spent in the Emergency Ward shown in Figure 3, can be attributed to the large number of immediate interventions at the scene of the accident. Over the last decade, the number and effectiveness of interventions on site have improved considerably both in terms of quantity and quality. Indicatively, in 2006 the iEMS database reveals that the ECC-Crete personnel have intubated after general anesthesia at the scene of the accident 95 injured persons compared to 24 in 1998. In the same time frame, 53 multi-trauma patients were extracted with the use of KED vest, collar and long spine board, compared to 8 in 1988.

Protocol based triage and color-coding of episodes

After the original color coding of the emergency episode, the health condition of the injured is regularly updated in the iEMIS database, as new values are recorded manually by ambulance crew or automatically through telemonitoring. 4680 severely injured cases were selected out of the iEMIS database, involving traffic accidents with average RTS at the critical level 9 and HES at the critical level 11. Analysis indicates that in 25% of these episodes characterised as Red or Orange in triage, response was instant and in 57% immediate. Assessment of the episodes from doctors and paramedics at the scene of the accident, showed that 31% of these episodes were characterized as RTS < 9 (mean RTS 10,04) and 26% of the episodes were characterized as HES < 11 (mean HES 14,41). Thus, there is a significant correspondence between the initial color-coding of the episodes at the time of triage and the observed severity at the scene of the accident based on the recorded vital signs. In cases where the HES score was below 15, the episode was color-coded by the dispatcher as Red or Orange, reflecting the value of iEMIS on decision support.

Discussion

Since 1869, when the first automobile fatality was recorded in a small Irish town, cars have become an integral part of our daily life. Road injuries were chosen by the World Health Organization as the focus of the World Health Day in 2004, since according to WHO resources, traffic accidents are a frequent

cause of death or a source of permanent disability. For Crete, driving conditions are grave: the 1243 fatally injured, 4680 severely injured, and 18901 injured are a quite high tall for a relatively small and closed community of 750000 people. The fact that most victims of traffic accidents are young 17-30 years old, should be a source of further concern as traffic accidents affect the most productive and vibrant part, the hope of our society. For Greek nationals, the gap in traffic education is noteworthy (31% of injured violated the traffic code), whereas for foreign nationals and tourists, alcohol is a major cause of accidents (52% of fatally injured). Nationals of countries driving on the left are involved 2.5 times more frequently in accidents that others. Driving without a helmet is critical for motorcycle drivers involved in an accident (135 in 2006).

The interventions of ECC-Crete in terms of training, education, technology, and guideline-driven procedures have positive impact. The creation of new sectors in ECC-Crete has improved overall effectiveness through improved access to the scene of the accident. Recurrent incident analysis and continuous assessment using the iEMIS database supports decision making regarding the creation of new sectors and the possible disbanding of existing ones, maintaining high operational efficiency. In terms of training and education, the recent Prehospital Trauma Life (PHTLS center) helps engage citizens, volunteers, and professional rescuers. However that is not enough, intense lessons of driver conduct to young people as part of primary education are needed, while visitors particularly those arriving from countries driving on the left should receive information or brief training before renting a vehicle.

The remarkable reduction of 50-75% in the average times of managing emergencies has lead to further thoughts regarding embracing innovation and closer collaboration with other organizations in the chain of emergency management, including not only health organizations, but also law enforcement, firefights and their disaster management units. On top of that, stronger links with primary care facilities and volunteers should be established through regular tele-education sessions based on real episodes from the iEMIS database. Innovations considered include experimenting with vehicular emergency data transmission to ECC. There are also plans for the iEMIS database that is currently episode-based to be reorganized to form a citizen-centered emergency record. That would further improve emergency management involving people of chronic conditions or special needs who are frequent or likely users of emergency services. It would assist triage by proactively supplying valuable information not only in the management of the emergency, but also to the Emergency Ward of the receiving hospital. Finally, the valuable experience reported here needs to be regularly revisited, in the frame of a long-term strategy of continuous assessment of emergency management procedures setting standards at a national and European level.

Conclusion

The island of Crete is facing a serious problem with traffic accidents, due to the ever increasing number of vehicles and poor road infrastructure. ECC-Crete has set up and continually updates its operational plan to effectively cope with increasing traffic accidents in Crete. The cooperative use of technology, training, and organization change has proved particularly effective in terms of Time, the most precious emergency resource. A major challenge for ECC-Crete is to develop and establish integrated technology-driven processes with all actors in emergency management using technological progress and innovation for better health outcomes in traffic accidents.

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Traffic Accident In Cuiabá-Mt: An Analysis Through The Data Mining Technology

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Abstract

The traffic road accidents (ATT) are non-intentional events with an important magnitude worldwide, mainly in the urban centers. This article aims to analyzes data related to the victims of ATT recorded by the Justice Secretariat and Public Security (SEJUSP)in hospital morbidity and mortality incidence at the city of Cuiabá-MT during 2006, using data mining technology. An observational, retrospective and exploratory study of the secondary data bases was carried out. The three database selected were related using the probabilistic method, through the free software RecLink. One hundred and thirty-nine (139) real pairs of victims of ATT were obtained. In this related database the data mining technology was applied with the software WEKA using the Apriori algorithm. The result generated 10 best rules, six of them were considered according to the parameters established that indicated a useful and comprehensible knowledge to characterize the victims of accidents in Cuiabá. Finally, the findings of the associative rules showed peculiarities of the road traffic accident victims in Cuiabá and highlight the need of prevention measures in the collision accidents for males.

Keywords

Traffic accidents, Data mining, Public health informatics

Introduction

The traffic road accidents are non-intentional events with an important magnitude worldwide, mainly in the countries with medium and low income. The numbers show high number of deaths, disabilities and psychological sequelae, being one of the negative factors of the epidemiological transition that Brazil has experienced over the last decades [1-2].

Brazil is among the countries that have registered the largest frequencies of individuals injured in traffic accidents, with rates showing that in 2002 the number of victims were 219,5 per 100 thousand inhabitants [3] and 18,7 deaths per 100 thousand inhabitants [4].

In 2006, death by traffic road accidents were in a rate of 39,4 per 100 thousand inhabitants. In the same year, the state of Mato Grosso, presented a risk of 56,8 per 100 thousand inhabitants, and the capital Cuiabá recorded a lower rate of 25,2 per 100 thousand inhabitants [4].

The relevance of the traffic accidents in Cuiabá is revealed by the mortality rate per external causes. The data of hospital morbidity in Cuiabá is also higher than the indexes presented by the national record, the Center-West region and by the State of Mato Grosso [5].

This article presents an analysis of relating data in traffic road accidents recorded by the Justice Secretariat and Pubic Security using hospital morbidity and mortality records at the city of Cuiabá in 2006, using data mining technology.

Materials and Methods

Type of study

It is an observational, cross-sectional, retrospective and exploratory study of the secondary databases of security and public health in the municipality of Cuiabá, Mato Grosso State, in 2006.

Source of data and ethnic considerations

The sources of data were those of the State Secretariat of Justice and Public Security (SEJUSP) that made available the database of the victims in traffic road accidents assisted by the Military Fire Brigade and SAMU including the Police Records.

Complementing the database of the public security area, we included data from the national health information systems which contain the register of the accidents and the hospital admissions records at SUS - the Hospital Information System of the Unified Health System (SIH/SUS). In addition, data from the system for recording deaths, the Mortality Information System (SIM) were also included.

The databases and the collecting data files or instruments of data collection, were provided by the Municipal Health Secretariat in Cuiabá-MT and by the State Secretariat of Justice and Public Security (SEJUSP), authorized by their directors and approved by the Ethic Committee at the Federal University of São Paulo under protocol number 1595/07.

Data processing

The databases received from SEJUSP (the Municipal Health Secretariat of Cuiabá-MT), SIH/SUS and SIM were structured in an Excel datasheet, Microsoft Office Excel 2003, comprising 2,547; 38,273 and 3,198 registers, respectively.

A manual checking of the databases was made to investigate the existing variables to verify key attributes for record linkage. The phase of the selection of the registers in the databases took into account all the registers that had the key attributes. In this cleaning phase 1.137 registers were excluded from the SEJUSP databases totalizing 1.410 selected registers.

In the SIH/SUS all the registers were selected (38.273). However, in the SIM database, there was an exclusion of 97 registers. Consequently, the total was 3.101 selected death records.

Data processing was divided into two phases: (a) the record linkage of the databases and (b) the data mining technology.

Record Linkage

The database linkage probabilistic method was used to join the data of the Information System of SUS with the data from the State Justice Secretariat and from Public Security (SEJUSP) to obtain information about common individuals that were victims of traffic accidents in the city of Cuiabá-MT.

Three record linkages were carried out separately, SEJUSP *versu.* SIH/SU which resulted 111 pairs; SEJUSP *versus* SIM with 25 pairs; and with the registers of the first record linkage SEJUSP/SIH *versus.* SIM which resulted three pairs, totalizing 139 real pairs. This process formed a single database with 139 registers. Subsequently, the 13 variables were selected as showed in Table 1.

Data mining

The tool used to obtain knowledge from the data bases of accidents in Cuiabá was the WEKA - *Waikato Environment for Knowledge Analysis.* The reasons for selecting it were: it is a tool developed in the JAVA language that has as the main feature the portability (it is easy to be executed in several platforms of the Operational System); has the source code open; easy access by internet and, available at http://www.cs.waikato.ac.nz/ml/weka/.

After processing the formating of the variables and the structure of the database for data input at the selected tool, the Weka software version 3.6.0 was prepared. It reads a text formatted file with .arff extension. In addition, in the pre-processing phase of tool, the preliminary analysis of the data was done. Next, it was perfomed the selection of the association (*Associate)* in the WEKA tool. The selected algorithm was APriori - which consists in identifying and describing associations among the variables of the same item or associations among different items that frequently occur simultaneously in the data base [6-7].

Table 1 – Variables, description and their categories

Variable	Description	Categories
VictimCode	Victim Code	Arabic number
	Gender	M, F
Age group	Age group (from 0	0-9; 10-19; 20-29; 30-39; 40-49; 50-59; 60 years and more
Month of occurrence	Month of occurrence	Jan, Feb, Apr, May, June, July, Aug, Sept, Oct, Nov, Dec
Type of Accident	Type of accident	collision, overrunning, overturn, shock, vehicle crash, fall, none
Victim's transport	Victims's means of transport	On foot, vehicle, motorcycle, automobile, bicycle, none
Type of victim	Type of victim	driver, passenger, pedestrian, ignored
Days of hospitalization	Days of hospitalization	Arabic number
Residential zone	Residential Zone	north, south, east, west, none
Ocurrence zone	Occurrence zone	north, south, east, west, none
Medical Assistance	Medical assistance	yes, no
Place of assistance	Place of Assistance	HCANCERMT, HGU, HUJM, HJDCBA, HMBOMJESUS, HPSMCBA, HSTAHELENA, HSTAROSA, SOTRAUMA, STACASA, None
Evolution	Evolution	Hospital discharge, death

As parameters for the execution of the association the *default values* of the software 0,1 (10%) minimum support (sup.); 0,9 (90%) confidence (conf.); 1,1 minimum Lift and number of rules 10 were maintained.

Results

With the application of the APriori algorithm and its parameters previously established, three sets of data were created. The first comprises five attributes which were combined to create a second set (*itemsets)* that contain six combinations; each one with two attributes. With the combination of the second *itemsets,* a third item/sets was created with two combinations and three variables.

In the three *itemstes* created, it is observed that the supports of each combination are higher than the minimum (10%) suggested by the *default* of the WEKA software. Of the last two combinations in the third *itemsets*, it is verified that 64,0% of the 139 male victims received medical assistance and were discharged from hospital.

In the second combination, of the 139 victims, 41,0% occurred by collision and also had medical assistance, receiving hospital discharge. After the combinations of the *Itemsets*, the 10 best associative rules created by the *APriori* algorithm were ordered by the *lift*. Of the 10 best rules created by the algorithm,

four were not considered since they presented one of the parameters smaller than what was established.

In addition, of the 10 rules created by the algorithm of association of the traffic accident victims it was verified that, in all the rules created, the attributes referring to hospital medical assistance (Yes) and evolution (discharge) were present, as antecedent or consequent. Two other frequent variables in the rules created were the type of accident by collision and the male gender. The frequency of these variables in the rules indicates possible standards found in the related data.

In relation to the rules, it can be observed that the first presented confidence of 92,0% (0,92), which is higher than the minimum established, (TP_ACCID=COLLISION - MED. ASSIST=SIM 62 ==> EVOL=H. DISCHARGE 57). Also, it can be observed that 92,0% of the victims according to the type of accident, more specifically, the collision, received medical assistance and were discharged from the hospital, which means that 62 collision accident victims received hospital medical assistance and 57 were discharged. Five victims died. Related to the support of 41,0% (also higher than the minimum established) of the 139 victims of traffic Road accidents that occurred in the city, 41,0% were due to collision, received medical assistance and were discharged from the hospital. This rule was classified as the Best rule by the *lift* parameter. The *lift* of the rule (1,16) was higher than the minimum *lift* (1,1) established in the *default* of the *software*.

The second rule, (MED-ASSIST=SIM 121 ==> EVOL=h. discharge 110) shows that 121 victims of accidents received hospital medical assistance and 110 presented evolution for hospital discharge with confidence level of 91,0%. From the total number of the Road traffic accident victims, 79,0% received medical assistance and were also discharged.

The third rule shows that 100,0% of the victims were discharged from hospital because they received medical assistance.

In the fourth rule, the variables male gender and hospital discharge appear as antecedents, indicating that 100,0% of the male victims were discharged because they received hospital assistance. It also can be observed that 64,0% of the total number of accident victims were males and also were discharged because received hospital assistance.

The fifth rule shows that 100,0% of the traffic accident victims by collision were discharged also due to medical assistance. But of the 139, only 57 (41,0%) collision accident victims received hospital discharge due to medical assistance.

The last rule considered by the parameters higher than those established, shows that 90,0% of the victims were males and received medical assistance, and because of this factor they were discharged.

Discussion

In this study the use of the data mining technology was presented through a data base related by the probabilistic method, since the Brazilian health databases do not present a common single identifier. Leles [8] highlighted the importance of the probabilistic method to integrate databases, mainly those database in the healthcare area.

Through the Apriori algorithm, the six rules selected, have parameters higher than those established. The knowledge obtained from the rules was comprehensible in consonance with the results and previous studies performed in Cuiabá-MT [9], and Cuiabá surroundings [10-11]. However, it is worth mentioning that these studies did not use the data mining technology to analyze the data.

The two variables that constantly appear in the subsets of the created rules indicated that there is an association between medical assistance and evolution to hospital discharge. It is also known that these can be called valid standards [12], since they were frequent presented in all the subsets. Two other frequent variables were the male gender and the type of accident by collision. The result (standards) is very similar to that found in other studies carried out by other methods and technologys of analysis in Cuiabá-MT [9], in the surroundings of Cuiabá [10-11], Alta Floresta-MT [13] and in the Distrito Federal [14].

It is worth emphasizing that the rules created, though trivial, show that the type of accident by collision makes victims and fatal victims; illustrating that all the types of vehicles are not invulnerable armors and that the drivers need to be prepared to drive.

In the rules presented, it is also emphasized that males were the main accident victims, even if a large number received medical assistance, and were discharged. It is known however, that the situation interferes in the family economy, since the most affected age group was that of the individuals economically active. There is also the immeasurable social loss that is caused by the trauma. It is difficult to evaluate quantitatively the social impact of the sequelae that the trauma causes for the population; on the other hand, there is a concern about the financial cost of their attendance (medical assistance), follow-up rehabilitation.

Finally, despite a few rules created and considered, there are enough elements to propose preventive measures of these accidents by collision involving male drivers. It is highlighted that these rules were based on real data that effectively show the scenery and can support programs dedicated to prevent violence in the traffic.

Conclusion

Finally, the findings in the associative rules revels the peculiarities of the road accident victims in the city of Cuiabá, Mato Grosso State, in 2006. It emphasize the need for preventive measures in the accidents by collision and also educational program dedicated to the male gender for the reduction of these events. The public policies on transportation, the guiding plan of the city, and the statute of the city must be reevaluated

Finally, the mining data technology can be considered a powerful tool in the analysis of secondary data, even with related data, and also to help the decision-making process, provinding

useful knowledge of databases from the health information systems and public security.

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Investigating health information needs of community radio stations and applying the World Wide Web to disseminate audio products

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Abstract

The Web and Media Technologies Platform (WMTP) of the South African Medical Research Council (MRC) conducted a pilot project amongst community radio stations in South Africa. Based on previous research done in Africa WMTP investigated the following research question: How reliable is the content of health information broadcast by community radio stations? The main objectives of the project were to determine the 1) intervals of health slots on community radio stations, 2) sources used by community radio stations for health slots, 3) type of audio products needed for health slots, and 4) to develop a user friendly Web site in response to the stations' needs for easy access to audio material on health information.

Keywords:

Radio, Education, Internet, Consumer health informatics, Needs analysis, Health information, World Wide Web.

Introduction

The South African Medical Research Council's (MRC) vision is "*Building a healthy nation through research".* One of the nine strategic objectives implemented by the MRC to address this is research translation. As defined by the MRC *"Research makes no difference to health and quality of life unless it is translated into interventions such as policy, practice and products, which can have an impact on the health and quality of life of the nation"* [1]. The Web & Media Technologies Platform (WMTP) which forms part of the eHealth Research and Innovation Platform (eHRIP) of the MRC focuses on the implementation of eHealth[1] solutions for knowledge transfer to specific target audiences within the framework of the strategic health objectives of the MRC.

[1] **eHealth**
According to the World Health Organisation (2005), eHealth refers to the use of information and communication technologies locally and at a distance – presenting a unique opportunity for the development of public health. The strengthening of health systems through eHealth may contribute to the enjoyment of fundamental human rights by improving equity, solidarity, quality of life and quality of care.

Research studies in today's technological age have shown that when looking for health and medical information, frequently, before visiting their physician, the health consumer's first point of call is the Web [2]. In the case of rural communities where the Web is not easily accessible, more traditional eHealth solutions are sought, such as listening to health information broadcast by community radio stations [3].

In 2006, an analysis by the United Methodist Communication Foundation [4] found that the only effective form of communication, e.g. to deliver messages or communicate health information to the poorest people living in shantytowns and rural areas throughout Africa, was through community radio stations. The research question of this study is: "How reliable is the content of health information broadcast by community radio stations?"

Community radio is defined as a service that caters to the interests of a certain area, broadcasting content that is popular to a local audience, but which may often be overlooked by commercial or mass-media broadcasters [5]. Radio has long been the most accessed form of media in South Africa, reaching beyond urban centres deep into the poorest and most remote rural areas. South Africa has more than 200 community radio stations that broadcast in many different languages [6].

A case study, conducted in 2005 by Lloyd and Fordred on Radio Zibonele, a community radio station in Khayelitsha, Western Cape [7], brought forward the importance of transferring health information and health education to their listeners.

Radio Zibonele has a daily audience of 200 000 and states that their mission is to enhance the quality of life of their listeners by improving their health standards. This is done through regular broadcasts of health care information and health education in order for individuals to take better care of themselves and their families. Self-help is the underlying theme of the station with many programmes that deal with practical issues. An example is a programme on how to take care of a sick child and health information for children on how to take care of their sick mother. Radio Zibonele's success could also be attributed to the station's endeavours to broadcast health information where possible in isiXhosa, the mother tongue of the majority of the listeners.

WMTP's pilot study utilizes the combined approach of a Radio to Public Transfer Model (RPKTM) and a Web to Public Knowledge Transfer Model (WPKTM), based on the theories of informatics and knowledge management.

The RPKTM aims to develop audio products to inform, educate and communicate health related information to the South African population. A secondary aim of the model is to guide community radio stations to source health related information that is 1) accurate, 2) appropriate, and 3) relevant.

The WMTP of the MRC has access to reputable scientists when audio products are developed. These audio products such as audio documentaries, key messages and panel discussions also undergo a rigorous editorial process to ensure that a high quality is maintained. Audio documentaries are accompanied by articles that are placed on a Web site. The articles serve as aid for the person compiling the health slots and supply background information on aspects that are discussed in the audio documentaries.

The Web to Public Knowledge Transfer Model is an eHealth approach used to transfer scientific information to audiences via the World Wide Web. The WMTP has gained experience over many years on structuring health and medical information on the World Wide Web; guiding health consumers to recognize trustworthy health information, or learn how the MRC structures such content for its consumption on the Web. The process is based on a knowledge transfer (KT) model to simplify knowledge uptake by health consumers, while linking content to generic principles and a recognised code of conduct based on ethical standards.

According to Drucker (2001), "Knowledge is information that changes something or somebody, either by becoming grounds for actions or by making an individual (or an institution) capable of different or more effective action," [8]. Thus, the knowledge transfer model can be used to influence the health decisions people make.

Research question

Community radio stations serve an important role in communicating health information to rural communities. The research project aims to answer the following question:

How reliable is the content of health information broadcast by community radio stations?

Goals

The pilot project attempts to answer four research questions. The questions are:

1. How often do community radio station broadcast health slots;
2. What are the sources of information used for health slots;
3. When obtaining health information from a Web site, do they make sure the information is accurate; and
4. What are the preferred formats and methods to receive audio documentaries?

Method

This research project focused only on community radio stations in South Africa. Commercial and campus radio stations will be considered in follow-up studies.

A list of all the South African community radio stations was obtained from The Media Connection [9]. Contact via telephone was established with 60 community radio stations representing all nine provinces. The questionnaire was then administered to 60 community radio stations of which 12 responses were received back.

A questionnaire consisting of 13 questions was developed and sent via email or fax to the participating radio stations. The questionnaire consisted of four parts. The first part dealt with general information about the community radio station. These questions related to where the participating radio station is situated and the languages used by the station. The second part of the questionnaire aimed to answer questions with regards to the frequency of health slots and the sources consulted for health slot content. The third part of the questionnaire focused on the type and format of audio products needed by community radio stations. The last part of the questionnaire focused on preferred methods of communication between WMTP and the participating community radio station.

The pilot study results are based on the feedback of the community radio stations that was received.

Results

All the responding community radio stations indicated that they have regular health slots ranging from once a week to five times a week. One radio station broadcast health information "…when the hospital or clinic needs to bring something to the communities' attention".

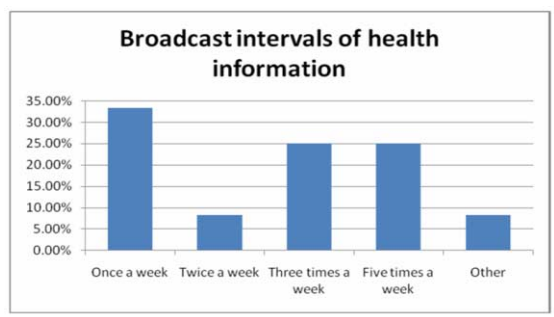

Figure 1 – Broadcast intervals of health information

Results indicated that 33.3% of the community radio stations who participated have a health slot once a week. Results have also shown that 25% of the stations have health slots three times a week and another 25% indicated that they have health slots five days a week. (Figure 1)

The respondents were asked to indicate the sources from which they obtain health information for their health bulletins. All the community radio stations indicated that they make use of multiple sources. The two most popular sources were Clinic Nurses and Community Health Workers with 75% each. (Figure 2)

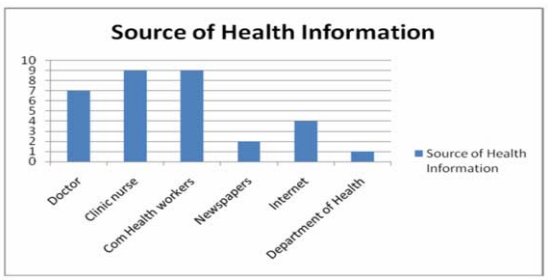

Figure 2 – Source of Health Information

Results from the questionnaire revealed that 100% of the respondents preferred audio documentaries and live interviews followed by panel discussions with 66%, and newsflashes with 58%. The radio stations were also allowed to choose more than one option.

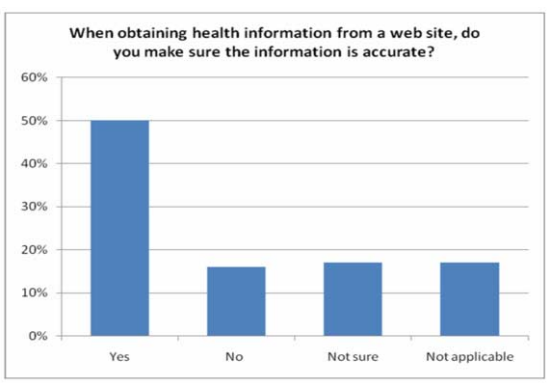

Figure 3 – Quality assurance in seeking health information?

In order to establish whether community radio stations could verify the accuracy of health information that they obtain the following question was asked; "*when obtaining health information from a Web site, do you make sure the information is accurate*". As shown in Figure 3, 50% of the respondents answered "yes", 16% answered "no", 17% were not sure and 17% said it was not applicable to them. This question was further expanded. If they answered "yes", by asking them how they verified the accuracy of the health information. The answers varied from; "they contact a specialist to verify the health information"; they "contact Department of Health and verify the health information with the relevant department"; and they "only use trustworthy sources". This is a clear indication that 50% of community radio stations in this study were not aware of the fact that not all health information on the Internet is accurate or reliable.

Table 1 – Audio documentary format and method of downloading

Indicate your preferred format for audio documentaries	
mp3	91.67%
other format (unspecified)	8.33%
Indicate the preferred method to obtain audio documentaries	
Download from Web site	58.34%
File Transfer Protocol	33.33%
Compact Disk	8.33%

As shown in the cross tabulation of two questions of preferred format of audio documentaries and preferred method to obtain these audio documentaries, Table 1 indicates that 91.67% of the respondents prefer the audio documentaries to be in mp3 format, with 8.33% indicating that they prefer the audio documentaries to be in another format. 58.34 % of the respondents would download it from the Web site, with 33.33% accessing the audio documentaries via the File Transfer Protocol (FTP) and only 8.33% would obtain the audio on a Compact Disk.

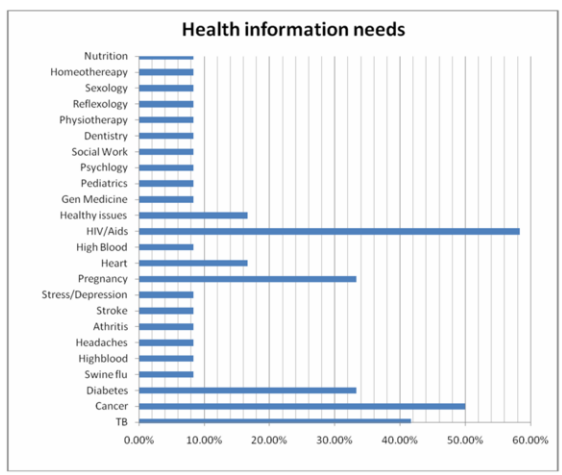

Figure 4 – Health information needs

As the MRC audio production studio develops audio health documentaries according to the health days identified by the Department of Health, which might not be the health information that community radio stations need, a question "*Indicate the preferred topics for health information*" was included in the questionnaire to establish which health topics the community radio stations were interested in. As shown in Figure 4 the health information needs of the community radio stations were as follows: 58.33% on HIV/AIDS, 50% on Cancer, 41.66% on Tuberculosis followed by 33.33% on Diabetes.

Discussion

As shown in the results of the pilot study, health slots amongst community radio stations are an important part of their broadcasting agenda ranging from once a day to five times a week.

The full study could explore whether there is any relation between the frequency of health slots, e.g. once, twice or five times a day and the amount of sources accessible to find information or audio products to fill these health slots. Thus, will community radio stations include more health slots or programmes dealing with health issues if there were more sources they could consult or audio products they could utilize to fill these programmes?

The majority of sources used by community radio stations for health slots are clinic nurses and community health workers. Although they have knowledge on certain health topics, such as diabetes and HIV/AIDS, they may not have the facts readily available to give advice on epidemic outbreaks such as H1N1 (swine flu). Therefore it is important to inform the community radio stations of the radio Web site that is available for them to expand their source of up to date, reliable and accurate health information.

As the results indicate, community radio stations prefer to receive audio documentaries of health information in mp3 format. The majority of respondents preferred to download these audio products from the Web site. These audio documentaries are already available on the radio Web site for radio stations to download as they have been developed on health topics, specified in the health calendar of the Department of Health. Based on the results of the health topics as specified by the radio stations, WMTP could further expand on the development of audio documentaries and play a role in supplying material for the health bulletins.

Results from the pilot study show that there is a definite need for accurate and reliable health information in audio format for community radio stations. In an era of increased Internet access and connectivity where more and more health consumers turn to the World Wide Web for guidance on health issues, the compliance to standards has become essential.

A full study could also determine if community radio stations would increase their health slots based on an increased amount of 'healthy' audio material.

Conclusion

The results also show that a Web site developed according to the WPKTM, incorporating the generic principles and a recognised code of conduct based on ethical standards and good practice guidelines, with the option to download audio in mp3 format, would be an effective tool for community radio stations that have access to the Internet.

The way forward would be to engage more community radio stations and to include campus radio stations and commercial radio stations in a full study.

WMTP aims to introduce the radio Web site as the preferred source of health information and a *"one stop shop"* for community and campus radio stations.

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Documentation in Pharmacovigilance: Using an ontology to extend and normalize Pubmed queries

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Abstract

Objectives: To assess and understand adverse drug reactions (ADRs), a systematic review of reference databases like Pubmed is a necessary and mandatory step in Pharmacovigilance. In order to assist pharmacovigilance team with a computerized tool, we performed a comparative study of 4 different approaches to query Pubmed through ADR-drug terms. The aim of this study is to assess how an ontology of adverse effects, used to normalize and extend queries, could improve this search. Material and Method: The ontological resource OntoEIM contains 58,000 classes and integrates MedDRA terminology. The entry point is a ADR-Drug term and the four methods are (i) a direct search on Pubmed (ii) a search with a normalized query enhanced with domain-specific Mesh Heading criteria, (iii) a search with the same elaborated query extended to the MeSH sub-hierarchy of the adverse effect entry and (iv) a search with a set of MedDRA terms grouped by subsomption in the OntoEIM ontology. For each of the 16 queries performed and analysed, relevant publications are selected "manually" by two pharmacovigilant experts. Results: The recall is respectively of 63%, 50%, 67% and 74%, the precision of 13%, 26%, 29% and 4%. The best recall is provided by the ontology-based method, for 4 cases out of 16 this method returns relevant publications when the others return no results. Conclusion: Results show that an ontology-based search tool improves the recall performance, but other tools and methods are needed to raise the precision.

Keywords:

Adverse drug reaction reporting, Adverse drug reaction, Information retrieval, Databases bibliographic, PubMed, Ontology.

Introduction

Pharmacovigilance is the science focusing on detection, analysis and prevention of adverse drug reactions (ADRs). Spontaneous reports of ADRs by health care professionals allows the collection of case reports by central agencies and/or pharmaceutical companies [1]. Case reports (namely *ADR*-Drug pairs) are coded with the WHO-ART[1] and/or MedDRA[2] terminologies for the ADR and the ATC terminology for the drug, and stored in databases that constitute putative knowledge on suspected adverse drug reactions.

The pharmacovigilance team has the task to code newly reported ADR-drug cases but also to document and analyze them with relevant and up-to-date information retrieved from various sources. The sources presently requested during this review task are 1) drug summary of the product's characteristics (SPC), 2) pharmacovigilance-related data sources (such as Martindale, Meyler's Side effects of Drugs, other databases like Micromedex), 3) medical literature 4) previously reported cases. We address the documentation issue in the context of the Vigitermes project[3] which aims at developing a semantic portal to improve documentation of pharmacovigilance case reports for the pharmaceutical industry and regulatory authorities [2]. In the Vigitermes platform, for a given case, one action button performs the search on the drug SPC, Pubmed and pharmacovigilance databases. The PharmARTS tool is used to group cases with a close meaning, it relies on an ontology of adverse drug reactions (OntoEIM) that is based on the formal definitions of WHO-ART and MedDRa [3, 4]. In the present work, our objective is to evaluate the benefit of using the OntoEIM ontology in the request process on PubMed database. Our aim is to automate the search of relevant publications that correspond to a given ADR case. In a previous work, we presented a Pubmed querying web service for retrieving abstracts from the MEDLINE database based on Mesh heading and Mesh qualifier pattern criteria [5]. In this study, we performed a comparison of four different search methods using our Pubmed querying web service.

First, terms clustering and information retrieval with MEDLINE are presented in the background section. We then

[1] World Health Organization - Adverse Reaction Terminology
[2] Medical Dictionary for Drug Regulatory Activities
[3] http://vigitermes.univ-rennes1.fr

present the OntoEIM ontology and PharmARTS, the browsing tool used to query the ontology. The general architecture of the Vigipubmed toolbox is described and we detail the comparison study used to assess the "plus-value" of the ontology. Results are reported on a set of 13 ADR-drug cases are presented and discussed.

Background

Information retrieval with Medline

Several studies have shown that researchers report difficulties when searching electronic resources to document adverse drug reactions [6, 7]. Among others, these difficulties are due to poor indexing, to the wide variety of articles that may potentially be useful, to variation in their qualities, as well as the lack of tools to perform systematic search. Literature, specifically MEDLINE, is the main source of documentation used to detect whether a drug may be responsible for ADRs. Nowadays, literature searches are mainly done manually. However, the exhaustive retrieval of such information may not be straightforward, for three reasons. Firstly, the query is not easy to formulate: the terms have to be translated in English (for non-English speakers), and even mapped to MeSH entry terms. Secondly, the large number of publications in MEDLINE makes the search difficult and time-consuming. Thirdly, it is not easy to determine manually the level of evidence that should be the most appropriate to characterize the relation between a drug and a possible adverse effect.

Grouping similar ADRs

ADRs are coded with MedDRA or WHO-ART in pharmacovigilance databases. The MedDRA terminology, recommended for the description of ADRs by the pharmaceutical industry and regulatory authorities, includes entirely the WHO-ART terminology, but is considerably more extensive (15,000 preferred terms versus only 3500 for WHO-ART).

The structure of relationships used to organize terms is particularly important to retrieve similar medical conditions in the database and has a direct impact on the specificity and sensitivity of pharmacovigilance signal detection [8]. We have previously shown that neither WHO-ART nor MedDRA allows similar clinical conditions to be clustered together due to the lack of polyhierarchy. For instance in MedDRA, the term "gastric ulcer hemorrhage" is linked to the "gastric ulcer and perforations" term but not to the "gastric and esophageal hemorrhage" term. This deficiency limits the detection and the evaluation of ADRs [9].

We have developed an ontology (OntoEIM) describing ADRs that enhances the structural organisation of terms [3]. A web tool, PharmARTS, was developed as an interface to this ontology [10]. This ontology is under evaluation in the context of signal detection [4]. We investigate in the present article the relevance of this ontological resource to retrieve relevant articles in Medline for a given query.

Material and Method

Material

The OntoEIM iontology was previously developed and mapped with MedDRA and WHO-ART terminologies [3] PharmARTS, an online web service tool developed to query the ontology [10], is used to extend the query by grouping .MedDRA and WHO-ART terms with close meaning using OntoEIM.

OntoEIM

OntoEIM includes ADRs concepts obtained by aligning WHO-ART and MedDRA terms with SnomedCT[4], using the synonymy link in the metathesaurus of UMLS[5]. Relations in the ontology are associative relationships extracted from SnomedCT (e.g. "bladder neoplasm" is associated with the localization "bladder structure") and the relationship "is a" is used to indicate taxonomic relationships (e.g. "renal failure" is a "renal disease"). The ontology contains 5 798 WHO-ART classes, 37,892 MedDRA classes and 14,342 SnomedCT classes and includes 1,621 defined classes. The primary concepts of the hierarchy account for 4.6% of SnomedCT (308,677 concepts in the used version).

PharmARTS

PharmARTS is a web service developed in JAVA [10]. This tool can be used for querying (related to a clinical condition) and for grouping terms together by subsumption, (e.g. the terms "BLOOD_TRIGLYCERIDES_ABNORMAL" and "CHOLESTEROL_BLOOD_EXCESSIVE" could be used to encode two cases of dyslipidemia). PharmARTS can also be used to provide a more effective visual display of groups of terms and of associated pharmacovigilance cases [10].

Method

In order to assess the contribution of the ontology in the retrieval of relevant documentation from MEDLINE, we conducted a comparative study of four methods used to query the Pubmed database. Figure 1 displays the web service workflow of the evaluation system. The entry point is a pair of ADR-drug terms of a given case.

[4] http://www.ihtsdo.org/
[5] http://www.nlm.nih.gov/research/umls/

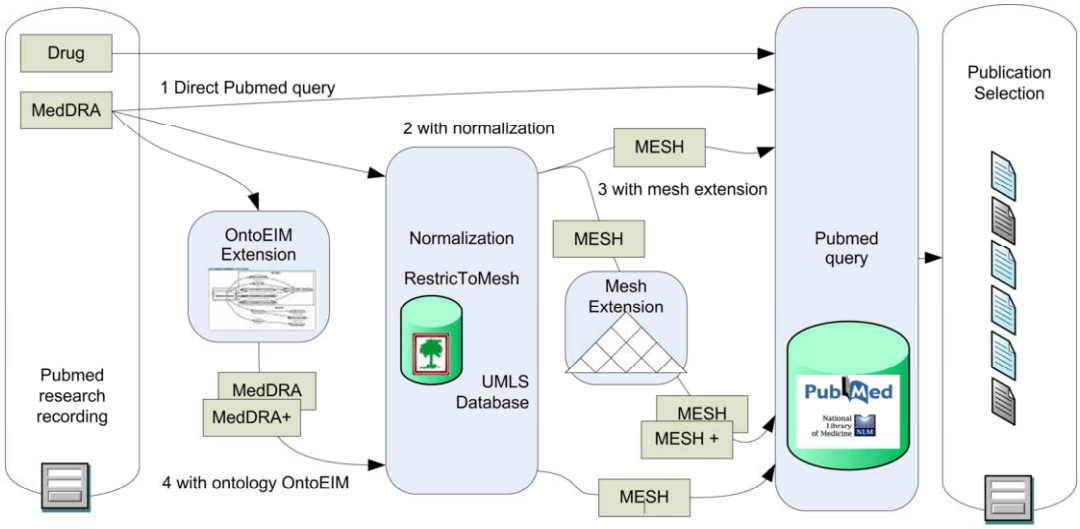


Figure 1- Web services work flow

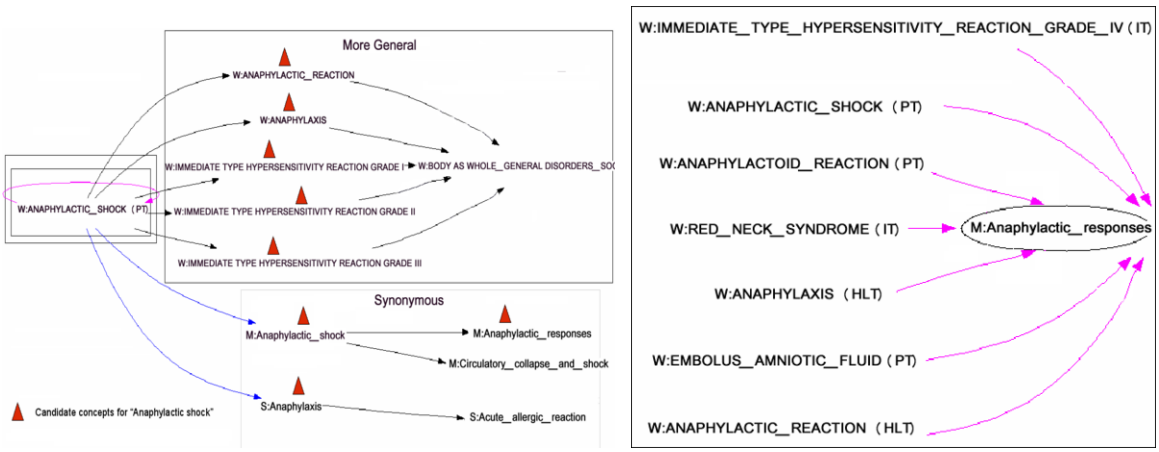
Method 1 uses the Pubmed web service without any refinement, just as the pharmacovigilant will use PubMed. Method 2 uses our own web service VigiPubmed that builds a normalized query for pharmacovigilance. The MedDRA terms are first normalized with UMLS and matched on the MeSH thesaurus [11], then the Pubmed query is built similarly to the one previously proposed [5]. Both methods 3 and 4 also use the VigiPubmed web service. For method 3, the queries are developed successively with all the terms of the MeSH subhierarchy of the adverse effect entry. For method 4, PharmARTS.is first called in order to extend the initial MedDRA entry terms with the OntoEIM ontology, then the group of MedDRA terms is processed with VigiPubmed. The evaluation system is a simple web form application developed in php that integrates the different web services written on a java/axis2 platform.

The relevance of the selected articles is evaluated independently by two pharmacovigilance experts; then the results are compared and in case of discordance, discussed until consensus. A relevant publication is a publication that contributes to the analysis of the ADR case, that helps its comprehension; it is likely to be cited in the literal case report written by a pharmacovigilant.

In method 4, the OntoEIM extension consists in searching OntoEIM for concepts similar to the label used by the pharmacovigilant. We begin by identifying one or several terms associated to the label (WHO-ART term or the SnomedCT and MedDRA Synonymous), using PharmARTS. In a second step, we select candidate concepts in OntoEIM designed by these terms as well as the ascendant when the concept itself doesn't allow any grouping (a leaf concept in the ontology). Finally, the method returns the union of concepts subsumed by all candidate concepts. For example, for the label "Anaphylactic shock" we identify three terms: 1) Anaphylactic shock from Who-ART, 2) Anaphylactic_shock from MedDRA and 3) Anaphylaxis from SnomedCT, these terms are associated with concepts in the OntoEIM ontology and we can therefore carry out three queries with PharmARTS returning three sets of concepts designed by terms from the various terminologies. Figure 2 shows a graphical representation of the organization of these concepts within the ontology.

Example : Anaphylactic shock

List of grouped terms : (ANAPHYLACTIC_REACTION, ANAPHYLACTIC_SHOCK, ANAPHYLACTOID_REACTION, ANAPHYLAXIS, EMBOLUS_AMNIOTIC_FLUID, IMMEDIATE_TYPE_HYPERSENSITIVITY_REACTION_GRADE_I, IMMEDIATE_TYPE_HYPERSENSITIVITY_REACTION_GRADE_II, IMMEDIATE_TYPE_HYPERSENSITIVITY_REACTION_GRADE_III, IMMEDIATE_TYPE_HYPERSENSITIVITY_REACTION_GRADE_IV, RED_NECK_SYNDROME)



(a) *(b)*

Figure 2-Graphical illustration of the ontological extension. (prefix W for Who-ART, M for MedDRA and S for SnomedCT) a) Candidate concepts for term "Anaphylactic shock" b) List of subsumed concepts for candidate concept "Anaphylactic_responses"

Results

The study was performed on the following entry points, based on cases or questions transmitted to the pharmacovigilance department. There are 13 cases grouped in 8 groups which correspond to 16 queries on Pubmed : 1) ADR=lupus, Drugs=statin (atorvastatin, fluvastatin pravastatin rosuvastatin and simvastatin), 2) ADR=purpura, hematoma, petechia or thrombocytopenia, Drug=levetiracetam 3) ADR=anaphylaxy , Drug=rituximab 4) ADR=neutropenia, Drug=ciprofloxacin 5) ADR=hair disorder, Drug=valproate or clonazepam, 6) ADR=Lyell Syndrome, Drug=paracetamol 7) ADR=thrombocytopenia, Drug=infliximab, 8) ADR=Aseptic meningitis, drug=sulfamethoxazole trimethoprim. For instance, in the first group, one can see that there are 5 cases corresponding to the 5 drugs. In the second group, one can see that there is only one case but corresponding to 4 different queries (4 possible terms for the ADR).

The choice of these queries was deliberate in order to check various situations : drugs largely prescribed and with extensive publications (like statins), drugs not widely prescribed (levetiracetam), ADRs that are also indications for the drug (neutropenia and ciprofloxacin), ADRs not clearly defined (purpura, hematoma, petechia or thrombocytopenia), and an expected ADR (aseptic meningitis and sulfamethoxazole trimethoprim). Table 1 displays quantitative results of the comparative study based on 13 reported ADR-drug cases. In the domain of bibliographic review the gold standard is not easily defined, in our study we use a relative reference to calculate recall and precision. For each given case, the reference is the set of relevant abstracts selected by any of the four methods.

Main publication types are "case reports" for 501, unspecified "journal article" for 421, "clinical trial" for 378, "review" for 214, "comparative study" for 96, "letter" for 75, etc.

Table 1- evaluation results of the four search methods

Method	Pubmed	VigiPubmed		
	Method 1	Method 2 Alone	Method 3 + Mesh extension	Method 4 + ONTOEIM extension
Abstracts	480	184	218	1780
Relevant Abstracts	60	48	64	74
Recall	63%	51%	67%	78%
Precision	13%	26%	29%	4%

Compared to the direct request on PubMed, VigiPubmed works as a filter as the 184 VigiPubmed abstracts are is a subset of the 480 Pubmed abstracts. Hence VigiPubmed does improve the precision however other tools are needed to get a better recall. The best recall is provided by "VigiPubmed + OntoEIM", the ontology-based method (78%). In four cases out of 13, this method returns relevant publications when the others methods return no results. For instance, in the case of anaphylactic shock with rituximab, methods 1 to 3 retrieve 8 abstracts but none of these abstracts is relevant while, for method 4, 34 articles are retrieved, and 6 of them, associated with the "RED_NECK_SYNDROME" term, normalized in "hypersensitivity", are selected by the reviewers to be relevant.

Extending the Pubmed request with the ontology causes a loss of precision (4%), this result is expected when we enlarge the context of the bibliographic search, however, for this study, our focus is on the recall in order to demonstrate the "plus value" on the ontological approach in terms of the retrieval of relevant paper. In the future, we can imagine various methods

to browse the results in an efficient manner for increasing the precision: scoring and filtering based upon Mesh heading and qualifier, graphical interface associated to the ontology, etc.

Discussion and conclusion

As of today, we don't have a good evidence for what constitutes an effective search strategy for adverse effects in the medical literature. As the combination of an ADR and a drug is infinite, any method that could normalise and help this search is useful. Moreover, interrogation should not be expert-dependant and should be reproducible whoever realizes it. In the current practice, pharmacovigilance experts start by choosing a term for the adverse effect studied. When the effect is correctly described and well-known, as the choice is easy, the results are easy to analyze, but when few or no documentations are found in the searched databases, experts extend the term to a close adverse effect. The automatic extension to these close terms may therefore be very useful.

Considering the results of this preliminary study, the best way to achieve the bibliographic review on PubMed in terms of cost (that is the number of abstracts to be read) and efficiency (that is the number of relevant articles) is a combination of the different methods. In a first step, the request can be done with the VigiPubmed web service directly or with the MESH extension, the result of the program is a list of articles reduced of about 60 % with regard to a direct request on PubMed whereas recall are 51%, 67% versus 63%. In a second step, when the first request returns no result and also to enlarge and complete the bibliographic review, the request is extended with terms provided by the ontology. The contribution of the ontology is to define a concept into a context by relationships to the others. For instance, a question about thrombocytopenia related to infliximab returns two publications but three additional publications, retrieved with the ontology-based method, reporting another close haematological effect, were useful for the analysis and the comprehension of the case studied.

Another major issue is when the potential adverse effect studied is also a condition or a disease that the drug is used to treat. The best example is neutropenia occurring after antibiotics. The addition of a term such as adverse effect, drug toxicity is not always useful as authors do not always add a specific term for pharmacovigilance data. Global recommendations about pharmacovigilance publications (Drug safety public ERICE) should be applied more systematically [13]. In this first study we adopt the point of view of ADRs. In a future second phase, a similar approach could be applied with the point of view of drugs and active ingredients.

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Chapter 7.

Care at a Distance

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Leapfrogging Paper-Based Records Using Handheld Technology: Experience from Western Kenya

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Abstract

Problem: There is limited experience with broad-based use of handheld technologies for clinical care during home visits in sub-Saharan Africa. Objective: We describe the design, development, implementation, and evaluation of a PDA/GPS-based system currently used during home visits in Western Kenya. Results: The system, built on Pendragon Forms, was used to create electronic health records for over 40,000 individuals over a three-month period. Of these, 1900 represented cases where the individual had never received care for the identified condition in an established care facility. On a five-point scale, and compared to paper-and-pen systems, end-users felt that the handheld system was faster (4.4 ± 0.9), easier to use (4.5 ± 0.8), and produced higher quality data (4.7 ± 0.7). Projected over three years to cover two million people, use of the handheld technologies would cost about $0.15 per person – compared to $0.21 per individual encounter entered manually into a computer from a paper form. Conclusion: A PDA/GPS system has been successfully and broadly implemented to support clinical care during home-based visits in a resource-limited setting.

Keywords:

Handheld computers, Computerized medical records systems, Developing countries

Introduction

Many people in developing countries have little to no interaction with the healthcare system. The problem of accessing healthcare in these settings is usually two-fold: "*On the supply side, good quality, effective health care may not be offered. On the demand side, individuals may not utilize services from which they could benefit*." [1] As an example, in sub-Saharan nearly, 80% of HIV-infected adults are unaware of their HIV status [2] - this despite an interest by individuals in being tested [3]. Similar deficiencies are also seen in the diagnosis and management of diabetes, hypertension, chronic cardiovascular disease and tuberculosis, among others [4, 5]. Such poor access to healthcare leads to increased mortality and morbidity in these settings.

Approaches that take health services directly to individuals (as opposed to waiting for patients to come to the care facility) are being increasingly adopted to improve access to care. There is increasing adoption of home-based counseling and testing methods for HIV [6]. In addition, governments in developing countries are increasing the number of community health workers tasked with delivering care services directly into homes and communities.

By their very nature, home-based clinical encounters lead to care outside established health facilities. In the setting of sub-Saharan Africa, these visits often represent the first interaction of some individuals with the healthcare system. Such individuals typically have no established medical records, and data collected during home visits often represent the first medical records on them. As such, it becomes very important to collect this clinical information in a way that is useful not only during return visits to the home, but also for clinic-based follow up and for reporting purposes.

The USAID-Academic Model Providing Access to Healthcare (USAID-AMPATH) [7] in Western Kenya recently embarked on an effort to conduct home visits to the two million individuals in its catchment area. The goal was to collect basic health information and offer focused care services to individuals when needed. Typically, records collected for such visits would have been paper-based. We however hypothesized that it would be possible to completely leapfrog paper-based records, and create electronic health records (EHRs) for each individual for whom we conducted a home-based clinical visit.

The premise of our approach was based on the observation that resource-limited settings like ours had already made similar technological leaps [8]. The classic example was the leap from no telecommunication services to broad use of mobile telephony [9]. In addition, mobile devices had also been successfully used for limited research and clinical purposes in settings similar to ours [10, 11]. However, there was very

little evidence to demonstrate the feasibility of broad-based implementation of mobile handheld technology for direct clinical care in these settings.

In this article, we describe the design, creation, and implementation of a customizable, modular-based handheld program to support Community Health Workers (CHW)s during home-based visits in a resource-limited setting. We also reports findings of a satisfaction survey of the end-users of the program and cost implications of using this system.

Materials and Methods

Setting

This work was conducted in Western Kenya, within a catchment area served by the USAID-AMPATH partnership. This program (made up of Moi University School of Medicine in Kenya and a consortium of universities in North America led by Indiana University School of Medicine) has provided comprehensive HIV care to individuals in western Kenya since 2001 [7]. In the last two years, the program has begun a transition into primary care.

Recognizing its responsibility to improve access to care for all individuals, the USAID-AMPATH program decided to conduct population-wide, clinically focused home visits to all households in its catchment area of two million people. The primary goal of this undertaking was to identify HIV-positive patients who were unaware of their status, and to offer care services as needed. In addition, this program aimed to identify pregnant women not receiving antenatal services; orphaned and vulnerable children; children who had not received all recommended immunizations for age; and individuals at higher risk of tuberculosis infection. During the home-visits, eligible individuals were offered rapid testing for HIV, sputum testing for Tuberculosis, deworming medication, and mosquito bednets. All clinical data gathered during these visits were captured on handheld devices.

Design and Development of Handheld Program

We started by engaging an interdisciplinary team of providers (including public health providers, nurse CHWs, and physicians), overseen by an executive steering committee. This team identified the data elements to be collected during the home visits, provided information on criteria and algorithms to be used (e.g. algorithm for HIV testing), and informed the team about the workflow relevant to the home visit exercise.

Modules

Several modules were identified as necessary for the home-based visits, and were programmed into the handheld devices. (Figure 1) The modules included:

Individual registration

Each individual who was visited by a CHW received a unique identifier. Households were also assigned unique identification numbers. These identifiers were generated from one central location, and had a check-digit. For the household, we captured the Global Positioning System (GPS) location and other information about the household, including number of residents. The individual demographic information collected included: first, middle, and last name; gender; birthdate [with ability to record estimated dates]; address; and phone number (when available).

HIV Module

The HIV module collected information about each individual's HIV testing history. We documented whether the individual had previously been tested, the year of their last test and the results. If the individual was known to be HIV-positive, we captured details of the HIV-treatment program to which they were enrolled. During the home visits, eligible individuals were offered HIV testing, and details of the testing were also collected. These included information about pre- and post-test counseling during the home visit; consent or assent to testing; results of two parallel rapid tests and of a third tie-breaker test (when it was done); referrals; and information on whether the

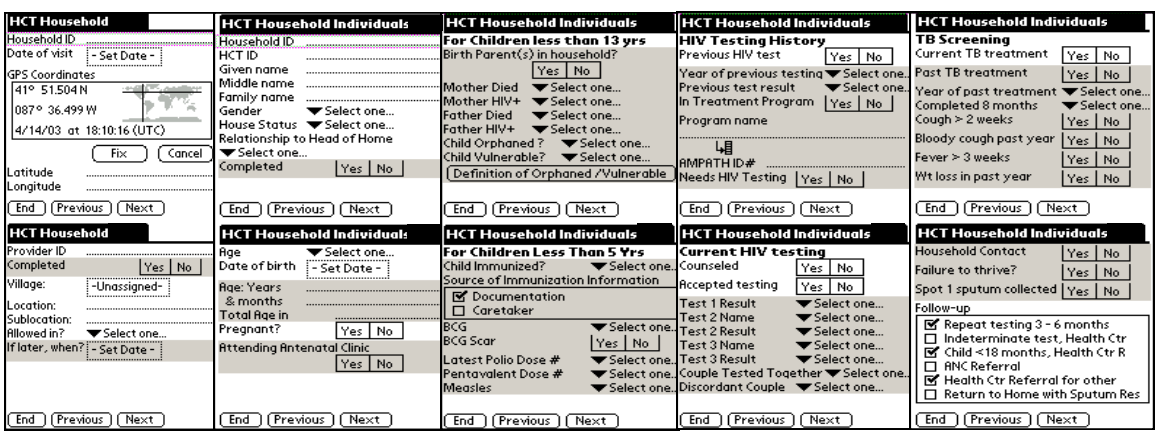

Figure 1-Screenshots outlining the various modules

HIV-statuses of a couple were discordant.

Pediatric Module

For children, we determined whether the child was orphaned or vulnerable (OVC) using a pre-defined set of conditions. A child was eligible for testing if their mother's HIV status was positive or unknown, or their mother had died or living status was unknown, and the relevant information was recorded. For children younger than five-years, we also recorded immunization history - including the source of the immunization information; details of measles, polio and pentavalent vaccination; and whether there was any visible BCG scar to signify immunization against TB.

Tuberculosis Module:

For all individuals visited, we documented history of current or previous TB treatment and responses to TB screening questions (e.g. bloody cough, fever, and weight loss). We also documented whether a sputum sample was collected for at-risk patients and the phone number to contact the individual with the results.

Antenatal Care Module:

For females of reproductive age, we documented pregnancy status. If pregnant, we documented whether they were enrolled into an antenatal clinic.

Software and Hardware

We developed the program to collect individual health data using Pendragon Forms software (Pendragon Software Corporation, Illinois, USA). Like most other Personal Digital Assistant (PDA)-based form-creation software, [10, 11] Pendragon Forms has a Windows application for designing customized data-collection forms. This program supports over 20 field types, and has scripting capability for data validation, calculations, and for form navigation control. Once developed, forms can be uploaded to Pendragon's PDA runtime application that runs on Palm-powered handhelds and on Windows Mobile Pocket PCs. Data collected on PDAs can be synchronized into a database (like Microsoft Access or SQL server) or exported to ASCII and Excel. Pendragon Forms support multiple users, and synchronization can be bidirectional.

Using the Pendragon Forms software, we programmed data-collection forms containing information for our various modules. In addition, we programmed basic data validation, branch logic, and reminders/alerts into the forms. The forms were uploaded into Palm T|X PDA devices (Palm Inc®, California, USA). We also loaded valid identifiers, a check-digit verification algorithm, detailed information about the administrative locations in the region, and provider identifiers. Global Positioning System (GPS) coordinates were captured with an external e-Trex GPS device (Garmin®, Kansas, USA) linked via a cable connection to the PDA.

Data Collection

The handheld tools were iteratively tested and improvements made. We then conducted two days of formal training for the CHWs who would be the end-users of the PDA/GPS devices and software. Each CHW was assigned a specific device, and had primary responsibility to ensure that the device was always in good working condition. The CHWs carried the handheld devices during home visits, and recorded all needed data during the encounter in the Pendragon forms after seeking consent of individuals in the household – these individuals had already been sensitized about the home visits and the use of these gadgets through a concerted community-wide mobilization effort. Data managers would, on a weekly basis, transfer the data from PDAs to a central Microsoft Access database (Microsoft Corp®, Redmond, WA, USA).

User Survey

To assess end-user attitudes toward the PDA/GPS handheld tools implemented, we gave an anonymous self-administered survey to CHWs who were present at a full-group meeting. Respondents were asked to rate the reliability of the PDA program and the GPS device. They were also asked to compare the utility of these handheld tools relative to paper-and-pen based systems. Respondents also gave information about their PDA and computer experience.

Data Quality and Cost Calculations

We used data collected during home visits in the Turbo Division in Western Kenya to evaluate completion and quality of data collected using the handheld devices. Findings are reported using descriptive statistics. Our cost calculations were based on the expected resources needed to reach the two million people in our catchment area within three years (780 workdays). From home visit data from Turbo Division, we knew the average number of individuals a CHW could see per day. Using this number, we determined number of providers (and hence handheld devices) needed to complete the visits with the three-year timeframe. Our calculations accommodate a device breakdown rate of 25% per year. We also include the cost of developing the system, training, and maintaining the PDA/GPS devices, and compare this cost with one using paper-and-pen based system.

Results

EHRs during Home Visits in Turbo

Between July and October of 2008, 93 CHWs visited 14,648 households in the Turbo Division in Western Kenya. During these visits, they interacted with and created electronic health records for 40,111 individuals. Of these individuals, 55% (22,182) were female and 26% (9,509) were below 13 years of age. On average, each CHW saw and created records for 12 ± 6 individuals per day. In the first year of use, only one device was lost, and four failed (out of 93 devices).

The visits in Turbo Division uncovered cases for which the individual had never presented for formal care in an established facility – and where no records (paper or electronic) existed. Four hundred and three of 899 (45%) pregnant women identified were not receiving antenatal care. Of the 1,131 individuals with positive HIV test results at the time of the home visits, 693 (61.3%) had never had a previous HIV test. 376 individuals had been exposed to or had symptoms sugges-

tive of tuberculosis. In all these cases, the electronic records created on the handheld devices were the first documented health records for these individuals or for their condition.

User Satisfaction

We administered our survey to a convenience sample of 70 CHW. At the time, there were 78 active CHW who had been using the PDA/GPS devices. All CHWs surveyed responded, for a response rate of 90% of all CHWs at the time. Sixty-five (94%) of the respondents had never used a computer, and 65 (94%) had never used a PDA prior to our implementation.

Compared to paper & pen-based systems and on a five-point scale, CHWs felt that using the PDA/GPS devices was faster (4.4 ± 0.9), easier (4.5 ± 0.8), and resulted in higher quality data (4.7 ± 0.7). Surprisingly, CHWs also felt that using the handheld devices made their interaction with the patient easier (4.0 ± 0.9). There was a sense that the devices made them look more professional. One CHW captured this sentiment in their written comments about the PDA: "*It boosts someone[s] moral[e] on duty, and puts [them] in a high class.*" In addition, CHWs reported being highly satisfied with the training received on the handheld tools (4.8 ± 0.5), and all wanted to continue using the devices during home visits (4.8 ± 0.5).

Data Quality

Analysis of uploaded data revealed that all individuals and households were assigned unique identifiers, with no duplicates. GPS information was captured for all households, but in 4,695 (32%) of the cases, the CHW had to enter this information manually into the PDA. Manual entry had to be done when the cable connection between the PDA and GPS device was not working properly. Despite programming the PDA to allow for easy manual-entry and verification of coordinates, there was always a chance of errors being made. Other quality checks confirmed that no males were assigned a pregnancy status, and that each record was completed. Queries of the number of daily visits recorded per provider revealed some outliers – as an example, four of the 93 CHWs had days with more than forty individual encounters entered. This seemed unrealistically high and demanded further investigation.

Cost

We plan to visit two million unique individuals in our catchment area within three years (780 workdays). To meet this goal, an average of 2,565 individuals have to be visited each workday. From our Turbo Division data, we know that a CHW visits, on average, 12 individuals each day. This would mean having about 214 CHWs with PDA/GPS systems working on any particular day. Assuming that we have a breakdown rate of 25% for the PDA or GPS devices per year, we will need about 320 total PDA/GPS units over the period of the evaluation – i.e. an additional 53 devices at the beginning of the second year, and another 53 at the beginning of the third.

At a rate of $299 per PDA, $55 per Pendragon Forms license, $189 per eTrex GPS device, and $30 for the cable to connect the GPS and PDA devices, the cost of setting up PDA/GPS units per CHW would be $573 – bringing the total to $183,360 for 320 units. The data collected on handhelds will be synchronized into computers located at one of the 18 USAID-AMPATH clinics. At $1,500 per desktop computer, the cost of 18 computers will come to $27,000. Personnel costs include one-month programming time by a dedicated mid-level programmer based in Kenya for a cost of $1,600, 50% of an IT person's time ($22,000 for three years), 50% of a data manager's time ($22,000 for three years), and two dedicated data assistants ($45,000 for the three years). Training costs will come to about $1000, assuming two day training sessions for CHWs in groups of 70 to 80.

Adding all expenses, the total implementation costs for the handheld technology comes to $301,960. For each of the 2 million individuals visited, the cost of using the PDA/GPS technology per individual will be about $0.15. This estimate does not take into account the fact that the PDA/GPS devices can still be resold, or used for other purposes in the future. For comparison, if paper-and-pen based systems were used during home visits and the data entered by data-entry clerks, it would cost about $0.21 per record to simply enter this data – a typical data entry clerk is paid $17 per day and is expected to enter 80 encounters. In fact, the pen-and-paper based system would have other costs, including the supplies, the cost of computers, data management, and data cleaning.

Discussion

Our implementation in Western Kenya represents one of the largest applications of a PDA/GPS system for clinical care during home-based visits in a resource-limited setting. Most of the previously described, PDA-based eHealth applications have been largely used for research purposes or in limited clinical settings [10]. As our home visits focus on improving access to care, we found many cases where individuals had never received care in an established clinical facility. In such cases, no medical records existed, and our system (which created electronic health records) simply leapfrogged the typical paper-based charts found in this region.

Our approach, which is well-liked by the end-users, is scalable. The software created can be easily installed to more devices, and new clinical modules can easily be added into the existing software. We demonstrate that end-users with little experience with PDAs and computers can learn to use handheld devices. The typical concerns about reliability of the handheld system and theft of devices in settings like ours proved unfounded in our case. We find that CHWs who are given primary responsibility for a PDA device take as good care of it, as they do for their own personal mobile phones.

There is mounting evidence that collecting data via handhelds has multiple advantages over pen-and-paper systems. The data collected via PDAs frequently contain less errors, are often more complete, require less cleaning, and might not be any more expensive [12]. End-users also generally prefer handheld systems over pen-and-paper methods [13] – an observation reinforced in our survey. As Dwolatzky et al. point out, data collected electronically via handheld devices are also available for re-use in queries to generate reports, for case-management, and for follow-up within established clinics. The

GPS information can also help find patients lost to follow-up and signal disease outbreaks.

The handheld system we created is being linked to the electronic medical record system currently in use at USAID-AMPATH. Since 2004, USAID-AMPATH has been using the AMRS EHRs to support care of its patients [14]. AMRS was the first implementation of the open-source OpenMRS software [15] which already interacts with several mobile applications including EpiSurveyor,[16] the Android-based Open Data Kit,[17] JavaRosa-OpenRosa,[18] and Moca Mobile [19]. We chose Pendragon Forms because of its flexibility, but were fully aware that we would eventually integrate the data collected into our functioning, clinic-based EHRs.

Despite the success of the handheld technology in our setting, several key limitations of this technology need to be highlighted. Handheld devices generally have limited storage capacity and battery life. We also noticed that the connection between the cable PDA and GPS devices was not always reliable – we will be switching to PDAs that have inbuilt GPS capability. Handheld technologies also carry the risk of security breaches - either when devices are lost, or during transmission of data. As such, it is important to authenticate all users, and to encrypt data whenever possible [20]. Collecting precise locations using GPS also increases the risk of confidentiality loss, and appropriate measures must be taken to protect individual privacy [21]. We also have to remember that the success of handheld technologies will depend heavily on the use-case and the organization within which the technology is implemented. For example, clinical encounters that required extensive free-text might not be amenable to use of handheld technology. Consideration also needs to be given to workflow issues, user-input, and training.

Conclusion

We have developed and widely implemented handheld-based systems for use during home-based clinical encounters in the resource-limited setting of Western Kenya. This undertaking has enabled us to create electronic records for numerous cases where paper records did not even exist. Users prefer these handheld systems over pen-and-paper based systems.

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Cell Phone Short Messaging Service (SMS) for HIV/AIDS in South Africa: A literature review

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Abstract

The HIV/AIDS pandemic is one of the most serious threats to global health. HIV/AIDS is a chronic illness, requiring patient empowerment to enhance adherence to treatment regimes if it is to be managed effectively. While healthcare costs are rising, people still have expectations of high-quality care. This literature review-based study explored the use of cell phone (mobile phone) short messaging services (SMS) in health care, in particular for HIV/AIDS in South Africa.

From an initial corpus of 212 papers, 28 were reviewed. The main findings include that SMS can improve service delivery through appointment reminders and improve communication between healthcare workers. It improves diagnosis, prevention, treatment and rehabilitation by supporting adherence to medication, and monitoring illness and medical interventions. SMS is useful in public health programmes, such as contact tracing and partner notification, therefore playing an important role in control of HIV/AIDS. As South Africa has one of the highest uptakes and demographic distributions of cellular technology in the world, SMS is feasible as a tool to deliver quality health care with low cost.

Keywords:

Enabling technologies, Mobile technologies, Cell phone, Mobile phone, Health care, HIV/AIDS, South Africa, SMS.

Introduction

South Africa has a population of 48.7 million, with 46% living in rural areas. Many South Africans are struggling with HIV/AIDS infection [1]. The data suggest that, in the decade to 2010, up to 7 million South Africans will die from AIDS [2], with life expectancy in South Africa falling to 43 years. With approximately 5.7 million people living with HIV in South Africa, including 280,000 children under 15 years old, young people are increasingly at the centre of the HIV/AIDS epidemic [3], [4]. Many social factors drive the HIV/AIDS epidemic in South Africa [5].

It is acknowledged that only anti-retroviral (ARV) medication can prolong the lives of people with AIDS, and the successful roll-out of the country's ARV program is therefore crucial. ARV drug treatment can maintain health and help people lead relatively normal lives, but few people in South Africa have access to this treatment [6]. By mid-2006, while some 711,000 people in South Africa were in need of anti-retroviral treatment (ART), only 225,000 were actually receiving it. [7]

Cell Phone and SMS Use in mHealth Services

ICTs (information and communications technologies) can have an important role to play in the HIV/AIDS crisis [8]. They are integral to mHealth (mobile health), defined as the 'emerging mobile communications and network technologies for healthcare systems' [9]. mHealth is a recent term that encompasses the use of mobile telecommunications devices and mobile computing, such as mobile (cell) phones, patient monitoring devices and medical sensors, PDAs, and other wireless devices, to support medical and health care, and public health practice [10, 11].

There were over 4 billion mobile devices in use around the world in 2009, with 64% of them in the hands of people living in developing and emerging economies [10, 12]. 80% of the world's population lives in areas with mobile phone coverage making mobile technology probably the most viable type of technology to reach the largest part of the world's population [13]. The National Department of Health (NDOH) has adopted a National Telemedicine Strategy for South Africa (NTSSA) which was established in 1998 [14]. However, the national telemedicine system is not working and has not solved the initially anticipated health problems [15, 16].

Cell Phone and SMS Use in South Africa

South Africa has one of the highest uptakes and demographic distributions of cellular technology in the world. There are around 30 million active cell phone users in the country, almost two-thirds of the South African population [17]. 60% of households in South Africa own a cellular telephone and 41% of adults have access to a cell phone.

People use cell phones daily for communication. They are an inexpensive and rapid way to be connected to the internet in areas where the fixed telecommunications infrastructure is poor or there is a lack of resources [8]. Low start-up costs, text messaging, and flexible payment plans, all make them

attractive to use as a healthcare intervention [18].

Since rural youth are at the front line of combating HIV/AIDS in their communities, cell phones and other ICTs might play a contributing role to linking these future leaders [19]. One of the benefits of mobile technology is that it is used as an agent for social change worldwide today [20].

Healthcare services are facing pressure to improve efficiency and meet expectations for high-quality care and customer service [21] and SMS is a well established technology and widely used around the world. SMS (short message service) is a method of communication that sends short (160 character) text messages over the mobile networks. However, it is not without limitations. There is no scope for graphics or audio, the messages are limited by size, speedy message delivery is not guaranteed and the issues of confidentiality and privacy are a matter of great concern.

Literature Review Method

This desktop literature review, mostly conducted between February and December 2008, explored the potential use of cell phone SMS in health care in South Africa. Several readily available literature sources were electronically explored, including Pub Med, Medline plus, Pub Med Central, AID Search, AIDS related database, Cochrane Library, Electronic Journals Services (EJS), and Google Scholar. Articles in a language other than in English language were excluded. In the beginning, literature was searched using these key words: enabling technologies, wireless technologies, mobile technologies, cell phone, cellular phone, mobile phone, health care, HIV/AIDS, HIV, home care, possibilities, potential, role, monitoring, working groups, volunteer organization, South Africa. Only 72 articles out of 28,703 search engine hits were included in the study.

Table 1--Summary of 28 studies.

	Study Design	**Resources Reference no.**
1	Pilot study (6)	[25-30]
2	Qualitative study (3)	[31-33]
3	Observational study (1)	[34]
4	Randomized control trial (6)	[35-39]
5	Cohort (2)	[40, 41]
6	Mix qualitative and quantitative (2)	[42, 43]
7	Case study (2)	[44, 45]
8	Interview (1)	[46]
9	Meta-analysis (1)	[47]
10	Peer review (1)	[48]
11	Systemic review (3).	[24, 49, 50]

Due to the relative lack of published articles found, the search strategy was modified, and most of the literature was retrieved from Pub Med/ Pub Med Central and Google Scholar. The key words used included: Potential use short messaging service (SMS) cell phone OR mobile phone OR cellular phone, health care, HIV/AIDS, patients, South Africa. Original articles or review articles in English were selected, and only 140 articles out of 1,656 search hits were included.

A total of 212 articles were reviewed for the study, of which, 184 (87%) were excluded from detailed review, as they did not explore the potentials of cell phone or SMS technology in detail. Finally, 28 (13%) of the original corpus of published articles were reviewed (summarized in Table 1). In addition, policy papers, such as the 1997 White Paper by the Ministry of Health for the Transformation of the Health System in South Africa [22], were reviewed.

Results

The main findings of this literature review were that:

1. SMS improves service delivery through: (a) Appointment reminders [23, 25, 34-36, 40, 51]; (b) Improving communication between healthcare workers [32, 52].

2. SMS improves diagnosis, prevention, treatment and rehabilitation of illness by: (a) Improving adherence to medication [23, 33]; (b) Monitoring illness and medical interventions [26, 30, 43]; (c) Prevention and intervention of illness [47].

3. SMS is useful in Public Health Programs via: (a) Contact Tracing and Partner Notification for communicable diseases [24]; (b) Smoking Cessation Programs [37, 51].

Discussion: SMS and Text Messaging for Health

Many of the examples of health applications of mobile phones are in the pilot stage and have yet to be implemented or evaluated on a significant scale [18]. Text messaging has been significantly used in health care, mainly as a means of reminding patients of appointments in the United Kingdom, United States, Norway, and Sweden [18]. SMS was found to have been used widely to improve quality of life in several areas, including health. All the randomized control trial studies available in this study have shown significant results ($p < 0.005$). Randomized controlled trial studies from Malaysia [35] and China [36] showed that text messaging reminders were effective in improving attendance in primary care and cost less than mobile phone call reminders. A systemic review study by Atun *et al* suggested that SMS has the potential to improve tuberculosis control, contributing to reduced non-compliance and better health outcomes with low cost [49].

Some other studies support the use of SMS reminders as an accessible, appropriate and more cost effective tool for patients needing TB medication in South Africa [54]. SMS lowers non-attendance rates, with less labor, in the UK [55] and improves attendance at outpatient clinic appointments in Melbourne, Victoria [23]. It increases patient compliance in taking medication for TB and HIV [57]. Atun and Sittampalam, in another systemic review, found that SMS improves efficiency in the delivery of healthcare. It has public health benefits [24] and is acceptable to patients. However, none of the studies included any formal economic evaluations.

Not all researchers have the same findings and opinion about

SMS technology, with some of them being more skeptical. Kaplan [50] stated that the majority of reports are pilot or feasibility studies, with limited generalization of their findings, and so possibly unreliable. More rigorous evidence is needed for drawing conclusions. Although most of the studies reported that SMS technology is feasible and that there is a good level of patient acceptance, there are methodological problems of either small sample size and lack of representativeness in many, or they were pilot studies done in a relatively short time. However, the studies manage to highlight the important issue of SMS technology and create a positive environment for further study.

Two in-depth studies claim that SMS technology is acceptable to most of the patients. One is a qualitative (in-depth interview) study done in Cape Town by Cell-Life [56], with another qualitative study (based on in-depth interviews) done in Lima, Peru [57]. However, the sample size of the studies was small, and they were conducted in limited areas and, as such, lack a holistic representation of the population such that the results cannot be generalized. There is a need for further studies despite the fact that this method gives more satisfaction to patient parties. Curioso *et al* found that most of their study participants were concerned about privacy and confidentiality as well as the wording of the messages [58]. They did not want "sensitive" words (e.g. 'HIV', anti-retroviral) related to HIV included in the system, and preferred using code words or phrases; something simple such as 'It is time for your candy/life,' but which was understood). Some participants also suggested erasing the reminder after receiving it. This study clearly indicated that the issues of confidentiality, privacy and security are serious considerations when using SMS technology.

Cell phones are widely used in health care in low and middle income countries. In addition to SMS or texting, multi-media messaging service (MMS) can be used [59]. In Brazil and Zambia, health workers consult dermatologists using newly available camera phones [18]. While only 18 percent of clinics in South Africa have Internet-connected computers, 96 percent have a least one cell phone [60]. A system created by Voxiva uses cell phones to boost HIV/AIDS care [61]. The system tracks people living with HIV/AIDS and now connects 75% of the country's 340 clinics and covers 32,000 people in Rwanda.

There are three types of benefit from SMS:

1. It has, improved efficiency in the delivery of healthcare by appointment reminders [24, 62-64],

2. SMS has provided direct benefits to patients in terms of better health outcomes and quality of service by improving the patients adherence to their medications and treatment; monitoring patients' conditions; providing psychological support to patients; communicating test results; queue management in health care facilities [64],

3. It has public health benefits as it has been used in contact tracing and partner notification for communicable diseases such as sexually transmitted infection (STI), tuberculosis (TB), HIV/AIDS and severe acute respiratory syndrome (SARS) as well as communicating health information to the public for the rapid communication of health information to the general public in public health emergencies such as an outbreak of a communicable disease [64]. SMS is also a convenient for deaf and hearing-impaired people to communicate. SMS can be used to send a message to a large number of people at a time, either from a list of contacts or to all the users within a particular area. SMS doesn't overload the network as much as phone calls, it is frequently used by TV shows to let viewers vote on a poll topic or for a contestant.

In Mali, cell phone has become a new tool to help to control the spread of HIV/AIDS [69]. However the hot application of SMS is mobile chatting. The San Francisco Department of Public Health sends safer sex recommendations to young people who request it via text messages on cell phones [66] the automated program is modeled after a similar campaign in London, aimed at youths ages 12 to 24. Mobile technology particularly SMS is used in education as a method of raising HIV and AIDS awareness [67]. In South Africa, the Dokoza system use SMS in HIV/AIDS and TB treatment for information management, transactional exchange & personal communication [68-69].

Conclusion

This study helps in understanding the present context surrounding HIV/AIDS globally and locally in South Africa. It has explored what has been done in this field both nationally and internationally. It has elaborated the encouraging finding that SMS technology could be a cost effective tool to fight against the HIV/AIDS and other chronic health conditions, such as diabetes mellitus and asthma.

HIV/AIDS is a chronic illness. It requires patient empowerment to enhance adherence to manage it effectively. SMS plays a role in adherence and therefore can play an important role in control of HIV/AIDS. It can be especially effective where other forms of communication between patients and health clinics are difficult and access to services is poor due to a weak infrastructure and geographical barriers. SMS offers further opportunities to deploy the benefits of mobile phone technology and improve access to healthcare and information [21].

This study can provide the basis for further research by the Department of Health and the Medical Research Council in South Africa, the private sector, and national and international non-government organizations to explore the potential of this technology. While the focus of this study has been on the technologies, their use for delivering effective services will also need to consider the human and socio-technical resources involved. Overall, SMS technology is feasible; it could be used as a potential tool to deliver quality health care with low cost in this beautiful rainbow nation.

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Exploring Feasibility of Home Telemanagement in African Americans with Congestive Heart Failure

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Abstract

Existing telemonitoring systems provide limited support in implementing personalized treatment plans. We developed a Home Automated Telemanagement (HAT) system for patients with congestive heart failure (CHF) to provide support in following individualized treatment plans as well as to monitor symptoms, weight changes, and quality of life, while educating the patient on their disease. The system is designed to be placed in the patient's home and to communicate all patient data to a central server implementing real-time clinical decision support. The system questions the patient daily on their condition, monitors their weight, and provides the patient with instant feedback on their condition in the form of a 3-zone CHF action plan. Their medication regimen and suggested actions are determined by their care management team and integrated into the system, keeping a personalized approach to disease management while taking advantage of the technology available. The system is designed to be as simple as possible, making it usable by patients with no prior computer experience. A feasibility assessment in African American patients with CHF and without prior computer experience demonstrated high level of acceptance of the CHF HAT system.

***Keyword**:*

Telemedicine, Congestive heart failure, Self-management

Introduction

Congestive heart failure (CHF) is a major public health problem which affects over 5 million Americans and costs $33.2 billion annually [1]. CHF morbidity is reaching epidemic proportions and African Americans are disproportionately affected [1-3]. Repeated emergency room visits and rehospitalizations for symptom relief contribute to CHF being the most costly cardiovascular illness in the US [1, 4-5]. Common reasons for CHF rehospitalization include delays in symptom recognition, medication and dietary noncompliance, and lack of knowledge and skills for competent self management [6-8].

Telemedicine approaches will be useful in patients with CHF for several reasons. First, telemedicine will improve disease monitoring through more frequent assessment of symptoms. Second, use of patient self-management plans will accelerate treatment in the setting of CHF symptoms and thus decrease the utilization of health care resources [8]. Home Automated Telemanagement (HAT) is a telemedicine system designed to assist health care practitioners treat patients according to current clinical guidelines, to assist clinicians in educating patients, to assist providers in monitoring patients, and to assist patients in following individualized self-care plans [9-14]. Our aim was to design a low cost telemanagement system for CHF patients and to perform an initial assessment of patient acceptance of such a system. This paper reports the success of design and implementation of the Home Automated Telemanagement system in patients with CHF.

Materials and Methods

System Design

The HAT system is based on Wagner's model of chronic disease care [15] and supports patient self-management, comprehensive patient-provider communication, and multidisciplinary care coordination. The CHF HAT system comprises a home unit, a decision support server and a web-based clinician portal. The HAT home unit consists of a notebook computer and an electronic weight scale. CHF patients answer questions regarding symptoms, side effects, adherence, and receive disease-specific education using the home unit. The home unit automatically transmits the results to the decision support server after each self-testing session. Data transmitted from patient's home are de-identified and encrypted. The data transmission can be carried out via Internet or direct modem-to-modem communication. For subjects without an active phone line, a cell phone is provided to transmit self-testing results over a secure wireless network to the server in a similar manner. The web portal provides an interface for the collected patient data. The web-based care management portal is used to set up customized clinical alerts and individualized action plans based

on patient disease severity and other individual factors. The care management team individualizes alerts and action plans for each patient on-line whenever warranted. The updated action plans are automatically transmitted to patient home units. If certain clinical conditions are met, email alerts are sent to the nurse coordinator. The coordinator reviews the information and if necessary consults the medical provider and the patient for management changes.

The HAT server runs Internet Information Services (IIS) which collects the patient's data and integrates it into a website which can be accessed by the patient's primary care management team. IIS is one of the most widely used web servers and provides a stable and compatible system for receiving and editing patient information. The web page was developed using Microsoft's .NET framework. This is a framework for developing dynamic websites which offers extensive built-in functionality and is supported by most browsers. The system is designed so that each patient has an "Action Plan" approved by their care management team. The action plan defines what a patient's actions should be based upon their self-test data and can be viewed on the HAT home unit and the clinician website. Prior to beginning home unit use, the patient has an action plan approved by their care management team. The action plan accounts for the possible cases of good, fair, and poor health; respectively corresponding to a green, yellow, and red 'zone'. An example of yellow zone of CHF action plan is shown in Figure 4. The patient responses from the self testing portion and weight measurement are used as a gauge for determining the action plan zone in which the patient currently belongs. At any time the patient may view their current zone or review the other zones on the home unit. CHF HAT action plan information flow can be seen in Figure 1.

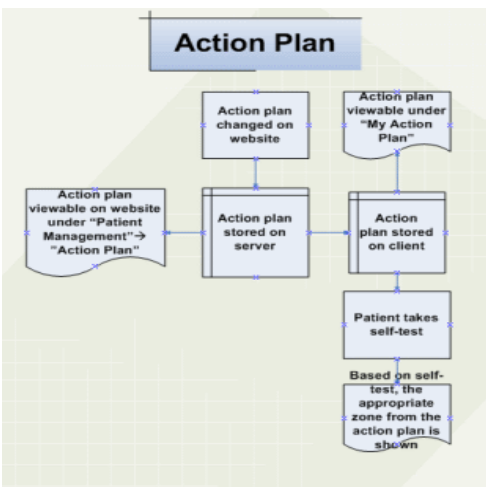

Figure 1- Action plan information flow

The HAT home unit allows a patient to complete a disease diary which asks the patient a series of questions, records their weight, and sends the information to the server, then gives the patient instant feedback on their current action plan zone, based upon their symptoms and weight measurement. This test provides the patient with immediate information on their condition and appropriate action steps for self management and provides their care management team with daily updates. Once a report has been sent to the server it can be viewed by the patient's care management team through the CHF HAT website.

On the server, the alert generator runs every night and uses the information from the self-test reports to send e-mails to the care management team when appropriate. Alert parameters are defined by a nurse case manager and can be set to generate alerts under various situations. Alerts can be generated if a patient's total score on the symptom questions falls above a specified number. They can also be generated if the patient's recorded weight falls above a specified threshold for the mean weight, percentage of last weight, or absolute change. Finally, if the patient is in a specified zone or has changed to a specified zone, an alert may also be generated.

The system also aids in medication compliance. The home unit can display a list of current medications with their dosages and frequencies. This can be updated by a nurse care manager on the website and will update on the home unit the next time it connects.

The HAT home unit also features a progress chart, which displays a graph of the patient's weight measurements or action plan zones on the most recent self-tests. The 'Frequently Asked Questions' section allows a quick access to general CHF educational information. The advanced features section on the home unit allows the patient to send a message to the server at any time. There are stock messages for the user to choose from or they can type their own messages. Upon receiving the message, an email is sent to their care manager, allowing for computerized patient-clinician communication. The message is also stored on the server and can be reviewed on the website by the care management team. The care management team may also send a message to the patient through the website. The message will be received by the patient the next time they connect to the server.

Pilot Study

A pilot study of the system has been conducted in ten CHF patients with no prior experience in using computers. Semi-structured qualitative interviews and cognitive walkthrough were used to assess patient acceptance of the CHF HAT system. In the study the patients received a twenty minute introduction and demonstration of the patient home unit and self-testing procedure. After the demonstration, the patient was asked to complete the self-test on their own and comment on the system as they performed the self-test. Once the self-test was performed by the patient, we administered a qualitative interview to get patient feedback on the system. Because

African Americans are disproportionally affected by CHF [1-3] we assessed feasibility of CHF HAT in this population.

Results

The HAT system was successfully designed and implemented on a notebook computer running Windows 2000/XP connected to a Lifesource 321P digital scale through the serial port. Information was successfully sent and received from a remote location to the IIS server using an active landline and cell phone connection. The website was successfully launched and provides full functionality. The home unit runs the HAT program when it starts up and the user can navigate through the menu using the labeled arrow keys and the enter button. The text is large and easy to read while all the instructions are kept as simple as possible. The home unit options are broken into six sections. The first section is self-testing. In this section the patient will begin with a self-testing portion where they answer a series of questions pertaining to their chronic condition. A symptom diary question screen is show in Figure 2.

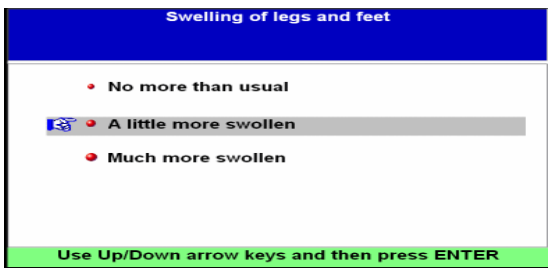

Figure 2-Symptom diary question

The responses are used to gauge the overall health of the patient, as well as to raise flags when the patient may be experiencing congestive heart failure symptoms that require immediate attention and treatment. After answering general symptom questions the patient is prompted by voice and text to correctly mount a weight scale in order for the CHF HAT software to weigh the patient. The scale instructions are shown in Figure 3.

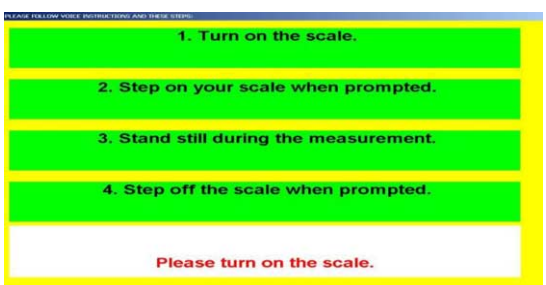

Figure 3-Weight scale instructions

The current patient's action zone is then immediately calculated and displayed. A screen displays weight and an absolute weight change from the previous day. The zone of the action plan is determined using the information provided earlier in the self-test. A sample action plan is seen in Figure 4.

Figure 4-Sample "Yellow Zone" action plan

After completion of the self-testing portion the patient is given an educational "Tip of the day." Each successive educational portion will end with a question about the previous day's tip. The question will be repeated each session until the patient is able to answer correctly. Then a new question is offered during the next self-testing session. At the end of an educational section, the patient will be asked several questions from the specific section. Upon completion of the educational portion, the symptom diary responses as well as the results of weight monitoring are stored for transmission. The system connects to the server using an active landline or wireless connection and relays all stored results/messages. This is shown in Figure 5. After transmission the main menu is displayed.

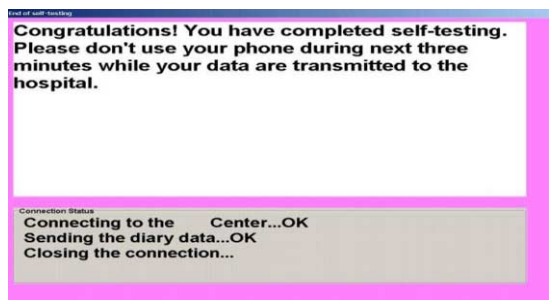

Figure 5-Data transmission screen

The HAT home unit also allows the patient to access their Action Plan. The patient can view their current action plan and their other plans for different zones. They can also view a graph of their recorded weights or action plan zones and the medications currently prescribed to them. The patient can also send either a personal or pre-written message to the care management team.

The CHF HAT website is hosted on our servers and can be accessed securely by the care management team using any computer with a web browser and an internet connection. The care management team can also view a monthly report which displays graphs and statistics of the patient's information collected over the past month. A section of a sample report is seen in Figure 6.

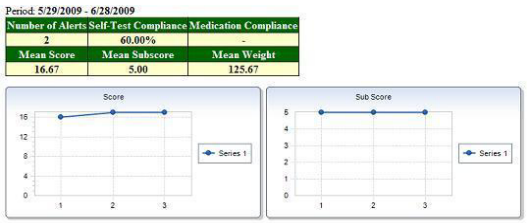

Figure 6-Sample monthly report data

The website also shows any current alerts for the patient and allows the care management team to log their response to the alert as shown in Figure 7.

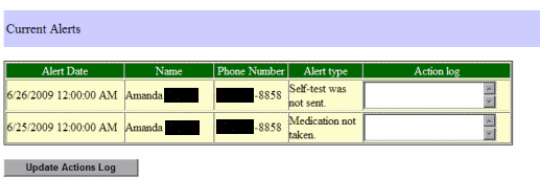

Figure 7-Current Alerts

The care manager can change their alert parameters for the patient, send a message to a patient, or view a list of the messages sent from the home unit to the server as seen in Figure 8.

Figure 8-Messages from the patient

Pilot study

After successfully using the system, patients were asked to complete demographics, attitudinal survey and qualitative interview. Average age of patients was 56 years, and they completed an average of 13 years of education. 60% of subjects were females, and 100% were African Americans. About 50% reported that they had moderate heart failure symptoms, and 50% answered that their heart failure had been about the same during the last 12 months. 60% and 70% never used the computer and internet respectively, and 30% reported that they never used ATM machine.

Table 1 – Attitudinal Survey Results

Questions	%
1. How complicated was the self-testing process?	
Moderately complicated	10.0
Not complicated at all	90.0
2. How difficult was it to use the weight scale?	
Slightly difficult	10.0
Not difficult at all	90.0
3. How difficult was working with the computer?	
Not difficult at all	100.0
4. How difficult was answering the symptom diary?	
Not difficult at all	100.0
5. Did you get all the necessary information about self-testing including the first introductory meeting?	
All information	80.0
Partial information	10.0
Very limited information	10.0
6. How much of your time did the self-testing take?	
Considerable	10.0
Very little	90.0
7. Would the self-testing interfere with your usual activities?	
No	90.0
Little	10.0
8. Would you feel safer while monitored by the system?	
Significantly safer	80.0
Moderately safer	10.0
Same as usual	10.0
9. How important for you is it to know that the results of your self-testing can be reviewed by the study staff immediately after the test?	
Extremely important	80.0
Very important	20.0
10. How often would you review the test results?	
Once a week	80.0
Occasionally	20.0
11. Would you like to use this self-testing program in the future?	
Certainly Yes	90.0
Maybe	10.0

Patient overall response to the system has been positive (see Table 1). All patients were able to complete the self-testing procedure by themselves with little or no difficulty. 100% of

subjects responded that they didn't have any difficulty working with the computer and answering the symptom diary questions. Also patients reported that length of self-testing was appropriate that it would not interfere with their usual activities. All the patients we have interviewed so far did not consider themselves computer literate and did not own a computer. Overall we have concluded that the interface is sufficient for people with no history of computer use. Patients responded favorably to the educational portion of the self-test, indicating a desire to learn more about their condition. The content and interface also received positive feedback in patient responses. Patients commented that they believed the CHF HAT system would help them better manage their congestive heart failure and reduce their amount of hospital visits.

Discussion

The CHF HAT system's ease of use and convenience can provide reluctant patients with an easy way for care management teams to receive daily feedback from the patient. While care management team visits would still be important to the patient's care, allowing the patient to monitor their health frequently and educating them on their condition will hopefully increase their condition awareness, self management, and quality of life. The CHF HAT system can successfully provide support to patients in following their CHF action plans and to aid them in being adherent to their treatment regimens. We are also looking toward expanding the HAT system to other computer platforms. Mobile computing is becoming smaller, faster, and cheaper, creating more potential environments for the HAT disease management system. Systems such as the Apple iPhone, iPod Touch, Blackberry, and mobile phones are becoming viable options for the CHF HAT platform.

Conclusion

The Home Automated Telemanagement system is a viable system to test in the management of congestive heart failure patients. This system can be efficiently implemented for congestive heart failure, as well as other conditions, and is recommended for future use and expansion.

Acknowledgment

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The Emergence of Mobile-Supported National Health Information Systems in Developing Countries

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Abstract

A major challenge for national health information systems in developing countries is their scalability and sustainability at the lowest levels where primary health care is delivered. This paper contributes to the discourse on how national health information systems can scale to the lower levels and how mobile technology is supporting the collection, handling and dissemination of data. But can mHealth go beyond the 'hype' and visions it has come to be associated with? Using an action research methodology in a long-term action research project, the usability and then scalability of mobile solutions for large scale national health information systems are studied. In this paper, initial successes and challenges with using m-Health for national public health information systems is reported and discussed.

Keywords:

Mobile, Health, Information system, Nigeria, India

Introduction

Health information systems (HIS) are having a major and ongoing impact on the lives of people in both low and high resource settings. A robust health information system is a basic foundation of public health [1]. The achievement of the health-related Millennium Development Goals (MDGs) will depend upon the effectiveness and efficiency of health systems. HIS remains the backbone for providing information to track progress for improving and strengthening the different health system components and monitoring the MDG goals. On the ground, however, HIS development in developing countries has proven to be difficult due to organizational complexity, fragmentation, lack of coordinated organizational structures (that maintain disparate information systems), unrealistic ambitions, and more generally due to the problem of sustainability. Poor availability and quality of data and a resultant poor knowledge and "culture" of use of information for planning and decision-making characterize HIS in many countries. Importantly, poor physical infrastructure has remained a serious obstacle in ensuring an efficient health information infrastructure in many developing countries.

The world over, both within the domains of research and practice, there is an increasing recognition of the role mobile technology and mobile phones can play in supporting public health systems. There is an emerging field and research domain for the application of mobile technology for health, mHealth. Mobile phones have a particular status across all developing countries. There are 2.2 billion mobile phones in the developing world, compared to 305 million computers and only 11 million hospital beds [2]. Between the end of 2007 and the end of 2008, mobile phone subscriptions increased by approximately 1 billion [3]. Mobile technology comes with the unique potential that it has already become a routine part of most peoples' everyday lives. It is becoming increasingly affordable and accessible, and has the required infrastructure (for example, the network coverage) even in villages to support its easy use and maintenance.

There are over 4 billion mobile phones, 64% of which is in the developing world [4]. The majority of the mobile subscribers are now outside the major cities and wealthiest states. For example in India there are 65 times more mobile connections than Internet connections [4]. This creates opportunities to use mobile phones to capture data at the source, thus removing significant sources of data quality problems usually associated with manual transfer of data between paper reports. In addition the aim is to use mobile phones as a channel for feedback to the community health workers. We explore to what extent this technology can be used for effective data exchange and communication in public health; how mobile phones in general can secure routine health data as well as stimulate better health provision by better communication and training. A major concern is how mobile phones can be coupled to and leverage district health information systems.

In this paper we discuss the emergence of mobile-supported national health information systems in developing countries by describing two ongoing mobile health projects in Nigeria and India. The mobile solution will also be described and discussed.

mHealth Applications

There are numerous mHealth projects in developing settings: the alliance of UN, Rockefeller & Vodafone in Feb 2009 formed after e-Health ideas exchanged in Rockefeller's Bellaio Conference (UN Foundation, m-Health Alliance) [5]; Using Mobile Phones and RapidSMS to Improve Child Nutrition Surveillance in Malawi (UNICEF, Govt. of Malawi and Mo-

bile Development Solutions) [6]; SIMPill – embedded mobile phone chip in medicine bottle to remind patients in South Africa (2007). 90% took TB medicine while earlier only 22%-60% took it; mHealth for Development paper, 2009) [7]; Text-to-Change – Sends HIV awareness messages in Uganda [8]; Cell-Preven. Health workers use mobile phones to send SMS messages with real-time data on symptoms experienced by clinical trial participants, enabling immediate response to adverse symptoms [9]; Frontline-SMS – a bulk SMS solution [10]; OpenRosa [11].

Generally, m-Health projects can be broadly discussed according to: technology, domain area of application, the hierarchical level in the data flow; and data handling processes it is used for.

By technology, m-Health applications can involve SMS (Short Message Service) or 'texting', voice services and other packet data services such as WAP, GPRS, etc. These can be simple typed SMS from any phone; coded SMS texts (following some predefined logic (which gets interpreted at a central server); or SMS-based data transfer from applications (J2ME, Android, etc) installed on the phone. WAP and GPRS have been little used in the settings we are concerned with in this paper for the reason of unreliability (at this time).

By domain, m-Health has been applied to various health areas including maternal and child health, community health volunteering support, immunization, general emergencies, monitoring of patients with illnesses such as HIV/AIDS, supporting the control of diseases such as malaria, etc.

In this study, the focus is on mobile systems feeding routine data from the lowest levels where they are produced such as communities and health facilities, through different levels up to the national trunk. In this scenario, facility/community level datasets are transmitted to upper levels through the state to the country warehouse, with health information defining a whole range of data elements spanning from utilization data, maternal and child health data, mortalities, nutrition and disease surveillance data. In developing countries, the collection of such data has historically proven to be intractable.

Most mHealth applications are in the piloting phase. A community of practice for mHealth is still being developed and mHealth standards are yet to be developed. This paper thus reports on a significant phenomenon, the emergence and early institutionalization of mobile systems for routine data collection, with data flowing from the lowest levels to the national level.

Materials and Methods

Our research approach is action-oriented and interpretative and characterized as a 'network of action' methodology. The network of action approach is based on the principle of creating learning and innovation through multiple sites of action and use, and sharing these experiences vertically and horizontally in the network [12, 13]. It is premised on collective action where connected research units are able to share experiences and learning. The cases presented here are derived from units (or nodes) within the Health Information System Programme (HISP) network of action. The authors are actively engaged in these units (HISP-Nigeria and HISP-India) which are, with their respective partners, the principal development partners for this system in their respective countries. The pilot in India started in February 2009 and is ongoing. While that in Nigeria started in July 2009 and is ongoing. However, these pilots are converting into full-blown deployments and installations as the rate of adoption has been tremendous. Data sources for this study have been primary and secondary. Primary sources have included notes from participant observations, performing training, and formal interviews with health workers at different levels as well as administrative and technical personnel. The authors have also been involved in the iterative development of the solution. Secondary sources included formal reports from the projects highlighted.

Cases

Here two cases are presented which are significant by virtue of being based in the national system of two very populous and complex countries in Africa and Asia – Nigeria and India respectively.

The Nigerian Case

With a population of over 148 million people [14], Nigeria is the largest country in Africa and accounts for about half of West Africa's population [15]. Health service delivery is largely a government function and as in all countries, the establishment of a robust national information system is a priority. Though the HMIS framework was articulated (in 1992) and implementation commenced (in 1997) in a number of states, the HMIS is only recently (2003) beginning to be institutionalized [16]. This recent strengthening efforts (mainly donor-led) can be attributed to increased demand to show progress towards attaining the MDGs. Since 2003, a free and open source data warehouse solution, the District Health Information System (DHIS) [17] has been implemented at the national and state levels. However, a recent situational analysis has revealed the very low base from which the HMIS is being developed. Computer equipment is usually either in short supply or poorly maintained where it exists. Power supply is very poor; and transportation through long distances and from hard-to-reach areas is difficult. Data use is almost non-existent at all levels of the system. Reports are submitted late and data quality is poor in the HMIS.

It is in this premise and following from the observation that the mobile networks have greatly improved that this study is set. The application of mobile technology has a huge potential for circumventing the aforementioned challenges and improving data reporting. At the time of independence in 1960, Nigeria had a population of about 45 million people with 18,724 functioning fixed telephone lines - a tele-density ratio of 0.04 telephones per 100 people [18]. At the commencement of mobile telephony in 2001, there were only a few thousand lines available from the operators and services were too expensive for the average Nigerian. By 2002, the number of mobile subscribers stood at 1.5 million and prices fell [19]. By the end of 2004, the GSM operators had recorded well over seven mil-

lion subscribers, which was a real explosion when compared with about half a million working lines from NITEL in 2001 and is now reaching 60% penetration [20]. This shows that Nigerian telecommunication industries experienced rapid growth in terms of usage and subscription. By 2007, there were 34 million telephone lines with 1,670,767 fixed lines and 32,265,827 mobile phones in Nigeria [21].

This study thus set out to explore the possibilities with using mobile phones for communication of data from health facilities as well as at the local government area (LGA) level. A simple form-like data collection tool on mobile phones was developed for transmission of data securely and timely. The pilot was tested in 2 states, Katsina and Yobe in Northern Nigeria. This region is characterized by extremely low levels of health service utilisation, the existence of polio and measles outbreaks, low staffing levels and low skill levels of existing staff, absence of significant technology other than mobile coverage. It involved health workers in 26 busy facilities and 34 local government area Monitoring & Evaluation office thus covering the whole state of the Katsina and parts of Yobe.

Findings

A major finding was that the application was well received. As one of the state resource persons said, "let us not call this a pilot because it is bringing very useful results and is now part of the system". With this rapid adoption at facility, LGA and state levels, came specific interests in the sustainability of the system. Facility workers were concerned that they did not understand the data elements properly. The data elements used in the system were from the national standard for facility but they had not been properly trained on it. The implementers therefore had to do training on the data collection and what the elements mean. The LGA officers were particularly interested in an increase in the datasets collected particularly the addition of the full complement of disease surveillance reports. The state level officers were more concerned about the ability of the tool to strengthen the LGAs. As one expressed, "I am sure you have tested it elsewhere. Let us think of how to improve it and include other relevant data elements that the LGAs also need very much". Thus, the rapid adoption and acceptance of the mobile system led to an early discussion by stakeholders at different levels to improve it. These improvements have occurred at a rapid pace when compared to the DHIS computer-based installations. This is attributed to the fact that the mobile application is seen by many users (network effect) and its ease of use has allowed the health workers to be more engaged in data capture.

The Indian Case

India has more diversity within its border than any other country and its population of 1.1 billon people lives and work in very different circumstances and geographies. The mobile penetration is 30% and is the fastest growing market in the world.

The Society for Health Information System (HISP India) [22] which has more than 10 years experience of working with health information systems in India, and are developing and implementing the District Health Information System (DHIS) software for health management that is currently being deployed in almost all states in India to support sub district data registration and analysis activities, and is integrated with the national database through the Ministry of Health web portal. The DHIS deals with aggregated (non-patient) data collection and analysis in an integrated manner across health programs, including important monitoring of MDG 4 and 5 indicators.

Implementing software solutions at the lower levels of the Indian health system is a huge undertaking due to its enormous scale in terms of the vast number of installations, system maintenance and training activities. A mobile solution to strengthen the work of community health workers need to be coordinated and supported by backbone systems e.g. to produce the mobile collection forms, to store, process and report the data collected by mobile phones, and generate work schedules and feedback reports back to the mobile clients. The strategy was to install such a backbone system at the Block PHC level as lower levels is hard to computerize, and link the transmission of data from the mobile (such as through a SMS) to this backbone.

A pilot project was initiated by National Health System Resource Centre in India in collaboration with HISP India. Health workers in facilities at the lowest level were provided with a tool to report routine data to the district and state level through the DHIS. The mobile application for sub-centre reporting was piloted in 5 states: Kerala, Rajasthan, Gujarat, Himachal Pradesh and Nagaland. 189 health workers were given mobiles for reporting.

Findings

After 6 months the results are very promising. Data is reported and 100% said they prefer this way of reporting as it saves time – they do not need to travel to report – and it is more efficient. The role of social networks has a appeared in several ways as one users supports the other. Introducing mobile phones among health workers have changed the communication patterns and seems to go beyond what used to be hierarchical borders. For instance, an HMIS manager now could contact directly the health worker and vice versa. Earlier he/she had to send a written request to the PHC to get them to contact the health worker, for instance, to invite for a meeting. The work related communication increased and 88% said they had called other health officers for help and 85 % said they had contacted doctors for medical help in case of emergency. Introducing mobiles into public health is not only about introducing a tool for data capturing but it seems have the potential of changing the way of working and communicating which can have great effect on health provisioning.

The Application

In Nigeria and India, an open source Java-based mobile platform was built on the already existing DHIS-based national health information infrastructure. The solution consisted of a native Java mobile application installed on a mobile phone and a server gateway that plugged into the DHIS data warehouse (See Figure 1 below). In Nigeria, the mobile application was developed based on the existing national HMIS facility forms and implemented at the facility and district levels. In India, it

was based on the national HIS form for (ANM) coordinated by the National Rural Health Mission.

The application was designed to support the health workers in the filling and sending of the reports through the mobile phone. It is based on free and open software development facilitated by a commons-based production network established between developers in the HISP network.

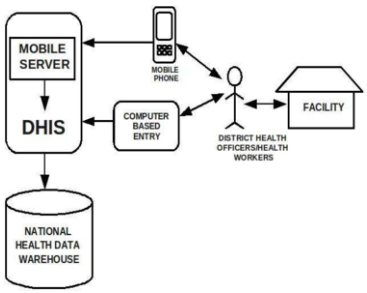

Figure 1 - An illustration of the mobile-supported health information infrastructure

The application allows for data entry based on period (e.g. by month) and by (sub-centre or health facility). Data elements collected are those for **antenatal care and pregnancy outcome, mortalities and births, family planning, immunization, nutrition and growth monitoring, community outreach services and facility utilization**. In designing the application, mobile network coverage fluctuations typical of such settings were considered. Data is stored on the phone using basic Record Management Store (RMS) functionality. This allows data to be stored on the phone and forwarded when reception of the mobile network returns. It thus allows for the retrieval of previously filled reports. Technically, it is a J2ME application utilizing only the basic Java functionality (MIDP 2.0 and CLDC 1.1) functionalities and it can be installed on very low end phones.

Discussions

The emergence of mHealth applications and projects is a significant phenomenon – not only because of a fast rate of adoption but also the ability to achieve instant results with data handling. This can be attributed to the relatively small means with which the important issue of the lack of quality data can be addressed. In short, mobile technology provides a fundamental leverage that had been lacking in these settings – a network infrastructure for electronic data transmission. This, combined with the ease of use of mobiles compared to computers, has allowed many applications of mobile technology to emerge. It is important to note that; as this is a relatively new phenomenon, it may be too early to discuss with precision the possible success rates. But it is an important question to ask if these will translate to institutionalized systems for large-scale national systems. We have found that this is the case - mobile phones have been adopted for the day-to-day work of data handling in cases of Nigeria and India.

In leveraging the mobile technology and infrastructure, there are inter-related challenges that have been encountered. We discuss these as use-oriented, technical and sociopolitical.

The introduction of mobile phones among health workers has changed their communication patterns and has led to a challenge of the hierarchical borders and bureaucratic protocols often associated with public work routines. Health workers can be contacted directly by the state bypassing levels in the data flow but allowing for rapid exchange of information.

In addition, mobile health solutions for national health data systems suffer from being coupled to an underlying installed base. This can have consequences if such underlying base is problematic and poorly functioning. It was seen that the introduction of the mobile solution made existing problems with the underlying system more transparent and addressed. This happened in the Nigerian case where the national reports were not well known due to lack of forms and the lack of competence to use them. The phone thus provided a 'window' into the operation of the system and allowed quick corrections to be made. In both countries, the mobile application was found to be an effective tool for training the health workers on the meaning of the data elements.

Planning and involving stakeholders – expectations are difficult to define as requirements were desperately varied. By growing the system gradually, we have found that stakeholders could be involved gradually and more easily. Cost of SMS has been an issue in Nigeria since the prices are much higher in Nigeria than India which has among the lowest prices in the world.

The phones are costly and the question of who shall own the phones arose. The challenge that people could lose them or sell them is there. In India we saw that the phones were very well taken care of and seen as very valuable for them individually. In a case where a phone was stolen, the health worker was able to negotiate the phone back with help from the community by paying 500 rupees (5 USD).

The fear of deleting the application as happened in India could be solved by installing the application in mobile chip memory, but we have seen that there are be frequent changes to application so flexibility is more important. As such, an over-the-air (OTA) approach is advised. We observed that only low-level phones are purchased for personal use and it is difficult to leverage robust applications on such. For example, in Nigeria in one of the states piloted, only two of the district health information officer surveyed had a Java-enabled phone. The phones found were mainly cheap Chinese-made phones. This implies that funds are needed to fully utilize the user friendliness of mobile application.

By adopting the 'the low-end phones' approach, the risk of phones being stolen is reduced, more phones could be purchased and scalability thus more easily achieved, especially when compared to deploying relatively expensive personal digital assistants (PDAs) and smart phones. In situations where only few data elements will be collected, where there are low funds or where the number of users is staggering (e.g. in the thousands), pure (typed) SMS solutions such as Frontline-SMS

may be advisable. Such systems may not be advised for forms with many data elements to ensure high levels of data quality. The cost of the phones therefore has been a concern when planning for scaling. There are ongoing negotiations with manufacturers in this regard.

Conclusion

m-Health support for public health systems is being institutionalized in developing countries. The rapid adoption and gradual institutionalization is partly due to the individual acceptance and familiarity with the mobile application as a standard tool for data collection and dissemination. However, beyond the mobile phone as a standalone device there is a systems perspective observing the other components and kinds of infrastructure – such as the paper registers at the facilities, the computers at the district levels, the networks and the servers at the state level, and also the basic infrastructure required to support the mobile phone use (charging facilities, support, network coverage etc). Mobile applications can be sensitively designed and introduced, so as to support the development of an 'integrated mobile supported health information infrastructure' in developing countries.

Future work would explore the incorporation of improved technologies (GPRS and X-forms) as well the role of social networking in supporting mobile-supported networks.

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Clinical users' perspective on telemonitoring of patients with long term conditions: understood through concepts of Giddens's structuration theory & consequence of modernity

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Abstract

This study involves conducting focus group discussions with clinical users (nurses and technicians) prior to the launch of telehealth service in Nottingham, UK, to elicit their initial perceptions about the service. It describes the findings from preliminary phase of otherwise a larger longitudinal study. Using Giddens's concepts from structuration theory and consequence of modernity, we were able to acknowledge trust and sense of security as two very salient aspects that govern adoption of new technological innovation. Unattended, these aspects contribute to arousal of conflict and contradiction within a system. In order for successful telehealth implementations in health care setting, providers of the service, need to focus on ways in which clinical users' trust can be gained and sense of security can be promoted while using the telehealth service and technology.

Keywords:

Telemonitoring, Structuration theory, User perception.

Introduction

Integrating telehealth with nursing case management has potential to improve patient health outcomes, clinical outcomes and allow clinical user to work more efficiently [1, 2]. However, despite its evident and noticeable advantages, telehealth has not been widely adopted. Although a search of literature reveals reasons for low espousal to range from technical difficulties to financial constraints and political motives [3, 4] , not much has been explored in relation to clinical users views on telehealth services especially in relation to nurses and technical staff involved. In addition, of those who have considered this aspect mostly questioned the users' motives behind the use of technology and extent of its integration in their routines, with users often being the stakeholders like GPs and managers [4, 5].

Taking the above argument on board, this qualitative study mainly aims to delve into main questions that need to be asked when implementing telehealth alongside case management such as: what does the user perceive the given technology as? and what issues surround its taking-up within a given context? We adopt Giddens structuration theory in combination with his work in consequence of modernity to guide data analysis and elucidate results presented in this paper [6, 7]. We found that telehealth by its very nature triggers conflict and contradicts the nursing practice, which depends on human contact and face-to -face interaction. This furthers the issues of trust and ontological security, previously not explored in its entirety. Understanding clinical users' perception and their concerns allows exploration of basic but dominating social aspects that govern successful implementation of technological interventions and at the same time provide an opportunity to resolve them [8].

The remainder of the paper unfolds as follow. We first present theoretical framework applied. After giving a brief overview of data collection and analysis method, we summaries the results and finally provide discussion on theoretical and practical implications of this study.

Materials and Methods

Theory

Our research uses concepts from Giddens's structuration theory (ST) and consequence of modernity to understand clinical users view on telehealth service when first introduced in their work setting. The main notion of structuration theory is that structures in terms of rules and resources are produced and reproduced by knowledgeable actors who continually monitor their actions [6, 9]. These structures are enacted through social interaction, and are therefore continually influenced by the agents' perception and in turn influence their perception. Giddens advocates use of specific constructs from ST to understand the duality of structure and expound their enabling and constricting effects [6, 9]. One study that presents an example of this is by Walsham and Han [10]. They use concepts of conflict and contradiction from structuration theory in order to depict reasons behind the resistance to introduction of new accounting system in an established accounting firm. According to Walsham and Han, contradiction is a "disjunction between different principles of system organisation" and conflict as "a struggle between actors and collectivities which tends to coincide with structural contradiction along its main 'fault

lines'" [10]. In our study, this concept helped in elaborating how inadequate training provision, support, and lack of information could lead to potential problems in up-take of service. Also, that the initial procedures of patient selection and education, and the monitoring of staff for their effectiveness levels by Primary Care Trust (PCT) contradict telehealths' original purpose of allowing clinical user to be more efficient with their time.

Although, Giddens does not consider technology in ST, in his later work- the consequence of modernity, he acknowledges the role that technology plays in modern world by "stretching" of social systems through disembedding mechanism [7]. By disembedding mechanisms he alludes to "lifting-out of social relations from local contexts of interaction and their restructuring across indefinite spans of time-space" [7]. Out of two types of disembedding mechanism, telehealth can be described as an expert system as it combines 'technical accomplishments' with 'professional expertise' that organise delivery of care for patients with long term condition in a modern healthcare system. According to Giddens, all disembedding mechanisms are based on trust due to absence of face-to-face interaction and hence lack of complete information available through facial expressions and body language [7]. In telehealth service various issues can be categorised under the main heading of trust, as it introduces dilemma of working with technology to monitor patients whom nurses use to visit at home prior to introduction of this service. It also questions the reliability of technology used, competence of new staff and managements' initiatives.

In addition, Giddens also presents definition of an abstract system in consequence of modernity, thus adding another dimension that would provide and interesting view on how change in routines in abstract system threatens ontological security [10]. According to Giddens expert system together with faith (which forms trust) constitute abstract systems and the "routines which are integrated with abstract system are central to ontological security", where ontological security refers to 'feeling of security' [7]. This notion explains how disturbance in daily routines threatens security of an actor within that system.

The combination of above theoretical prospective permitted to establish link between conflict & contradiction, trust and security as very salient social aspects that affect clinical users in modern healthcare setting and their decision on whether to use technology provided or not.

Research Approach

This study follows an interpretative approach using qualitative data. It is an approach that "goes beyond understanding the meaning of the data because it points the researcher to "read" the social world behind the words of the actors" [11].

Data collection method

As this research aimed to understand initial thoughts of clinical users about the newly introduced telehealth service, focus group discussions were chosen as a tool for data collection. Barbour argues that these discussions guide and lay foundation for later data collection and therefore should be conducted in preliminary research phase [12]. She further describes that focus group discussions are often seen as a feminist research method "for eliciting the prospective of women-patterns of interaction and exchange", and in our case 87.5% (14) participants were females [12].

The clinical users participating in this study were involved in delivering care to patients who were taking part in a randomised controlled trial, evaluating clinical effectiveness of telemonitoring of patients with chronic conditions such as heart failure and obstructive pulmonary disease in the city of Nottingham, U.K. Four main groups of clinical users namely the Community Matrons (CM-registered and highly experienced nurses), Congestive Heart Failure nurses (CHF), Chronic Obstructive Pulmonary Disease nurses (COPD) and Community Support Workers (CSW-staff recruited to provide technical assistance to nurses) were involved with the use of telehealth service. A purposive Sample of staff participating in this project was used, and their equal participation was ensured by requesting a representative from each group in each meeting. In total, 3 focus group discussions were held at Nottingham Primary care trusts' settings in the month of July 2009 and total of 16 staff took part in the discussions. During these meetings, it became quite apparent that nurses were often on call and due to nature of work at times could not attend the meetings or were bound with time restrictions. In one meeting for instance, none of the nurses could turn-up due to an emergency. This can be considered as a design issue, that other researchers would like to take on board.

Data analysis

The qualitative data colleted through discussions was transcribed and thematically analysed using Nvivo8 version3 software package. Guidelines for thematic analysis were adopted fro Braun and Clarke 2006 [13].

Results

Three main themes evolved after analysing the data collected from focus group discussions as shown in Table1.

Table1-Main themes

Theme	Contributing factor
Conflict and contradiction	Telehealth as 'monitoring tool' Management strategy Research strategy
Trust	Technology Patient Support staff Management
Security	Lack of control Work routines

These three of themes of conflict and contradiction, trust, and security often inter-mingle with each other and manifestation of one would lead to another. Following sections present detailed outline of each theme.

Conflict and Contradiction

The first concept mainly highlighted the concerns of clinical users due to the introduction of telehealth. Users discussed the impact of telehealth implementation in relation to working with technology, managements' strategy on granting support, and research ethics.

Telehealth as 'monitoring tool' only

Clinical users argued that telemonitoring of patients only allowed access to objective measurements of blood pressure, oxygen saturation level and weight gain related to main illness like CHF or COPD. However, theses parameters sometimes were inadequate to discover underlying infections such as urinary tract infection, which could be easily picked during personal visit.

Clinical users also feared that introduction of technology would lead to subtraction of human touch and face-to-face interaction and loss of 'Nursing Intuition'. In addition, clinical staff saw telemonitoring as contributing factor to social exclusion of elderly patients.

Management strategy

Telehealth was mainly seen as a service that would decrease clinical users' workload and allow them to work more efficiently. At least, this is partly how the project managers introduced the service to the users. Ironically, clinical users' workload, especially nurses increased and contributing factors included lack of appropriate support, patient assessment, equipment installation, and use of computer system to access data.

The issue with support revolved around promise to provide each nurse with a community support worker by the PCT. However, due to late CSW recruitment and training requirements, their assignment to nurses was severely delayed.

It was also noticed that CSWS had problems of their own. They were promised instant engineering support for faulty equipment but as one CSW put it-

"..once its passed the easier to fix things we need engineer support, I have never seen one yet. I have never seen the engineer. We got some people waiting two months for the repair of their equipment"

Research strategy: Randomized controlled trial

Staff expressed apprehension towards the randomisation of patient and maintained that handpicking of patients would have been a desirable feature. They did not fully appreciate the aims and objectives of randomised trial taking place. According to clinical users, handpicking of patients would have avoided anxious patients from getting telemonitoring equipment.

"It is about how you assess the patient. It is the thing. It is good doing what we are doing. Research is good thing, because its worth waiting. You choose the right patient for that. I mean I have got a lady who's really hypertensive who I would really really look to put on it, but it actually sends her stir crazy because she would not know how to cope with it……It is about assessment and putting the correct people up"

Staff felt uneasy about getting patient's consent to taking part in the trial as they believed it would be unfavourable towards patient's emotional and mental well being.

"I don't understand why everybody has been consented. Because I feel there is a physiological element there…..I think that does affect them. I cannot understand why 250 patients were not picked and then we consent them"

Trust

This concept draws association between the interaction of various clinical users and their expectation from this service. Reliability of the data transmitted, guarantee of correct equipment use by patient and dependence on other staff were emphasised as key topics.

Technology and Patient

As patients are to take their own measurements using telehealth equipment, clinical staff questioned the reliability of these observations and questioned whether machines were calibrated routinely and were functioning accurately.

"I am not sure how long is this equipment in some body's house for before it is tested? Just a regular check, you don't know if there is a hole in the blood pressure or getting the wrong reading or what?"

In addition, nurses trained patients on how to use the equipment, for example not to run to machine and take measurements. However, despite ongoing efforts by the clinical staff, examples of inappropriate use came to light.

New staff members: Community Support Workers

Recruitment of Community Support Workers (CSWs) was a welcomed initiative. However, some senior nurses expressed anxiousness over handing over part of their responsibility to the new staff and trusting them.

Management

One of the biggest concerns that nurses had was being monitored by PCT for number of patient visits. This currently adds to their workload but as telehealth consultations are not accounted under the current scheme, nurses' workload might appear lighter.

Security

The third and final concept of security widened the understanding of clinical users' personal dilemmas that they were feeling due to introduction of telehealth service.

Lack of control

Staff especially nurses, were uneasy about their patient using the equipment and perhaps start depending on it in long term. In addition, they expressed doubts about relying on newly recruited community support workers for monitoring the patient observations and informing them in case of possible deterioration.

"its that little bit of vary of actually saying well we are gonna do it all over the telephone from now on, obviously that is an

exaggeration ...doing it all on the telephone... but whether its fear of my own loss of control I don't know?"

Change in work routines

Clinical users recognised the advantages of telehealth, but due to heavy workload were hesitant about possible changes in their work routines because of this service.

"there is this change and transfer period ….so during this time having to reconfigure I suppose the way we work will be very difficult"

Discussion

This research contributes to the theoretical and practical consideration related to assessment of user perception.

Main **theoretical contribution** would be employing Giddens concepts, firstly to enable telehealth to be defined as an expert system and secondly explain features that need attention and require maturing for allowing this expert system to develop into a fully sustainable abstract system.

An abstract system involves 'faceless commitments' that are based on trustworthiness vested at access points which can be described as the ground where experts within an abstract system meet lay people (in our study the experts are clinical users and the lay people are patients) [7]. However, original nursing practice, involves trustworthiness established between different individuals based on "facework commitments' that relates to copresence. Introduction of telehealth creates access points, which lead to clinical users being overwhelmed by the feeling of loss control. In parallel to that, the level of expertise of experts with in a system is also an issue of concern. Many clinical users complained of inadequate training and support as this questioned their own expertise over certain issues such as equipment installation, computer system use and training of their patients.

It is also noticed that many clinical users questioned the reliability of telehealth equipment. This coincides with vesting trust in an expert system, and therefore, one could argue that unless full trust of experts is not gained; telehealth service could not become a self-sustaining abstract system.

From **practical view**, firstly it allows to understand the perceptions and feeling of clinical users as social beings' (view) then just abstract clinical users with defined mechanised roles and routines. Secondly, it permits to scrutinize conflict among groups and contradiction with managements' strategy associated with the launch of telehealth.

In a term 'bargain with modernity', Giddens describes the nature of trust that actors invest in an expert system to be *"governed by specific admixtures of deference and scepticism, comfort and fear"* [7]. Moreover, these are the feelings that are exhibited by participants in this study. Hence, they find it difficult to trust a technologically sophisticated patient monitoring system despite its much-appreciated success in other areas of healthcare delivery and other countries. Other cause of clinical users' trust being rattled is perturbing their daily work routines by introducing telehealth. Daily routines of an actor constitute their sense of security and when this is disturbed, trust in system is shaken. These various resultant conditions wreak direct insult on trust and security, and actors with such emotions continuously enact structures that are inherent with conflict and contradiction.

One of the lessons learned from this study is that clinical users tend to operate on very basic units of trust and security, like any other social beings. These feelings and emotions are much intense in instances where care of people is involved, as clinical users perceive themselves to be responsible for any outcome of their patients' health. Lapses in acknowledging these emotions can lead to differences in groups' interests and create misunderstanding with managements or systems' objectives. Which when stagnate lead to power practice as a direct result of conflict, for example, some nurses will refuse to use the service at all. This will also enact structure of domination due to the presence of contradiction for example where the management will use tactics such as firing staff for not using the telehealth service [6].

This study proposes to handle these issues by providing optimal training to the staff involved, giving clear information on what is required from each clinical user involved and offer technical support to nurses when and where required. It also calls for clinical users to be instructed on clinical trial methods so questions on patient randomisation and consent do not crop-up. Assurance that 1) telehealth will not replace nurse visits to their patient, 2) telehealth equipment is calibrated and safe to use and 3) telehealth would not impinge on daily routines of nurses is very crucial to win the trust and provide sense of security thus alleviating conflict and contradiction.

Conclusion

Trust and security are very crucial and play an important part in clinical users' decision of using a new telehealth service. If not acknowledged, these feelings dwell in form of conflict among individuals within a group or different groups and contradicts overall system objective. For telehealth service to be free of conflict and contradiction, equipment providers and management of healthcare facilities should recognise clinical users as social beings with heightened sense of responsibility. Taking users' view on board and allowing them to participate in decision-making (implementation etc) would be the first step to ensure that their need to establish trust and security are met.

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Usage of international standards for integrating extramural monitoring and personal health device data into medical information infrastructure

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Abstract

Integrating extramural measured devices data into medical information systems is becoming more and more attractive for integrated medical care. A lot of devices already have the ability to transfer measured data to mobile devices or computers and a few systems offer submitting data to a centralized information database or information system. Unfortunately, all of these devices use proprietary protocols and processes which makes integration into other systems a major problem. To address this problem the Healthy Interoperability project has been created with the objective of creating a framework for transferring health data based on international standards. The paper outlines how the framework architecture takes full advantage from the definitions of the international standards ISO 11073, HL7, IHE and CEN 13606. Even the definition of the user profiles and the security framework is based on standards from ETSI, ISO and CEN. By using these standards the framework can also perfectly be used for intramural communication.

Keywords:

e-Health, Medical device, Device communication, Personal health, PHD, ISO 11073, HL7, IHE, CEN

Introduction

Integrating extramural measured devices data into medical information systems is becoming more and more attractive for integrated medical care. Existing and new upcoming devices offer a big variety of possible use cases ranging from monitoring and alerting up to observing the own health status by using personal health devices. Using such device data is as useful for observing chronic disease parameters as for prevention. A lot of these devices have the ability to transfer measured data to mobile devices, mobile phones or personal computers and it would be very valuable to submit the data to health provider information systems or to integrate it into an electronic health record or a personal health record. At the moment there are only a few companies and systems that offer transmission of data to a centralized information database or information system. Unfortunately, device connectivity to enterprise services is however currently very proprietary and all of these systems use proprietary protocols and processes which makes integration into other systems a major problem. To address this problem the Healthy Interoperability project has been started in January 2009 with the objective to overcome the problem of non interoperable interfaces by designing and developing a communication framework that is solely based on international standards and thus enables technical and semantic interoperability. This framework shall also facilitate access to the many different types of available data and provides this data to intelligent personal services.

Materials and Methods

System Architecture

In addition to the main goals of the project some further requirements were defined to be considered in the first phase of the project.

- Sensors and devices should be capable of being integrated into the framework on a plug & play basis which means, that no specific setup has to be done be the user to start communication.
- The framework shall be very flexible and allow easy extension of functionality by integrating new software modules with a plugin concept.

Figure 1 outlines the systems components and architecture.

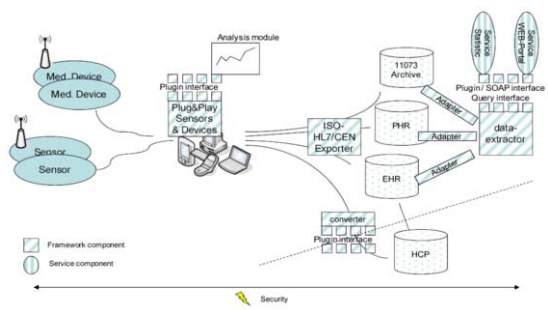

Figure 1- System overview

The framework has a modular architecture that enables a lot of different configurations and therefore the functionality of the system depend on the modules used in a specific configuration.

International standards and standard based framework

During the first six month of the project a lot of international standards have been evaluated to be used in the framework. The following standards have been chosen to be implemented in the framework modules:

- ISO/IEEE 11073 [4]: defines device communication and information exchange on a plug & play basis. Core part of the concept is an agent – manager communication where the device is the agent.
- HL7: the HL7 definitions of both message based standards are used in the project. The Version 2 messaging as part of the IHE profile definitions and the CDA specification (part of V3) for generating medical documents on a XML basis. The HL7 "Personal Healthcare Monitoring Report (PHMR)" implementation guide is used to convert device data to a CDA document.
- IHE: To integrate patient care devices into medical data flows IHE defined the "Patient Care Device Technical Framework" [6] with the DEC profile. In principle this definition fits well to the requirements of the "Healthy Interoperability" project but it had been developed for intramural processes. Nevertheless the profiles are implemented and the upcoming problems will be dealt with. But using the DEC profile means a lot of other profiles get involved – Figure 2 gives an overview of needed IHE profiles.

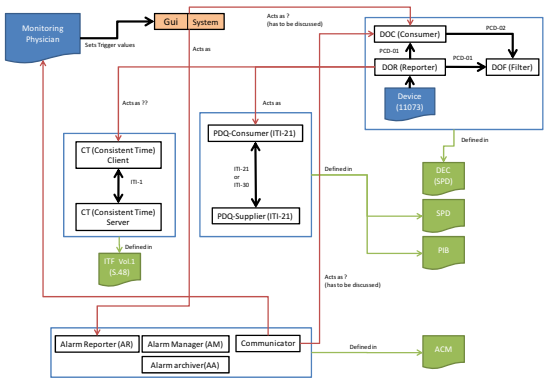

Figure 2- IHE profiles needed (without XDS)

Furthermore, the XDS profile definition of the IT Technical Framework is used to implement a document consumer module for the framework to integrate data into an IHE based EHR.

- CEN 13606 [3]: has been evaluated for defining domain models and flexible data structures. This standard really has high potential but as it is not part of the definitions of any other international framework (e.g. IHE) the usage in the project has to be further evaluated.
- Continua Alliance: the open industry coalition focuses their work to personal health (fitness, wellness), chronic diseases and solutions for aging population. They published the "Continua Design Guideline" which defines the basic conditions for device data communication (the guideline is based on ISO/IEEE 11073 and PHMR). They also offer a certification process for devices and systems.

Results

Device communication

Based on the ISO/IEEE 11073 basic and profile definitions device communications for three different devices has been set up and tested so far: a pulse oximeter (Nonin, USB based), a data logger (Bluetooth based) and a clinical thermometer (see next paragraph). Overall five device profiles for different device classes and the central 11073 manager module were implemented. The manager is already being able to integrate devices and start communication on a plug&play basis. At the moment the manager runs on mobile devices with Windows Mobile operating systems but because of the Java implementation it can be easily ported to any other system.

Clinical thermometer device

For testing purposes and to demonstrate the usage of the framework for intramural setups a hardware prototype for a clinical thermometer was developed (Figure 3) and the software for ISO 11073 conformant communications was implemented on the used microprocessor. The device has a RFID module to identify a patient via a RFID wrist band and it communicated with the manager via Bluetooth. At a further project stage the RFID identifier will be used to query demographic data from the HIS or any other system and the device displays the name of the patient the device display.

Figure 3- prototype of a clinical thermometer

Module architecture

After conception phase the module structure for the framework was defined and the basic modules to be implemented first were selected - Figure 4 shows the architecture and the modules. The core of the system is called "controller" a module which manages all the other modules and applications that are plugged into the framework.

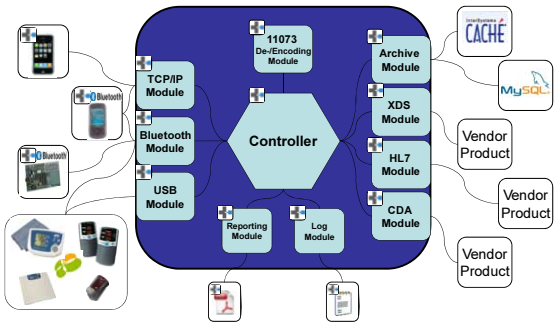

Figure 4-Module architecture

A module can be added easily by simply providing a java library file at a specific location. The controller mentions the new application and integrates it into the framework. At a second step each module has to register itself at the controller and as a part of the negotiation process the new module defines the type of data it can provide (write) or it wants to have (read). The controller administrates all the modules and manages a common data container. This container can be filled by different modules and can be accessed by others. The controller takes care of the data request done by all modules and notifies a module as soon as all requested data is available by releasing an event. This means that for instance a module needs data that can only be served by two other modules (e.g. a CDA Module needs data from the device and from a demographic query). Using this plug and play interface also third party modules can easily be integrated without any change of the framework.

All of the 11073 based modules (on the left side of Figure 4) have already been implemented. Also development of the log and archive modules was finished. The archive model writes the data into the object oriented Cache database. The HL7 and IHE modules are currently under development.

Standard based controller data container

The controller holds one or more data container, which are used for data exchange of the modules. The design of this container is also based on the selected standards. The container can hold ISO 11073 structured data (also raw data is provided for compatibility issues), HL7 data, a CEN 13606 EHR-Extract or any other data structure. The demographic data is currently designed to be stored in the HL7 RIM model. Figure 5 shows an UML overview of the container. Access to data is controlled by the controller.

Use case analysis

In parallel to the technical development the analysis of possible use cases and the related processes, which started at the beginning of the project, is continued. Among others this includes scenarios for patient to doctor communication, chronic diseases but also intramural use cases (see clinical thermometer). The results of this analysis project and the documentation will be published by ISO as part of an official ISO.

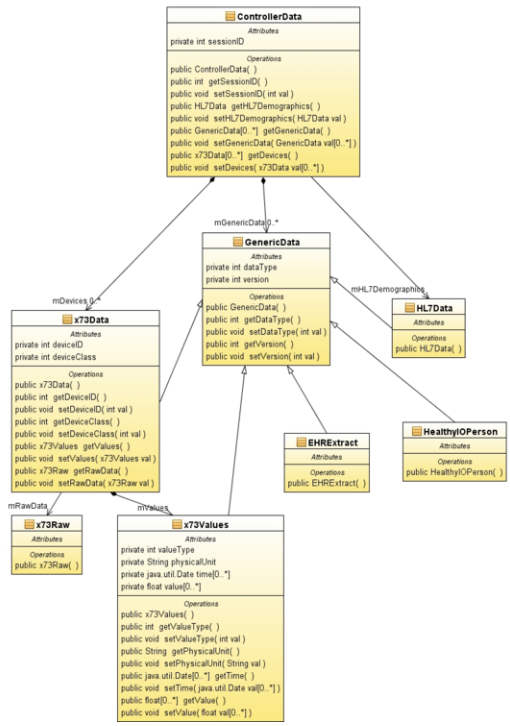

Figure 5-UML Model of the data container

Discussion

Continua Alliance

The Continua Alliance, their definitions and their certification process gets more and more attention as the interest in devices, which support data transmission to mobiles or PCs, grows.
Especially the market for consumer devices and devices supporting ambient assistant living (AAL) is growing. Especially for AAL the communication based on an international standard is a very important issue because it enabled interoperable systems and that massively reduces costs. But therefore the availability of Continue certified devices gets more and more into the focus. At the moment there are only a few certified device classes on the market, but according to Continua in January 2010 a lot of compatible devices should come to the market.

ISO 11073 reverse channel

At the moment the ISO 11073 agent – manager communication is mainly unidirectional, which means the device is sending data. The only exemption is that some devices can get configuration parameters from the manager. In some cases (e.g. the clinical thermometer) this seems to be too limiting, because sometimes the reverse channel should be usable for data transfer (e.g. clinical thermometer: questioning the patients name to be displayed on the device).

Remote configuration

It seems to make sense that a doctor who is monitoring a patient's data should be able to change the configuration of the monitoring device. But this raises a lot of problems especially in regard to security because it has to be ensured that a specific configuration really was entered by a doctor and that it is not a fake. This also has a lot of legal aspects. Therefore at the moment the communication is only unidirectional.

Security

As the Healthy Interoperability frameworks handles medical data special security and data protection definition has to be applied and sufficiently addressed. End to end encryption would be nice to have but fails because of current technical limitations, such as key distribution or using electronic certificates on medical devices. Hence also the security requirement of non repudiation is still vacant.

For securing the communication route from the mobile to the health provider information system currently the ISO/TR 11636:2008 about "On-Demand VPN" is evaluated.

Also the process for assigning a device to a patient is still not satisfactorily solved. The assignment still requires manual interaction. To optimize the assignment process or find a automated reliable solution will be part of future work in the next month.

Profiles

The behavior of such a system depends on the situation when and where it is used. So the system has to provide different profiles. Profiles can have different categories, for example "communication profiles" which control the data transmission channel or "situation profiles" like "at home" or "at restaurant" which for example controls the audio response of the systems. Profiles can be active or not and usually more than one profile is active.

Pilots

For the next year two pilot installations are planned to demonstrate the operation of the system. First pilot will be patient monitoring in the home care area. The pilot addresses older people at the age of 70+ who are currently served by a care organization. The pilot aims to monitor health parameter online and on a second step implement a kind of alarm management for abnormal data.

The second pilot will address self management of oral coagulation. Concerned people get a device for home and self measured device data is transferred to a server where a medical attendant periodically validates the values.

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Deploying Portable Ultrasonography with Remote Assistance for Isolated Physicians in Africa: Lessons from a Pilot Study in Mali

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Abstract

Objective : demonstrate the feasibility of deploying portable ultrasonography with remote assistance to improve the diagnostic capabilities of isolated physicians in Africa. Methods : the approach is based on the training of general practitioners for the use of ultrasonography, and the remote support by radiologists using dedicated tools for image transfer over low-bandwidth internet connections. Results : our early results in a pilot project in Mali show that this approach is feasible, and that isolated physicians can productively use ultrasonography to improve diagnosis and management decisions such as the need for a medical evacuation towards a reference hospital. Conclusion : these encouraging early results must be confirmed by larger-scale studies, in order to better understand the organizational requirements and demonstrate outcomes and return on investments for such telemedicine services. This scale-up project will start in 2010 in collaboration with the International Development Research Center of Canada.

Keywords:

Telemedicine, Teleexpertise, Teleradiology, Ultrasonography, Africa

Introduction

The usefulness of ultrasonography for improving diagnosis and patient management in rural Africa has been demonstrated by several studies [1-4], in particular for obstetrical and abdominal pathologies.

The possibility to train non-radiologists to the use of ultrasonography for emergency situations [5] and for obstetrical evaluation [6] has also been established. Such training requires significant efforts for initial and continuing education, as well as monitoring by radiologists.

However, such specialists are rarely found outside of capital cities in Africa. For example, there is only one radiologist outside of Bamako in Mali, a country of 2'421'000 square kilometers with a population of 14 millions. Projects have therefore been developed in order to provide a remote support by radiologists, to improve the quality of the service and to support isolated care professionals facing challenging cases.

In addition, projects enabling the remote control of ultrasound imaging have been developed, such as the TERESA project [7] of the University of Tours in collaboration with the European Spatial Agency.

As portable ultrasonographs are becoming cheaper and connectivity of isolated hospitals is improving, it becomes realistic to deploy such tools in remote areas, but there are still many questions related to the training of the professionals, the organization of the remote support, the usability of telemedicine software, and the effective use of usually poor internet infrastructures.

In this study, we investigate the feasibility of deploying portable ultrasound imaging devices in remote hospitals, with distance assistance, through low-bandwidth connections with national reference hospitals. The pilot site is a rural hospital in Mali, the reference hospital being based in Bamako, the capital, 875 kilometers away.

We use the infrastructure and organization deployed by the RAFT (Réseau en Afrique Francophone pour la Télémédecine), which provides connectivity to dozens of hospitals in French-speaking Sub-Saharan Africa [8,9] in order to support continuing medical education and tele-expertise for isolated physicians and care professionals. We also make use of the CERTES, center for expertise in telemedicine in Bamako, which provides services to telemedicine users in Mali, and more generally in the West African region [10].

Materials and Methods

Materials

The ultrasound imaging device is the Voyager® Compact Imaging Device [11] (Ardent Sound Inc., Meza AZ, USA) equipped with two probes (4 and 10 MHz) and powered by an

external battery. It is connected to a standard laptop computer via a USB cable. The imaging software, Ardent Examiner®, runs on the laptop and produces DICOM images which can be exported.

An additional software, Medbook©, has been developed within the scope of this project in order to receive these DICOM images, compress them and securely transmit them on a distant server where they can be retrieved for review by experts. The goal of this software is to be able to rapidly transmit these images over a low-bandwidth internet connection of 30-40 kilobits/second, the bandwidth that can currently be obtained on the cheap DSL or mini-VSAT connections deployed in the RAFT network. It contains a DICOM listener based on the open-source dcm4che platform [12], and uses the Theora [13] open-source video compression. It can produce various images at different compression levels (Figure 1.) thus enabling very high-level of lossy compression, as well as lower-, lossless compressions for specific images. This is particularly useful in order to define imaging and image transmission protocols that take into account the actual possibilities of the existing connections. Medbook© also helps collecting structured information to be sent to the expert, as well as an identity management tool to label cases.

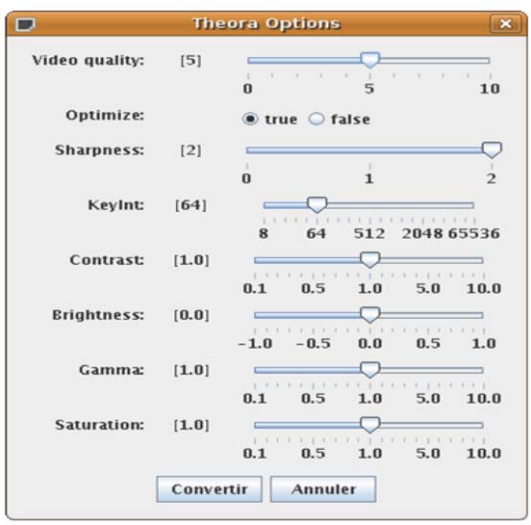

Figure 1 - Medbook interface screenshot: Theora options for defining and testing various compression levels

Methods

The RAFT network

Continuing education of healthcare professionals and access to specialized advice are keys for the quality and efficiency of a health system. In developing countries, these activities are usually limited to capitals, and delocalized professionals do not have access to such opportunities, or even to didactic material adapted to their needs. This limits the interest of such professionals to remain active in the periphery, where they are most needed to implement effective strategies for prevention and first-line healthcare.

In order to address these needs, the Geneva University Hospitals have developed a telemedicine network in Africa (the RAFT, Réseau en Afrique Francophone pour la Télémédecine), first in Mali, then in Mauritania, Morocco, Cameroon, and, since 2004, in Burkina-Faso, Senegal, Tunisia, Ivory Coast, Madagascar, Niger, Burundi, Congo-Brazzaville, Algeria, Chad, and Benin.

The core activity of the RAFT is the webcasting of interactive courses targeted to physicians and other care professionals, the topics being proposed by the partners of the network. Courses are webcast every week, freely available, and followed by hundreds of professionals who can interact directly with the teacher. 70% of these courses are now produced and webcast by experts in Africa. A bandwidth of 30 kbits/second, the speed of an analog modem, is sufficient, and enables the participation from remote hospitals or even cybercafés.

Other activities of the RAFT network include teleconsultations, and collaborative development of educational on-line material.

The network is currently organized and run by more than 30 national coordinators and a small coordination team based in Geneva. In each of the partner countries, the RAFT activities are supervised by the focal point, a medical authority (usually a university professor) that links the project to the national governmental bodies (ministry of health, ministry of education). A local medical coordinator (a junior physician) and a technical coordinator take care of the day-to-day operations, including communication with the care professionals, identification of training needs, technical training and support of the various sites within the country

Pilot site

The pilot site is the rural hospital of Dimmbal, in the Dogon country in the north of Mali, 875 kilometers away from Bamako, where the radiological expertise resides. Before being connected to the RAFT network, Dimmbal was quite isolated, the first telephone 15 kilometers away, and the first internet connection 120 kilometers away. The hospital, serving a population of about 30'000, and staffed with a physician, a nurse and a midwife, was equipped with a mini-VSAT satellite connection in 2004 (Figure 2.), and has served as a laboratory for the RAFT network to investigate the feasibility of deploying distance-education, telemedicine and de-isolation activities for care professionals in rural Sub-Saharan Africa [14].

Figure 2 - Dimmbal rural hospital, in the Dogon country (Mali), equipped with a mini-VSAT internet connection

Reference hospital

The reference hospital is the Hôpital Mère-Enfant "Le Luxembourg", one of the three main reference hospitals in Bamako, capital of Mali. This hospital hosts the CERTES, center for expertise, education and research in telemedicine. Amongst others, CERTES provides basic computer and internet skills courses, as well as specific courses for the use of distance education and telemedicine tools.

Computer and internet skills development

This is an essential phase as many care professionals still have limited computer and internet usage skills. Although the current physician of the Dimmbal hospital has acquired these skills through previous training courses, any deployment of such tools must be accompanied by such basic training, as the internet connectivity will be the umbilical link between the remote hospital and the centers for expertise, whether medical or technical. These skills are usually acquired through a one-week course, either in the CERTES in Bamako, or at decentralized workshops in regional cities where 10-15 care professionals are regrouped.

Additional skills for the specific usage of the ultrasound device and the image transfer systems are also needed.

Ultrasound imaging training

Basic training for the proper usage of the ultrasound imaging device requires approximately one month of practice with a trained radiologist. The duration of the training depends in part on the availability of appropriate cases. The goal is to develop the basic skills and make sure that the trainee will be able to reproduce the main, key images that are used for the evaluation of patients.

Organization of the tele-expertise service

Once trained with the basic skills for acquiring and interpreting ultrasonographic images the trainee is also taught how to decide when to seek expert advice for the analysis of an image or a video sequence.

At CERTES, a center of expertise is setup and physicians receive tele-expertise requests and route these to the appropriate specialists.

Ultrasound images, first acquired in a DICOM format, must be exported and compressed using Medbook©, then uploaded on a secure server where the specialists can access them for review. The requesting physician is then informed directly by the expert through the teleconsultation platform.

Results and lessons learned

A case-report from the Dimmbal pilot site

A 22-year old woman, at the seventh month of pregnancy, consults the Dimmbal hospital for musculoskeletal and abdominal pain. Anamnesis reveals that she has been battered by her husband. Physical examination shows multiple contusions. The ultrasound examination (Figures 3 and 4), reviewed in near real-time by the radiologist in Bamako, confirms that the fetus is not showing signs of suffering. The patient is therefore kept for observation at the Dimmbal hospital, and not evacuated to the regional hospital.

Image compression and image quality for diagnosis

One of the key limiting factors for this application is the bandwidth. It is unlikely that a remote hospital will be able to afford more than a basic internet connection, given the high cost of these outside the main cities. Currently, a reasonable bandwidth is about 200 kilobits per second for downloads, and 30-40 kilobits per second for upload.

For this tele-ultrasonography scenario, the uplink is critical, as images are sent from the periphery to the center of expertise. A video sequence of 150 frames (10 seconds), uncompressed, in DICOM format, weighs 170 megabytes. A frame-by-frame compression in JPEG 2000 will reduce it to 5.4 megabytes, whereas a Theora video compression will reduce it to 1.4 megabytes, with an output quality judged sufficient for diagnosis by several radiologists who participated in these experiments. With such compression rates, it is possible to send such video sequences in 4 to 5 minutes over a 40-kilobits per second uplink. This obviously requires a careful selection of the video sequences by the requesting physician.

Figure 3 - Portable ultrasonography setup. The same computer is used for acquiring the images, and then transmitting them, compressed, to the reference center

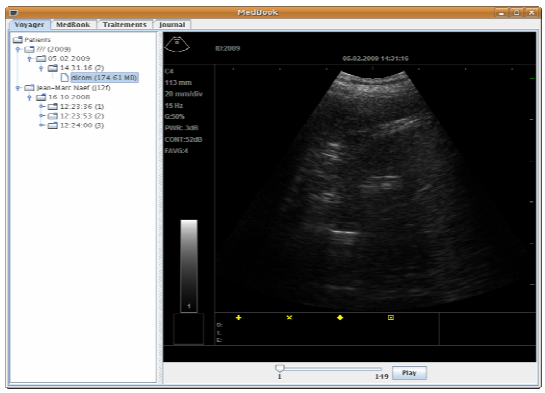

Figure 4 - Medbook screenshot: selection, compression and transmission of an ultrasonography video sequence

Localization of these activities within the health system

Although we piloted the tool in a rural hospital, it appears that the level of activity is not sufficient to justify such investments, and we are now moving to the first level of reference, i.e., district hospitals, where the number of cases is higher, and where the overall infrastructure of the hospital is sufficient to take care of many of the patients evaluated with this telemedicine service, thus improving the value of the ultrasound imaging for deciding whether or not to evacuate the patient to the next level, i.e., the regional hospital.

The same remark pertains to the sustainability of financing the internet connection, which is very difficult to achieve at the rural level.

Delegation of the ultrasound imaging to other care professionals

There are good arguments, and needs, to train non-physicians for the use of ultrasound imaging, in particular for midwives performing obstetrical evaluations. It is however important that these professionals don't replace specialists and that they respect the ethical and deontological rules for reference of patients. An easily accessible link to specialists has the potential to maintain a balanced distribution of roles and facilitate quality monitoring and continuing education of these care professionals.

Availability of timely expert advice

A critical success factor is the ability to access expert advice in near to real-time. If the delay is too long, or the expertise insufficient, then the requesting care professional will not bother trying to access it.

The experience of the CERTES, in Bamako, shows that this can be achieved through a properly-staffed operational center. Obviously, such a center can only be maintained if there is a high-enough level of activity, which can be challenging initially.

Conclusion

This pilot study demonstrates the feasibility of deploying portable ultrasound imaging in remote hospitals and providing timely access to expert advice for difficult cases. The success relies on the proper training of the users, the rigorous organization of the call center and the use of an adapted software for the secure transmission of the images over low-bandwidth connections.

This service complements other services already deployed to help de-isolating care professionals who work in remote areas [8,9], thus creating a critical mass of added value that can justify the investments and maintenance of telemedicine tools in district hospitals.

Although technical evaluations and anecdotal evidences are confirming the potential of these tools to strengthen health systems, it is now important to demonstrate patient outcome improvements and measure financial returns on investments, as these stronger evidences are necessary to drive the further development and deployment of such systems.

Acknowledgments

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Web-Based Asynchronous Teleconsulting for Consumers in Colombia: A 2-year Follow Up

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Abstract

Background: Remote consultation was implemented in 2006 in our institution, through an open-access Web-based Teleconsulting service: Doctor Chat. This tool was created with the aim of improving access to health care services in Colombia, especially in underserved areas. Objective: The aim of this paper is to report our experience with the free Web-based application for teleconsultation. Methods: After validating the tool, we analyzed the queries submitted between May 2007 and June 2009. Requests were classified into three axes: purpose of the query, specialty, and geographic area of origin. Descriptive statistics were gathered for each category (name, email, city, country, age, gender). Results: We received 1624 consultations, with an average of 59 requests per month. 52.7% of the users were aged 18 to 29 years. Users asked mainly about sexual and reproductive health issues. 79.2% of consultations came from Colombia and 32.91% of the users were students. Conclusions: Doctor Chat is an innovative tool to deliver health care information, but advertising, preventive and technical strategies must be implemented to improve its impact on Colombia's health system.

Keywords:

Colombia, Remote consultation, e-Health, Teleconsultation, Telemedicine.

Introduction

Among technological applications available today, teleconsulting services stand out as significant means to improve access to healthcare information [1]. Many concerns about health issues can be answered by a medical guidance through the Internet [2]. Due to high worldwide impact of these services, the Center for Virtual Education and Simulation (Centro de Educación Virtual y Simulación e-Salud, Fundación Santa Fe de Bogota [3]), offers a noncommercial, free web-based teleconsulting service in Spanish, called Doctor Chat [4]. This application was developed in 2006 with the aim of providing a tool that could serve as a basis to improve access to health care services in Colombia, especially for populations in-need located in underserved areas of the country. In 2007, we presented the first results of our experience with Doctor Chat [5]: During the first six months of operations, 270 teleconsultations were received. At the time, Internet penetration was already showing a steep rise, ascending from 2.1% in 2000 to 12.9% in 2006 and 44% in 2009 [6, 7]. This evolution is shown in Figure 1. Additionally, the number of internet subscribers raised 54% between June 2008 and June 2009 [7]. This information allowed us to expect fewer barriers in terms of Internet connectivity, more access in underserved areas, and therefore a progressive increase in the number of teleconsultations, which could translate into a continuously growing impact tool towards community health information empowerment. These facts served as strong motivators to continue with the program on a subsidized basis with a social sense. Three years after Doctor Chat´s launch, we analyze the follow up experience with the use of web-based asynchronous teleconsulting for consumers in Colombia and Latin America.

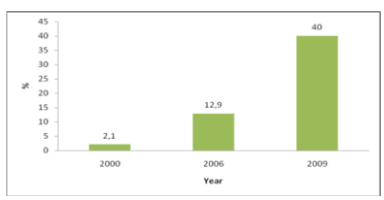


Figure 1- Evolution of Internet Penetration in Colombia

Materials and Methods

Doctor Chat´s Nature and Upgrades

Since its conception, Doctor Chat has followed a user-centered approach to allow anonymous virtual health consultations openly available to any Spanish-speaking person in the world via Internet. Compared to its first version described [5], in March 2009 structural changes were introduced:

(1) The formats for asynchronous teleconsultation and response were redesigned, allowing us to retrieve and analyze digitally more information about the requests, i.e. the purpose of the queries, the Specialty they corresponded to, and the Profession/Occupation of the consulter. To that date, this information was retrieved and stored manually, and for this reason, the data in those last categories analyzed in this paper were only retrieved since that date (see Results); the first data field ("Name") was replaced by ("Name or alias") to further protect user´s confidentiality. Also, the interface was modified to increase its dynamicity. (2) the supporting platform migrated

from a Web-based application structured as a series of HTML pages with e-mail feedback to one that is managed through a tailor "home-made" XHTML scalable application for Contents Management Systems (i.e. Joomla 1.5.X), which allows web-control for information capture and results generation, with transactional reporting via web, anti spamming security (Captcha) and Security Sockets (SSL), created by a Web server (Red Hat Enterprise Linux 4, Apache/2.0.63 Unix) to store and retrieve data in a relational database (MySql 5 – MySqli 5, PHP 5).

The new platform has allowed response automation: whereas previously each user query was directed to a centralized Doctor Chat email account to which only the medical team had access and responses were given by simply replying to the message, now the queries are stored in a web accessible data base, and the responses are given directly through the web-based application. This has significantly facilitated data analysis by allowing computerized data mining, while assuring all the data fields that are important for the analysis are collected.

All queries are received and filtered by a coordinating physician, who responds to primary-level health questions and redirects those specialized to the corresponding Department of our fourth level University Hospital.

(3) The user's satisfaction survey was extended and automated. Before March 2009, a single-question informal survey of user's satisfaction was sent along with the response ("Are you satisfied with Doctor Chat's service? Please send us your comments to improve the service"). Now, the new satisfaction survey includes 5 mandatory question fields (QF) with drop-down menus for each answer (A): (1) QF: "Did the answer provided by Doctor Chat meet your expectations?" / A: "Yes – No"; (2) QF: "Was Doctor Chat´s answer to your question clear?" / A: "Yes-No"; (3) QF: "What´s your general opinion on Doctor Chat´s response according to the following criteria" / A: "Insufficient – Indifferent- Acceptable – Good – Excellent"; (4) QF: "Given that the standard response time of Doctor Chat is 48 hours, what is your overall satisfaction with the response time?" / A: "Completely satisfied – Satisfied – Unsatisfied – Completely unsatisfied"; (5) QF: "Comments and suggestions" /A: Blank field.

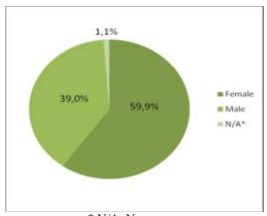
Data Analysis

Content analysis was performed according to three classifications: (1) the purpose of the query, (2) the specialty, and (3) the geographic area of the query. Kravitz et al [8] "taxonomy of patient requests" was used to categorize the purpose of the query, and each request was classified according to the topic into one of the 31 specialties available at our institution.
Descriptive statistics were gathered for each of the data categories (name, email, city, country, age, gender and the newly included profession/occupation) and the location from which each query was submitted was determined by the response to the "country" and "city" cells.

Results

Gender and Age Ranges

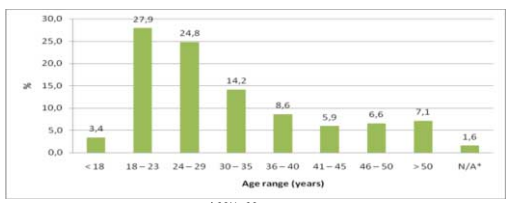
Between September 15th 2006 and July 8th 2009, we received a total of 1624 remote consultations, 973 were submitted by women and 633 by men, which represent the percentages shown in Figure 2.



* N/A: No answer

Figure 2- Distribution of consultations by gender

The monthly average of remote consultations was 59, whereas a mean of 2.3 were received per day. This average practically doubles that of 1.4 consultations per day, found from September 2006 to march 2007 [5]. Regarding the age groups, most of the users were aged 18 to 29 years (52.7%), as shown in Figure 3. This result is very similar to the one we reported in 2007, in which 54% of the users belonged to this same age range [5].



* N/A: No answer

Figure 3- Distribution of consultations by age range

Purpose of the requests

By taxonomical category (as described by Kravitz et al [8]), the majority of teleconsultations were requests for information (n=1482; 91.3%), and particularly about symptoms, problems or diseases (n=991; 66.8%). Inquiries for medications/treatments accounted for 22.2% (n=330) of the Request for Information category.

Requests for Action accounted for 7.2% (n=117) of all consultations, and among these, 70.9% (n=81) belonged to the Medication/treatments, 15.3% (n=17) and 12.6 % (n=14) to the "Referral to other physician" and "Laboratory test, x-rays, or other study" subcategories, respectively. These results are shown in Table 1.

Table 1 – Distribution of consultation per taxonomical category

Taxonomical category	n	% of the category	% of total
Request for Information	**1482**	**100**	**91,3**
Symptoms, problems, or diseases	991	66,8	61,0
Medications/treatments	330	22,2	20,3
Other administrative issues	44	3,0	2,7
Test or diagnostic investigations	48	3,2	3,0
Other request for information	44	2,9	2,7
Prevention	17	1,2	1,1
Other physicians	7	0,5	0,4
3rd party payer or managed care issues	0	0,0	0,0
Index physician-patient relationship	0	0,0	0,0
The physical examination	0	0,0	0,0
Psychosocial problems	2	0,1	0,1
Request for Action	**117**	**100**	**7,2**
Medication/treatments	81	70,9	5,0
Laboratory test, x-rays, or other study	14	12,6	0,9
Referral to other physician	17	15,3	1,1
Other administrative action	2	1,8	0,1
Referral to nonphysician	1	0,9	0,1
Administrative action: 3rd party payer	1	0,9	0,1
Physical examination	0	0,0	0,0
Other request for action	81	70,9	0,0
N/A* (Information or Action)	**25**	**100**	**1.5**
Consolidated Total	**1624**	**100**	**100**

*N/A: No Answer

Requests by Specialty

As shown in Figure 4, most of the teleconsultations fell into the Gynecology and Obstetrics (GO) (n=414; 25.5%) and Urology (n=178; 11.0%) areas. These requests corresponded to sexual and reproductive health issues, i.e. Sexually Transmitted Infections (STIs) including HIV/AIDS (65.2%), and contraceptive methods (30%). Among the remaining questions related to GO, 20% concerned pregnancy, 6% infertility and 6% vaginal infections. Requests for information on Dermatology accounted for 9.8% (n=133) of all teleconsultations. In this area, most of the questions asked for information regarding removal of moles, scars, striae or tattoos (40%) and allergic reactions (30%). Other questions on Dermatology included topics such as treatment of acne and skin cancer.

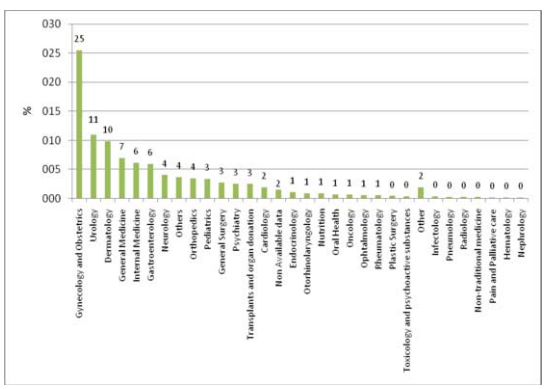


Figure 4- Requests by specialty

Origin of the Requests

79.2% (n=1286) of the consultations were originated in Colombia. However, as shown in Figure 5, we received inquiries from all around the world, especially Hispanic countries like Mexico (n=87; 5.3%) and Spain (n=63; 3.8%).

In Figure 6 we can see that most consultations from Colombia were originated in Bogota (n=690; 55.4%), Medellin (n=89; 7.1%) and Cali (n=66; 5.3%), the three main cities of the country. 22.7% (n=283) came from intermediate cities (State capitals except those described above), and 9.4% (n=118) from remote or underserved areas.

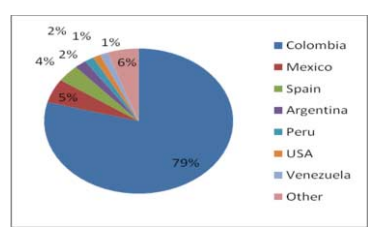


Figure 5- Requests by country of origin

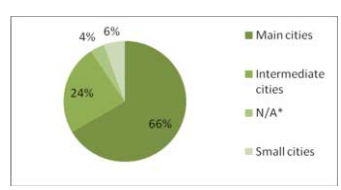


Figure 6- Requests by city of origin (Colombia)

In Table 2 we can see that in comparison to the 2007 results [5], the percentage of consultations originated in intermediate and small cities presented an important increase, whereas the percentage of requests from the main cities varied only slightly.

Table 2 – Comparison of distribution by city of origin between 2007 and 2009

Group	n (%) 2007	n (%) 2009
Main cities	137 (67.2)	693 (66.5)
Intermediate cities	40 (19.7)	251 (24.1)
Small cities	2 (0.7)	58 (5.6)

Requests by Profession/Occupation

From March 16th (date in which the "Profession/Occupation" field was added) to July 8th 2009, we received 237 teleconsultations. Among these users, the majority were students, followed by "other" types of Professions/Occupations, housewives and Merchants. The results are shown in Table 3.

Table 3 – Distribution by Profession/ Occupation

Profession/Occupation	n	%
Student	78	32.91
Other	56	23.64
Housewife	27	11.39
Merchant	14	5.91
Assistant, manager	10	4.22
Employee	10	4.22
Teacher	8	3.38
Lawyer	7	2.95
Administrative	7	2.95
Engineer	7	2.95
Miscellaneous	7	2.95
Independent	6	2.53
Total	**237**	**100**

Discussion

Since its implementation in 2006 and as seen in Figure 7, Doctor Chat has shown a fluctuating behavior. The peak in May 2008 shows its sensibility to "publicity". Although no marketing has been put in place to promote the tool among potential users, when the service was presented in an interview for Semana [9], a nation-wide spread magazine, a dramatically rapid increase in the number of teleconsultations shown in Figure 7 was accounted, with a total of 240 requests received only during that month. Nevertheless, without ongoing publicity, the use of the service declined as rapidly as the peaking rise, to stabilize at the previous baseline, thereby probably behaving accordingly to Eysenbach´s Law of Attrition [10], which states that e-Health applications "allude to a common problem" consisting of a decrease number of users through time, due to a loss of users over time. It would be interesting to put in place a continuous marketing strategy and evaluate its impact in terms of usage among the community, but because we predict a massive response, we would need financing to support the infrastructure and human capacity to anticipate to that demand. In this scenario, we consider that the tool may behave differently from Eysenbach´s Law trend, but a further follow up in the presence of continuous publicity would be needed to confirm this hypothesis. Another fact that must be considered in this matter is that the number of users of our application varies a great deal over time, with new users entering each day, some of the old users dropping out or consulting one time only, and some others using the application regularly.

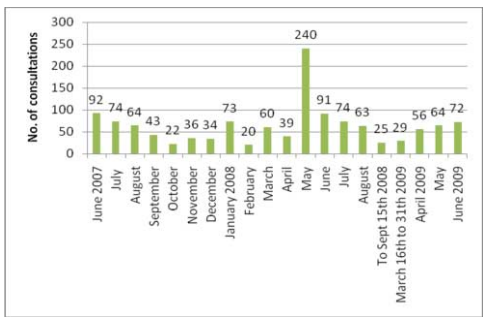


Figure 7- Number of requests per month

Regarding the geographical origin of the requests, few changes have occurred since 2007 [5]. Despite the increase of internet penetration in Colombia, 58.2% of all Internet connections are concentrated in the four main cities of the country [11], probably explaining the fact that most of the requests are still coming from non-distant places. However, it is fortunate that we have also accounted an important increase in the number of consultations coming from smaller cities and underserved areas.

Colombia´s National Plan for IT has established the year 2019 as the cutting point for universal internet coverage among the country [12], and is currently undertaking important efforts to achieving this goal. As internet penetration continues to expand as well as an "IT culture" to incorporate in the daily lives of distantly-located populations, we anticipate an exponential growth of the usage of teleconsulting services such as Doctor Chat as means to obtaining reliable health related information. Another interesting information retrieved from this study is the fact that most of the users of Doctor Chat are young students and housewives and that the majority of consultations were related to sexual and reproductive health issues. This is particularly important in developing countries like Colombia, where unplanned pregnancy is a main cause of school desertion and a major cause of unsafe abortion [13]. The importance and the impact of tools such as Doctor Chat to support sexual and reproductive health prevention and promotion activities and strategies is still to be assessed.

Penetration of mobile phones in Colombia is one of the highest of Latin America, reaching 85.45% [14] (compared to the national 44% internet penetration [6]) with a total of 40.28 million subscribers in the second trimester of 2009 [11]. Additionally, there has been an increase of 56.8% in the number of Internet connections through mobile networks in the last year, with a total of 495.730 users by the end of June 2009 [6]. With these data in mind, in collaboration with Universidad de Los Andes we are currently developing a new application for mobile phone consultations called mobile Doctor Chat ("*Doctor Chat móvil*"), which will be available for all-types of mobile technology users all over the country by the end of the first semester of 2010. With this application, we aim to reach communities with limited or no internet access, especially in underserved areas, as well as that majority of the Colombian population which have incorporated mobile phoning –but not internet- into their daily routines.

Conclusion

Doctor Chat has proven to be an innovative tool to deliver health care information to Spanish-speaking communities. However, strategies like publicity, specific prevention and promotion activities and expansion of the services through mobile telephony should be strongly reinforced in order to effectively reaching underserved areas and achieving population-wide impacts in developing countries like Colombia .

Acknowledgments

We thank the working team at the Division de Educación of Fundacion Santa Fe de Bogota, the institution´s Center for Telehealth, the University Hospital and its specialists, without whom the case experience hereby presented would have been impossible or irrelevant. We also thank the group of Systems Engineering at Universidad de Los Andes for its continuous support in the materialization of mobile Doctor Chat which has constituted a long-lasting goal of our R&D team.

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Chapter 8.

Education

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Medical Education & Health Informatics: Time to join the 21st Century?

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Abstract

This paper reports a component of a larger study, Informatics: enhancing the Clinical Experience? (ICE), which explored the impact on the therapeutic relationship of the implementation and use of Electronic Medical Records (EMR) in British Columbia, Canada. As anticipated, EMRs were found to negatively affect the relationship in many clinics. However, surprisingly paper-based clinics were as likely as EMR-based clinics to report problems with maintaining eye contact with their patients. This led to an interesting finding; that as a result of this difficulty few family care providers actually chart when their patients are with them, preferring to build rapport and chart at a later time. Consequently three recommendations are made: 1) Improve medical education in the area of charting (paper & EMR-based) with the patient present; 2) Explore the affect different technologies and skills have on the ability of providers to chart with the patient present and 3) Develop an understanding that unless the technology and training improve Canadian family medicine will never gain the asserted benefits of EMRs, and that other incentives are needed if Canada is to meet its target of delivering Electronic Health Records (EHR) to 100% of all Canadians by 2015..

Keywords:

Medical education, Charting, Therapeutic relationship, EMR/HER

Introduction

Traditionally general practitioners have been taught that the way to develop and maintain a good relationship with their patients is through developing a personal interaction style that relies a great deal on direct eye contact with the patient. Likewise, it is the nuances of body language and facial expression that often cues a doctor in to what is really troubling a patient as opposed to the words they are speaking. Consequently, the introduction of an Electronic Medical Record (EMR) into family medicine brings with it a number of challenges. Not least of which is the interference the use of an EMR could potentially cause with this requirement for direct eye contact.

Methods

This paper reports part of a much larger study (ICE) undertaken in British Columbia, Canada during 2005-2008. It involved 30 family medicine/general practitioner clinics representing all demographic populations as well as rural/inner city and large and small (single-handed) clinics. Extensive interviews were undertaken with all members of staff within each clinic, on three occasions, during the three-year period. Additionally, interviews were also undertaken with random patients from each clinic over that same three-year period, a program of information management facilitation was conducted with 2/3 of the clinics, and a mail-out survey and a workshop were held with all participating clinics. Data from these activities are not reported here.

Clinics were categorized into one of two groups: Paper-based (a computer was used for billing and administrative activities only), or EMR-based (a full EMR was used, with charting conducted on the EMR and not in paper charts). The focus of the ICE study was the impact of charting method (paper vs. computer) on both the therapeutic relationship and patient outcomes.

We purchased a mailing list from the British Columbia College of Surgeons and Physicians, and then sent a recruitment letter to all 4,319 registered family physicians in B.C. inviting them to take part in the study. Several hundred physicians responded, representing a total of 78 clinics.

Clinics which had been using an EMR for more than twelve months were then excluded from the sample as we wished to investigate clinics in the dynamic early stages of implementation, rather than those whose work practices had already adapted to the EMR. There were no exclusions based on culture, religion, race, disability, sexual orientation, ethnicity, gender or age. Clinics were geographically dispersed, and represented each of the five Regional Health Authorities in British Columbia.

Clinics were then categorized into three groups. Group 1 clinics had had an EMR in place for less than 12 months as of January 2005. Group 2 and Group 3 clinics did not use an EMR at the time of enrolment, and did not plan to do so for several years.

Knowing that our EMR-based clinics had encountered varied training experiences from their EMR vendors, we provided all our EMR-based clinics with training in information management. Thus, in addition to participating in data collection, all clinics from Group 1 participated in a facilitation program led by myself. Additionally, Clinics from Group 2 and Group 3 were also randomly selected for participation in this facilitation program. These sessions, held over the lunch hour at the

clinic involved all staff. Sessions consisted of a program of change management, information management, and skills training and development designed to improve practice function regardless of the type of information management system in place.

Clinics in the three groups were clustered geographically. That is, Clinics 1a, 2a and 3a were all located in the same town, or region within British Columbia.

In the interest of retaining the desired goal of 30 participating clinics, the research team over-recruited and initially included 33 clinics in the study (11 in each group). As anticipated, three clinics did not complete the entire study. Two clinics withdrew from the study and the research team de-enrolled one clinic. Thirty primary care clinics completed the entire study during 2005-2008. The clinics selected for data collection were randomly assigned to the two project interviewers.

Data Collection

The ICE study employed a mixed methods approach to data collection. Qualitative interview guides were developed to interview health professionals. Patients were both interviewed and completed surveys; using semi-structured interview guides and questionnaires (see details of data collection below). General observations about each clinic environment were documented within the field notes and in sketches of the clinic layout. Facilitation data included a combination of field notes and survey instruments. In addition, the final stage of data collection involved administering a mail-out survey, designed to tap into organizational culture issues as well as patient information management and patient care. This paper reports on the face-to-face interviews with healthcare providers only.

To obtain rich data about a clinic's patient information management practices, and insights into the therapeutic relationship between the patient and health care providers in clinics, semi-structured face-to-face interviews were conducted. In addition to obtaining general demographic information about the respondent (age, sex, educational/training background of health care providers and the primary contact physician, employment status of patients/providers, and a profile of the clinic), we asked physicians and other clinic staff a series of questions about patient record management practices, both in paper-based and EMR-based clinics, including questions about:

- charting practices, record transfer practices, administrative tasks involved in the management of patient records;
- accessibility to all patient information during and after consultation, stewardship of the record, confidentiality and privacy issues;
- training opportunities;
- perceived competence in technology use, the perceived effects of EMR versus paper-based system on patient relationship/care, including patient self-care training/education, decision support capacity and use; perceived effects on interface/communication with external providers;
- overall perceptions of problems with current information management practices (and desire for improvements/changes).

Interviewers were careful to avoid asking specifically about the clinic's EMR system. They remained neutral in their questioning, asking only about the nature of patient information management practices, to collect both positive and negative evaluations.

Interview guides were semi-structured and flexible. Over the three interview periods the guides evolved to respond to the unique management and performance practices of each clinic, and accommodate changes occurring in the clinics.

Sample Characteristics

During the three interview phases, the research team conducted 263 semi-structured, face-to-face interviews with 124 physicians, nurses and office staff [such as medical office assistants (MOAs)]. Of the 30 clinics that completed the study, 38 physicians were interviewed, with a total of 99 interviews taking place over the three interview periods. Seventeen of the 38 physicians worked in EMR-based clinics, while 21 of the 38 physicians were from our paper-based clinics.

The majority of clinics served patients in an urban/suburban setting (13 paper-based clinics, 6 EMR-based). Four paper-based and 2 EMR-based clinics served patients in a small town. A small minority of clinics served patients in a rural region (2 paper-based, 1 EMR-based), while 2 EMR-based clinics were located in a geographically isolated/remote region of B.C.

Data Collection Period and Procedures

Data collection was spread over three interview phases, each about five months apart. The first set of interviews provided us with baseline information about patient information management practices. To examine any changes over time, we conducted our first set of follow-up interviews approximately five months after the baseline interviews. A second follow-up interview occurred approximately five months later. We chose to interview in 5-month intervals in order to ensure that we interviewed participating clinics at different times of the year.

The first interview phase began in July of 2005 and extended to October of 2005. Phase-three site visits were completed by September 2006. All interviews took place inside clinics, during regularly scheduled office hours. The interview date and time was negotiated with clinic participants, giving priority to their availability.

When the ICE study commenced, the research team planned to conduct five interview phases. In 2006, however, those plans changed. The British Columbia Physician Information Technology Office (PITO) was established as part of an agreement between the British Columbia Medical Association and the provincial government to develop and implement a standardized system of EMRs in B.C. As a result we found during our third round of interviews that our EMR-based clinics were on hold waiting to hear if their specific system would be approved for funding and our paper-based clinics were concerned about being forced into using EMRs. As a consequence, we suspended plans for interview rounds 4 and 5, anticipating that we would recommence them once the PITO had established guidelines for progress in the province. When it became apparent that this wasn't going to occur within our timelines we

adapted our protocol and replaced interviews 4 and 5 with the mail-out survey and a workshop, including all participating clinics.

Ethics and Analysis

Ethical approval was received and maintained from the University of British Columbia and the University of Alberta's human research ethics boards. Informed consent was obtained from all participants prior to each interview. All interviews were audio-recorded and transcribed verbatim. Following transcription, interview transcripts were anonymized, with references to names, places, clinic names and websites removed and replaced with codes. All transcripts were then independently analyzed by two researchers using the constant comparison technique and the framework approach.

Results

The results reported here pertain to the impact on the therapeutic relationship during the use of paper-based or EMR-based charting, and based on the interviews with healthcare providers only. Future papers will report on other findings from this and from other data collected during the ICE study.

Interference with therapeutic relationship

As anticipated providers reported that both they and their patients found that using the EMR for charting interfered with their relationship:

"But they don't like a person spending time with the computer and not with them."

(Clinic C4 PH2 Int. 1)

"They'd rather you take the time to talk to them."

(Clinic C5 PCP Int. 1)

Eye contact

The main issue for providers was the inability to maintain eye contact during charting. However, much to our surprise, paper-based providers reported this to be an issue just as commonly as EMR-based providers.

"I think it looks very impolite to do it [chart on the EMR] during the consultation and I've tried it but I feel like I'm losing eye contact with my patients…"

(Clinic C3 PCP Int. 1)

"Because I'm always a person who talks to the patient I very rarely ever - the only time I ever look down [at my paper chart] is if we're looking through the chart for old lab work or something..."

(Clinic A5 PCP Int. 1)

Charting after the patient leaves

Interestingly, although they reported that the inability to maintain eye contact and chart at the same time was an issue, providers didn't report that this impact was as significant as we thought that it would be. Consequently, we spent a considerable amount of time exploring how providers were managing their charting.

We found that it was very rare for providers, whether paper or EMR-based, to chart while the patient was with them. Even clinics which had invested heavily in their EMR, and were proficient with the technologies, opted to chart after the patient left.

"Well I think it's easier on the patient they feel that you're not sort of looking down all the time and writing. I find it much more easier for them."

(Clinic A5 PCP Int. 1)

"Because it detracts from the interview. It detracts from the building up of rapport. And it detracts greatly the ability to, the clinical skills, to take a history and do an examination. You just become much less observant because you're looking at the computer all the time."

(Clinic C4 PH2 Int. 1)

Communication style

Despite a prevailing tendency to chart after the patient left we did find cases where charting was undertaken with the patient present, and where the providers and patients didn't complain about charting being a negative impact on their relationship, but rather spoke glowingly of their ability to communicate. Invariably these cases were ones where the communication style of the provider was exceptionally interactive and personable. Whether using paper or EMR-based charts the providers drew the patients into a mutual review of their charts and discussion of their ailments and treatment plans.

"They feel more involved. It's not like I'm looking into a little book and secretly writing things."

(Clinic C7 PCPC Int. 3)

Mitigating technology

For some it was the choice of specific technologies that allowed them to chart with the patient present and to engage them in their own care:

"..that's probably the best way so that you can talk to them and introduce the information at the same time. If you have a tablet you can face them, … is a little bit better, because you don't have to sit it any way, you can just hold it with you in your hand. It looks like a famous paperclip [clipboard] thingy."

(Clinic C1 PH1 Int. 2)

"They [patients] really like the graphs, I mean if you show them the graph, you know, how their weight is going, how their blood pressures are going, they like that 'cause it lets them see, you know, am I getting better?, am I getting worse?. I really think they like going through the results at the same time as you are going through them. I think they think, yeah, "They actually did get a result and it really is there," you know. Pointing out, you know, well see here - this is good, you know, this is excellent."

(Clinic C3 PCP Interview 3)

Discussion

To my knowledge this is the first time that such a study has investigated the impact on the therapeutic relationship of charting including both paper-based and EMR-based charting. When planning this study I expected that we would find that EMRs interfered with the interpersonal relationship, that the forced lack of eye contact necessitated by computer-use would negatively impact the patient. However, instead we found that:

1. Providers often find that the use of a paper chart also directly affects their ability to maintain eye contact and to develop rapport with their patient. Consequently, many professionals do not chart, on either paper or computer, when the patient is with them;
2. When the EMR is used with the patient, providers report that patients find the encounter satisfactory. However, we noted that this was true only when the provider's personal interaction style led to the patient being actively included in the documentation and review process;
3. Some technologies can mitigate some of the negative impact of charting while with the patient.

Given that many of the anticipated benefits of an EMR rely on the provider charting while actively engaging with the patient, it is discomforting to realize how rarely this actually takes place. Let's just look at one example: the use of computerized alerts and prompts within an EMR which have been reported to have a positive impact on clinical outcomes[1].

Consider the instance of a female patient taking oral contraceptive medication being prescribed an antibiotic. Common belief suggests that when the provider is prescribing the antibiotic the EMRs integrated decision-support system would first check for allergies and other contraindications, and then remind the provider to inform the patient to be sure to use other precautions against pregnancy while she completes the course of treatment. Therefore if the provider doesn't chart until after the patient has left the clinic this alert and decision-support will not be provided. This timely informational discussion and relationship building opportunity would then be left to the dispensing pharmacist alone.

Perhaps this is acceptable in this scenario. However, what about when the provider misses the alert to remind them that their patient, who rarely comes in to see them, is overdue for their PAP smear, again? Since the patient has left it's now up to the provider to follow-up with that patient at a later time. Or will it slip their mind with the result that the patient may miss an opportunity for preventative care potentially leading to a delay in treatment for an, as yet, undiagnosed cervical cancer.

Initially I wondered whether this choice to chart after the patient had left was a behavior specific to British Columbia however our recent (2008) series of 20 Canadian case studies of EMR use that included representation from all Canadian provinces and one of the territories also observed the same behavior [2-3] suggesting that this is a general behavior in Canadian family practice.

Therefore, it is clear from the fact that so many providers opt to chart after the patient has left that much remains to be understood about how charting impacts the therapeutic relationship; specifically when using an EMR. Consequently I turned to medical education* to ascertain what new providers are being taught in this area.

Medical Education

Sadly, it quickly became apparent that while informatics is recognized [4] as a necessary component of training for our new providers it tends to concentrate on either 1) the use of information technology as a teaching tool for educating (E.g. [5]); or 2) information retrieval and appraisal (E.g. [6]). Additionally, it seems that not only is EMR training currently inconsistent but that actual use of an EMR is rarely considered a training need. As one faculty respondent stated in this 2007 scan *"The teaching on the use of health informatics and EHRs is very limited but that doesn't seem to be an impediment for new grads. They learn on the job."* [4 p.5].

Personal experience suggests that this attitude is pervasive within medical faculties internationally. Additionally, while the vast majority of medical schools do evaluate clinical skills in terms of history taking and the ability to synthesize information to arrive at a diagnosis or management plan [7] such evaluations do not take into account the impact that an EMR has on these skills.

Given that we are also continuing to graduate new providers with doctor-centered and paternalistic attitudes despite a greater emphasis on patient-centered attitudes in medical schools [8] it is of great concern to me that we are not addressing these technologies within our medical curriculum.

If you give a child a stethoscope they can fairly quickly work out which ends to put in their ears and that you can hear things through it - learning on the job. Yet, we still spend hours in the medical curriculum teaching our students how to listen with a stethoscope and how to interpret what they hear. How then can we justify *not* teaching our providers how to use a new tool that can have such a strong impact, both positively and negatively, on their relationship with patients?

It is clear from the fact that so many providers opt to chart sent.

Conclusion

Canada has a mandate, charged to Canada Health Infoway, to provide Electronic Health Records to 100% of all Canadians by 2015 [9]. Whilst progress towards this target is ever-increasing with 5 jurisdictions on target for the former goal of providing EHRs to 50% of Canadians by 2010, the prior lack of support for EMRs in primary care within Infoway's remit was a significant omission. The revised mandate [9], which recognizes this gap, specifically addresses support for chronic disease management across the continuum of care. For this to be achieved in primary care EMRs (a necessary foundation for EHRs) must contain clinical decision support [10] which means that providers must chart while the patient is present to gain the benefits of these technologies.

* Medical Education being that training provided to educate new health professionals whether that is doctors, nurses, pharmacists etc

It is clear from the fact that so many providers opt to chart after the patient has left that much remains to be understood about how charting impacts the therapeutic relationship. Therefore my first recommendation is that this be explored further both in research, and also within medical education. Subsequent to developing an understanding as to how charting affects the relationship we need to improve medical education in the area of charting with the patient present. Using a chart, paper or EMR-based, with the patient present is a skill that needs to be developed and taught within our medical curricula.

This leads to my second recommendation, which is that we need to explore how different technologies such as tablets, or the development of skills, such as touch typing, affect the ability of providers to chart with patients present.

Providers are voting with their actions and only using EMRs *with* their patients when they can use them in an interactive manner, drawing the patient into the documentation and review process. Therefore, EMR designers must seriously reconsider the way that their product supports workflow. Rather than simply presuming that providers will use the EMR with a patient present they must design their applications so that they make it easier for the provider to build a rapport with their patient, as they chart. This may mean that EMRs should be keyboard driven (rather than mouse driven) during charting as it is possible to maintain eye contact and touch type whereas it is not possible to maintain eye contact and use a mouse.

Finally, proponents of electronic records must understand that many of the benefits they attribute to EMRs will never be fully realized until these issues are addressed. Chronic disease management relies heavily on primary care where the therapeutic relationship is of the utmost import. Anything that negatively affects this must be mitigated. Critics have decried Canadian providers for being behind other countries in their take-up of EMRs. However, this research suggests that there are good reasons for these delays which must be addressed. I believe that the willingness to engage exists but that our knowledge, understanding and most importantly our provision of medical education in the area of charting with patients present is distinctly lacking. As one provider succinctly summarized:

"Some [patients] are quite impressed that we're-have entered the 20th century. Shame it's the 21st Century now!"

(Clinic C7 PH1 Int. 3)

If we want to provide 21st Century care isn't it time we left the 19th Century?

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Investigating the potential of e-Learning in healthcare postgraduate curricula: A structural equation model

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Abstract

The objective of this paper is to assess the future adaptability of e-Learning platforms within postgraduate modules. An ongoing empirical assessment was conducted amongst postgraduate students, based on the Technology Acceptance Model (TAM). The current paper presents the outcomes from the second phase of a survey, involving fifty six participants. Data analysis was performed using a structural equation model, based on partial least squares. Results highlighted the very strong effect of perceived usefulness and perceived ease of use to attitude towards using e-Learning platforms. Consequently, attitude towards use proved to be a very strong predictor of behavioral intention. Perceived usefulness, on the contrary, did not prove to have an effect to behavioral intention. Implications on the potential of using e-Learning platforms are discussed along with limitations and future directions of the study.

Keywords:

Educational technology, Technology assessment, e-learning.

Introduction

Over the past few years, the use of Information and Communication Technology (ICT) in education is gaining momentum, with e-Learning initiatives becoming more popular within university curricula, both at undergraduate and postgraduate level. Such frameworks provide flexibility on teaching and learning methods, as they are primarily characterized as location and physical presence independent.

In that context, the aim of this paper is to empirically assess the adaptability of e-Learning frameworks to a postgraduate course. By investigating the perceptions, the beliefs and the attitude of students towards e-Learning platforms and Web-based courses, useful deductions can be drawn for future implementations.

The rest of the paper is organized as follows: The first section provides a description of the methods, emphasizing on the theoretical framework used and the formulated hypotheses. The second section presents the results obtained along with their interpretation. The last section highlights key findings, providing a discussion on limitations and future work in the current field.

Materials and Methods

Theoretical framework and hypotheses

In order to assess the potential adaptability of e-Learning platforms within the postgraduate curricula, an adaptation of the Technology Acceptance Model (TAM) [1] was performed. TAM defines a set of dimensions under investigation along with a set of causal relationships amongst them. In particular, perceived usefulness interacts and affects attitude towards using a technology and behavioral intention, perceived ease of use affects attitude towards use and perceived usefulness whereas attitude towards use affects behavioral intention [1]. A variety of research works in the literature adopt TAM, in its original form or with proposed extensions in conjunction with other theoretical models or by introducing new dimensions under investigation, in order to conduct empirical studies. Such research works span into a plethora of disciplines [2-11], including healthcare [12-15].

In the context of the original TAM, a specific set of hypotheses, based on the theoretical relationships, were formulated. In particular, perceived ease of use (coded as PEOU) positively affects perceived usefulness (coded as PU) (H1+), perceived ease of use positively affects attitude towards Use (coded as ATT) (H2+), perceived usefulness positively affects attitude towards Use (H3+), perceived usefulness positively affects behavioral Intention (coded as BI) (H4+) and attitude towards use positively affects behavioral intention (H5+) [1, 6,10]. The notion of behavioral intention, in the context of the current study, attempts to measure the attitudes and intentions of the participants with regards to the potential use of e-Learning initiatives as part of the learning process at their studies.

Procedure and measures

The Faculty of Nursing at the University of Athens, either independently or through joint University initiatives, offers a broad range of MSc courses, varying from traditional nursing specializations to Health Informatics/Management and Crisis Management. The current study was initiated and focused only to the MSc specialization in Health Informatics-Health Management [16] and then extended in order to gather perceptions and beliefs from past and present MSc students from the whole range of MSc courses offered. Preliminary

results of the current initiative can be found at [16]. The adoption of TAM involved the creation of a questionnaire. Measures from previous research works were chosen, in order to utilize as much standardized metrics as possible (Table 1).

Table 1 - Constructs, measures and relative sources

Dimension	Questions	Source
PEOU	I find that online courses are very easy to use	[14]
	I find that interacting with online courses' doesn't demand much care or attention	
PU	Using e-learning would enhance my effectiveness in learning	[10]
	Using e-learning would improve my course performance	
	Using e-learning would increase my productivity in my course work	
ATT	The idea of using ILM is: (very bad _ very good)	[8]
	The idea of using ILM is: (very foolish _ very wise)	
	Using ILM would be: (very unpleasant _ very pleasant)	
	Using ILM is an idea: (dislike very much _ like very much)	
BI	If I get to use online courses, I intend to use the online courses	[14]
	If I get to use online courses, I expect that I will use online courses	

The questionnaire followed a seven-Likert scale of answering, varying from "strongly disagree" to "strongly agree". All questions were translated from English to Greek accordingly and migrated into a Web based environment, through Limesurvey [17]. Participants were asked to access the web survey through a Uniform Resource Locator (URL). Participation was anonymous and no data that could be correlated with any of the participants was used.

Data analysis was based on structural equation model, specifically partial least squares. Such an approach is well-established at the literature and can be found in a variety of empirical studies adopting TAM or other theoretical frameworks [18-20]. Regarding the software package, SmartPLS M3 v2 was used [21].

Results

Based on the current students enrolled to a variety of MSc specializations, a sample of fifty six (56) postgraduate participants responded at the current study, aiming to submit their intention to use Web based courses. Demographics data is outlined at Table 2.

Table 2 - Generated demographics data

Frequency		Percent (%)	Frequency		Percent (%)
Gender			**Postgraduate Program**		
Male	25	44.6	Health Informatics	23	41.1
Female	31	55.4	Health Management	20	35.7
			Clinical specializations	13	23.3
Age					
20-25	33	58,9	**Previous Experience**		
26-30	15	26,8	Yes	22	39.3
31-35	3	5,4	No	34	60.7
36-40	5	8,9			

Partial Least Squares analysis involved the assessment of the measurement and the structural model [18-20,22,23]. In terms of the measurement model, individual item loadings, internal consistency, convergent validity and discriminant validity were investigated [18-20,22]. All values for individual items loadings were considered reliable (exceeded 0.7) [18-20]. With regards to internal consistency, Cronbach's alpha and Composite Reliability produced values greater than 0.7 and 0.8 respectively [18-20] whereas convergent validity values exceeded the threshold value of 0.5 [24] for reliable results (Table 3). At last, discriminant validity was assessed based on the square root rule of the Average Variance Extracted (AVE) [24]. All constructs produced reliable results (Table 4).

Table 3 - Internal consistency and convergent validity results

	Cronbach's Alpha	Composite Reliability	AVE
ATT	0.8455	0.8969	0.6869
BI	0.7676	0.8937	0.8081
PEOU	0.7171	0.8691	0.7695
PU	0.8684	0.9189	0.7917

Table 4 –Discriminant validity results

	ATT	BI	PEOU	PU
ATT	**0.8287**	0	0	0
BI	0.6907	**0.8989**	0	0
PEOU	0.579	0.5109	**0.8772**	0
PU	0.6799	0.5984	0.3846	**0.8897**

Subsequently, the structural model was observed (Fig. 1). A bootstrapping technique was applied (500 resamples) [18-20, 22] with three statistically significant levels ($p<0.05$*, $p<0.01$** and $p<0.001$***), based on a two-tail test [18]. At Fig. 1, insignificant hypotheses are represented with dotted lines.

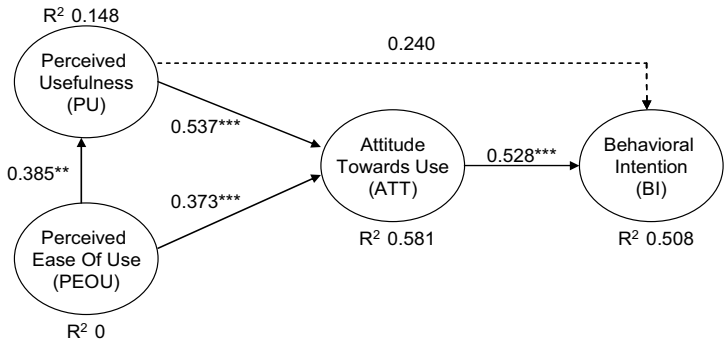

Figure 1 - Structural Model

Discussion

The findings of the structural model highlight the very strong effect of perceived usefulness (β=0.537, $p<0.001$) and perceived ease of use (β=0.373, $p<0.001$) to attitude toward using e-Learning platforms. Furthermore, attitude towards use is a very strong predictor of behavioral intention (β=0.528, $p<0.001$). Moreover, perceived ease of use proved to have a strong effect on perceived usefulness (β=0.385, $p<0.01$). The only hypothesis that was not confirmed is related with the effect of perceived usefulness to behavioral intention; this could be explained by the fact that the majority of the sample had no previous experience on e-Learning and clearly they could not assess pragmatically the usefulness, and consequently the behavioral intention to use such initiatives.

A comparison with the early stage of this research highlights several similarities and differentiations. Initially, most of the relationships were confirmed, with the exception of perceived ease of use in relation to perceived usefulness and perceived usefulness in relation with behavioral intention [16]. The outcomes of the current study strengthen the relationship of perceived ease of use with usefulness, leaving intact, however, the effect of usefulness to behavioral intention. At this point it should be noted that preliminary research was conducted with a limited sample of twenty (20) people. The enrichment of the sample from a diversity of MSc degree cycles reinforced the reliability of the overall model and its respective dimensions. Such an observation assists in producing more reliable results.

Conclusion

The current work attempted to focus on the empirical acceptance of e-learning initiatives from postgraduate healthcare students. In the basis of the Technology Acceptance Model (TAM) [1] adaptation, several dimensions and causal relationships were assessed and presented. Despite the known limitations, a positive proclivity towards the encapsulation of e-Learning initiatives within the learning lifecycle of postgraduate studies curricula was observed.

The current study possesses a series of limitations, mostly related with the hypothetical nature of the investigation. The assessment is not directly related with an actual e-Learning implementation or a specific class module. It attempts to examine the potential applicability of e-Learning platforms, towards the modernization of lecturing and class practices. Having this as a fact, participants may over or under estimated specific measures throughout the survey process. However, despite the known limitations, the current work aims to shed light and further exploit the adaptability of e-Learning initiatives within healthcare education.

The aforementioned limitations underline the framework for future research in the current field. In particular, a further enrichment of the sample and the assessment of specialized stakeholder groups may be applied as part of future research. In addition, an investigation of moderating factors such as gender or age, as proposed by Venkatesh et al. [25] that could potentially affect the intention to use e-Learning initiatives may also be conducted. Overall, the produced findings of the current work assist in identifying the attitude of students towards learning through technology. Consequently, the results obtained from 'pre-adoption' studies of this kind, may act as a valuable input towards the design and implementation of future plans for incorporating e-Learning initiatives within University educational curricula.

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Earnings in E-learning: Knowledge, CME credits or both? Hints from Analysis of Attendance Dynamics and Users' Behaviour

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Abstract

Many papers report and convey positive opinion about the use of e-learning in the healthcare sector. The issue is how to exploit at best such a powerful instrument. Starting from data regarding the usage of a CME e-learning course, attendance dynamics and users' behaviour have been inspected with the aim of getting some hints about how to improve the development and the delivery of e-learning courses for CME, and to promote knowledge acquisition at best. The different paths followed by 7811 users have been modeled, from enrolment to conclusion/drop-out, then the behaviour in terms of effort, elapsed time, achieved result have been analyzed. The obtained results point out: good acceptance (retention rate 83%) of a not basic educational model and effectiveness (success rate 79%). At the same time the inspection of behaviour has shown that there is a good margin of possible improvement in terms of knowledge acquisition. Conclusions provide a list of issues to keep in mind during system development, in order to provide CME e-learning meeting both credit and knowledge acquisition goals.

Keywords:

E-learning, CME, Attendance, Users behaviour.

Introduction

Many papers report and convey positive opinion about the use of e-learning in the healthcare sector. Quoting one for all [1], "E-learning represents a quantum leap forward in the education of healthcare staff. It has the potential to...provide a flexible, adaptable and highly accessible route to learning, which delivers a myriad of benefits for staff, hospital management and ultimately the patient". The issue is how to exploit such a powerful instrument at best, to let potential benefits become everyday reality.

As regards Italy, under-graduate distance education has gained ground, but e-learning for CME has been moving only short steps for years, despite of the common positive opinion of the potential users. This fact is due to two main reasons. First, problems related to the accreditation of e-learning courses within the not problem-proof co-existence of national and regional CME credit systems; for this reason the offer is limited. Second, the lack of consensus about the term "e-learning", often confused with simple delivery of documents and questions through the internet. This basic modality limits the evaluation of the learning experience and probably also the effectiveness of the intervention.

Within an experimental project funded by the Italian Ministry of Health, an e-learning system for CME has been developed for free of charge usage on the internet (http://fad.cbim.it). As described in the following section, the educational model proposed to users is not the basic one already experimented by Italian healthcare professionals.

International literature is quite rich of studies inspecting the attitude of users, and nurses in particular, to e-learning [2], but, as far as in our knowledge, lacks papers dealing with the behaviour of students attending e-learning CME courses and the relative dynamics. This information could be useful when starting developing a new system, in order to take advantage from previous experiences, and to limit, if not avoid, already faced problems and mistakes.

Thanks to the availability of a quite large amount of data regarding the usage of e-learning courses for Italian health professionals, an heuristic study of what works, what goes wrong, what can be improved has been carried out. Among all the available courses, a course about patients' handling (PHC) in hospital environment has been considered for the study presented here. The choice was motivated by a quite large number of enrolments and the fact that it addresses a large population of users (nurses and physiotherapists) for which the course is accredited by the CME system.

Aim of the present paper is hence to understand the dynamics underlying the usage of the system, and in particular:

- Users' flow from enrollment to conclusion/drop-out
- Students' behaviour and preferences in attending the course and achieving the final goal

in order to get some hints to improve the development and delivery of e-learning courses for CME, to verify the applicability of the educational model chosen, and find the best way to promote knowledge acquisition.

Materials and Methods

The patient handling course

PHC deals with: basic knowledge relative to musculoskeletal disorders, specifically linked to biomechanical load during lifting actions and flexed postures; Risk factors and the characteristics of spaces, patients, devices, furniture, and work organization which affect the way the operator works, and the ergonomics of movements; Proper use of different types of devices (ceiling and active lifter, low friction and assistive devices, bariatric solutions, ...) which concur to risk reduction and patient safety enhancement.

The educational model is based on:

- An initial test (IT) (one attempt allowed), mandatory to access the learning modules;
- Self-learning structured modules for free navigation (including PDF printable versions);
- Case-study exercises/test (CST) (4 attempts allowed, minimum score to pass the test: 75%), particularly effective [3] in order to reinforce the learning process;
- A final test (FT) (4 attempts allowed, minimum score to pass the test: 75%) for the evaluation of the results of the learning process in comparison with the IT;
- A satisfaction questionnaire that evaluates the subjective perception of the users.

PHC is expected to be concluded in five hours, tests included. To stand the course both CST and FT must be positively concluded.

Evaluation methods

All the enrollments to PHC in the span of time of 20 months have been retrieved and exported from Moodle database, and have been catalogued in terms of:

- Characteristics of the student: age, sex, profession
- Characteristics of the event: date of enrollment, IT result, CST result and number of attempts, FT result and number of attempts, date of course conclusion, final outcome (passed /not passed).

To identify and describe users' flow from enrollment to conclusion/drop-out, a Markov-like model has been used, taking into consideration time variance, due to the existence of the drop-out event.

Drop-out was defined according to the rule "course not concluded .AND. (end of the inspecting period – date of enrollment) > 30 days". This choice was necessary to avoid declaring as drop-out those students that have enrolled in the month just preceding the final date of inspection, and that maybe could have concluded the course subsequently.

To analyze users' behaviour and preferences regarding the way of achieving the goal, number of attempts to pass the tests and time used to conclude the course have been calculated. At this last purpose, the difference between date of conclusion and date of enrollment has been used; it refers to elapsed time, not to continuous learning activity.

Results

Users' flow model

Figure 1 provides a schema of the paths followed by users to conclude the course or abandon it. Basic actions have been used to describe the steps of the process such as: enrollment, IT execution, first and second test execution with results. In the graph circles represent actions and squares represent reached conditions (success, failure, drop-out). Branches represent the flow extent, expressed as number of users.

During the observed period, 7811 users have enrolled in PHC, but 5.2% of them dropped-out (*immediate drop out*) even before having performed the initial test (IT).

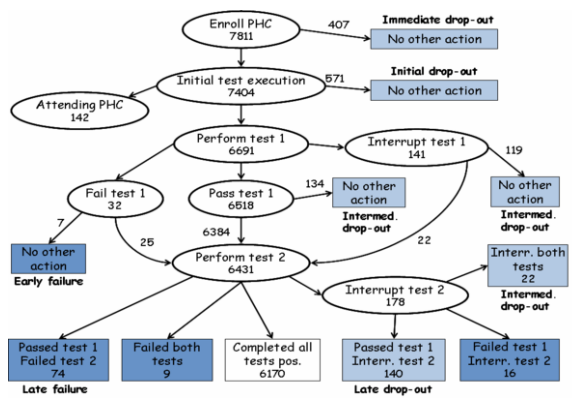

Figure 1 - Schema of the paths followed by the users

7404 users have regularly executed the IT, and hence they have got the possibility to view the contents and potentially attend PHC in an active way. This sample (mean age 40.6, range 21 – 58) is composed mainly by female (5513/ 7404, 74.5%). As regards professions, nurses (N) represent 80.0% (5922/7404), therapists (T) 13.6% (1008/7404), and the remaining 6.4% (474/7404) belong to other healthcare professions for which the course is not accredited.

At the time of the present analysis, 142 users were still attending PHC, so they were excluded. A second quite large drop-out event (*initial drop-out*, 571/7404, 7.71%) occurred before performing at least CST or FT. The sample of people actively involved into PHC attendance is hence composed by 6691 users, representing 85.66% (6691/7811) of the enrollments.

In the graph, "test 1" indicates one of the two tests without distinction between CST and FT. In case a student had performed two tests, priority has been given to the one success-

fully finished, or, in case of a combination failure/interruption, to the failed test.

The very great majority of students has stood one test (6518/6691, 97.41%). Only 1.8% has interrupted the test and has not undertaken any other action, reaching the condition of *intermediate drop-out*. The same condition is reached by those students (134/6691, 2%) who stopped attending, even in presence of a positive result, and by the users who have interrupted both the tests (22).

Considering the few cases of first test failed, 7 out of those 32 students abandoned the course definitively, reaching the condition of *early failure,* while some others (25) decided to perform the second test, even if they knew that they would have never been considered as eligible to get any credits.

The second test was performed by 6431 students representing 86.9% (6431/7404) of the population that actively attended the course and 82.33% of total enrollments. The group is composed both by many of those users who have stood the first test, and by some students who have already failed or interrupted the first test. Combining the results of both tests, the graph shows the ending points of the different paths. Success condition is reached by 6170 users representing 92.2% (6170/6691) of the active users. The second largest group is the drop-out group: overall the drop-out rate is 17.8% of all the enrollments, and *intermediate + late drop-out* represents 6.2% of the active users. 106 students didn't pass the tests of the course, but 70% of them belong to the status *late failure* since they have positively concluded one test. Table 1 represents the summary of the final conditions.

Drop-out

Looking at the users that have dropped-out, few issues can be analyzed but hypothesis are possible or reasonable. For *Immediate drop-out*, belonging to a not accredited professional category is not relevant. Only 51 out of 407 users could have dropped out for this reason. A further hypothesis is that the educational model with a mandatory IT, double typology of tests, and a limited number of attempts is not well accepted by users. In this case the educational model is not appreciated by a small number of people (4.7% of all the enrollments).

Initial drop-out: Out of the 571 users, only 42 belong to professions different from nurse or physiotherapist, similarly to what happens for immediate drop-out. Maybe the message sent to the user as evaluation of IT result has discouraged the student to go on. For IT results lower than 70, the message is "you do need to attend PHC …". This was the message received by 434 out of the 571 users that have abandoned just after the IT. But, as it will be pointed out in the next session, the same message was sent to at least other 1443 students, who have anyway concluded the course achieving positive results. Personal characteristics play anyway an important role in people behaviour.

Students' behaviour

The very great majority of the courses have been concluded (6276/7404, 84.8 %).

For positively concluded and failed courses, Table 2 shows a summary of students' characteristics and learning process indicators. Outcome in terms of knowledge acquisition can be evaluated through the mean values of test results. In particular Table 2 reports data grouped according to the different professions. Group "other" represents the users who have no right to get credits. The number of days used to conclude the course is calculated as difference between date of conclusion and day of enrollment, and if they occur in the same date, 0.5 day has been considered.

Table 1 – Summary of the final conditions

	% out of 7811 enrolments
Immediate drop-out	5.2
Initial drop-out	7.3
Intermediate drop-out	3.5
Late drop-out	1.8
Success	79.0
Failure	1.4
Total	98.2
Attendance still going on	1.8

The mean value of FT results for successful students points out that there has been a pretty good gain in terms of acquired knowledge. Similar comment can be done for students who didn't pass the course. CST and FT success rate are 23% and 51%, hence case-based tests seem to be more difficult. Anyway, the number of people (82) who failed CST is very small, in comparison with the number of successful students.

Table 2 - Summary of students characteristics and learning process indicators

		#	Mean elapsed time	Median elapsed time	Mean IT result	CST mean result (%)	CST mean # attempts	FT mean result (%)	FT mean # attempts
Course passed	N	4901	7.3	1	62.74	94.16	1.42	92.7	1.24
	T	897	10.3	2	71.39	93.8	1.48	93.7	1.21
	Other	372	9.19	0.5	65.71	93.10	1.53	93.5	1.29
Course not passed	N	82	8.15	1	48.39	70.6	3.7	68.10	2.54
	T	14	9.04	1	49.0	77.36	3.4	55.15	2.7
	Other	10	2.6	0.5	46.39	65.00	4.0	65.40	2.9

Table 3 - Percentages of users that have concluded PHC for number of performed attempts and elapsed times (days). Users are divided into 3 groups: success with high IT (SH), success with low IT (SL) and failure (F).

days	S H	S L	F	S H	S L	F	S H	S L	F	S H	S L	F	S H	S L	F	S H	S L	F	S H	S L	F	S H	S L	F
>3	16.3	11.9		7 . 4	5 . 3		4 . 2	3 . 6	3 . 8	2 . 5	2 . 1	11.3	0 . 9	1 . 7	8 . 5	0 . 2	0 . 7	6 . 6	0 . 3	0 . 3	8 . 5	31.8	25.7	36.7
3	2 . 4	1 . 7		1 . 2	0 . 6		0 . 3	0 . 6	0 . 0	0 . 3	0 . 3	2 . 8	0 . 1	0 . 3	0 . 0	0 . 0	0 . 0	0 . 0	0 . 0	0.0*	0 . 0	4 . 3	3 . 5	2 . 8
2	3 . 8	3 . 3		1 . 2	1 . 5		0 . 8	0 . 8	0 . 0	0 . 3	0 . 3	0 . 9	0 . 2	0 . 3	0 . 9	0.0*	0.0*	0 . 9	0 . 0	0 . 1	0 . 0	6 . 4	6 . 4	2 . 8
1	7 . 4	7 . 0		2 . 7	1 . 9		1 . 1	1 . 1	0 . 9	0 . 4	0 . 7	4 . 7	0 . 5	0 . 8	3 . 8	0.0*	0.0*	1 . 9	0.0*	0 . 3	3 . 8	12.2	11.8	15.1
0	33.6	42.0		7	5 . 5		2 . 8	2 . 8	1 . 9	1 . 4	0 . 9	17.0	0 . 5	1 . 0	5 . 7	0 . 1	0 . 3	6 . 5	0 . 3	0.0*	9 . 4	45.7	52.6	40.6
	2 attempts			3 attempts			4 attempts			5 attempts			6 attempts			7 attempts			8 attempts			total		

** values < 0.05.*

Behaviour in terms of elapsed time and attempts

The relationship among result of the course (passed, failed), effort (as number of attempts) and elapsed time has been analyzed. In order to understand the influence of pre-course knowledge on users' behaviour, the sample of successful students has been split according to the result of the IT (<50, >=50).

Table 3 shows the distribution of cases along the dimensions *number of attempts* and *elapsed time* for the three groups: success with low (SL) IT (1443), success with high (SH) IT (4727), failure (F) (106). A large number (2194) of successful students have completed the study of the learning objects and have performed both the tests in just one attempt each, on the same day of enrolment.

SL group, expected to need more time and effort to positively conclude the course, has the greatest level of task orientation: 42% performed 2 attempts with 0 day of elapsed time. From this point of view SH and SL show a statistically significantly different behaviour.

As regards F group, 41 out of 106 students have believed their learning activity sufficient, and have then used all the chances they had to stand tests in an elapsed time of 0 day. Among these students, 12 belong to the late failure category, having stood 1 test and missed the opportunity to pass the course.

Time flexibility offered by e-learning and the multiplicity of available attempts should have induced F users to study again in order to achieve the goal of standing the course. These opportunities have not been used by those people who could have needed them more.

Independently from the number of attempts and from the final result, most of users finalizes their activity not later than the day after enrolment: 57.9%, 64.4% and 55.7% respectively for SH, SL, F.

About 30% of the students in all groups have an elapsed time greater than 3 days. Most of them have probably started attending, then interrupted to restart and perform the tests only after a certain span of time. The range of the elapsed times is very wide (0-267 days), as the differences between median and mean duration in Table 2 show. The minimum mean value is 7. Elapsed time of 7 days has been hence chosen to distinguish between students who have been attending PHC for a quite long time, from those who have initially enrolled but have attended the course only "lately". Using this distinction, in Table 3 the total percentage (36.7%) of students that failed with an elapsed time greater than 3 can be split into long lasting attendance (9.3%) and late attendance (27.4%). For successful students, the percentage of long lasting attendance is higher. Considering for example in 2 attempts completion for SH and SL globally considered, 247 students out of 942 (26.2 %) behaved according to the definition of long lasting attendance.

It can be hence concluded that, in any case, there is a common attitude to finalize the course in a short span of time.

Behaviour in terms of achieved results

For the successful users, the previously reported results raise a question: have the users, who passed the course with few attempts, achieved the best possible results?

Taking into account the final score of the course, that is the sum of the best results of CST and FT (range 150 – 200), Figure 2 shows the mean final score values versus the number of attempts still available. Since the number of allowed attempts is 8, "6 remaining attempts", for example, means that the user has stopped performing both tests after the first attempt, having reached a sufficient result to pass the course. For each value of remaining attempts, the mean final score values are quite far from the maximum value (200). This fact points out that, once reached the condition for getting credits, the majority of users didn't exploit the possibility offered by the system to understand where they have done mistakes and hence to go back to the modules and further improve their knowledge.

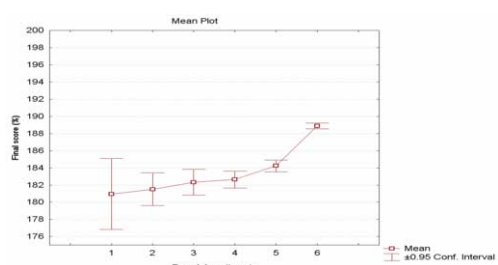

Figure 2 - mean final scores values versus the number of attempts still available

Discussion and conclusions

Attendance dynamic and students' behaviour, when applied to e-learning courses, should approach various processes related to the learning activity. In the present study only the basic actions have been inspected such as tests' completion, without taking into account, for example, how students have exploited the resources in terms of contents, and if they have preferred navigation to the usage of the printable version of the course. This issue will be addressed in a next study.

As regards the dynamics followed by the users, the reported results show that PHC has been attended, step by step, by a large number of users, until they have reached their goal.

For distance learning, literature [4] reports high drop-out rate. Moreover attrition plus limited informatics literacy and attitude are often mentioned as the most frequent causes for drop-out. In the present study retention rate is pretty high (83%), and probably it could have been even higher in case PHC had not been free of charge. The initial choice of developing giving priority to technological simplicity and usability [5] of the e-learning system has probably paid out. Some other causes for drop out have been analyzed [6].

The large number of attendees and the high success rate support the applicability and acceptability of the educational model with the constraints that have been used. Inducing a responsible learning approach, it should be more effective than the one with no limit to the number of attempts, commonly used in Italy.

Not only nurses and physiotherapists have attended the course, but also 474 health professionals for whom PHC doesn't provide credits. 80.6% of these users have completed the course. This fact points out that CME e-learning courses are appreciated and requested, but also that maybe people don't read carefully the instructions when on the internet. This last same hint comes also from the messages sent to the tutor. For the behaviour parameters that have been analyzed, there are no comparable results in the literature, as far as in our knowledge. The attitude to finalize the course in a short span of time is, in some way, in contrast with the valuable manage-your-time approach typical of e-learning. In particular, since PHC was expected to take up around five hours overall, the student, who have finalized it with elapsed time of 0 days, must have done it fairly quickly. The result of passing the course is often achieved, but not with the best possible outcome in term of knowledge acquisition. A way to promote and incentive better quality of results thanks to the flexibility of e-learning should be put in practice.

For this last purpose, but not only, the presence of a figure with role of mentor could be very useful. When dealing with e-learning systems available on the internet, the number of enrolments can be very large and mentoring very resource consuming. A sort of automatic mail delivery system with scheduled controls and planned remainder and encouragement messages could represent a good feasible solution.

We are aware that conclusions are based on heuristics and direct experience only. Anyway, we dare to give a list of advices to keep in mind, in order to help developing e-learning systems that could be useful tools to provide knowledge improvement and not only machines to collect CME credits.

- Robustness of the educational model doesn't imply reduced attendance
- Give priority to technological simplicity and usability
- Feedback messages should be designed considering different possible reactions
- State clearly and in a very visible way the rules and basic information. Redundancy is boring, but disappointment is even worse
- Develop courses that take up a limited numbers of hours (five hours are probably too much)
- Look for incentives to achieve the best results in term of knowledge acquisition, to prevent to go just for the credits
- Plan an affordable system to provide mentoring.

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Multidisciplinary Education in Medical Informatics – A course for medical and informatics students

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Abstract

Design and implementation of healthcare information systems affect both computer scientists and health care professionals. In this paper we present our approach to integrate the management of information systems in the education of healthcare professionals and computer scientists alike. We designed a multidisciplinary course for medical and informatics students to provide them with practical experience concerning the design and implementation of medical information systems. This course was implemented in the curriculum of the University of Münster in 2009. The key element is a case study that is performed by small teams of medical and informatics students. A practical course on management of information systems can be useful for medical students who want to enhance their knowledge in information systems as well as for informatics students with particular interests in medicine.

Keywords:
Medical informatics, Health informatics, Education, Management information systems.

Introduction

Information technology has a strong impact on public health and medical information systems play a fundamental role in the everyday life of many health professionals. Physicians spend about 25 % of their daily clinical work on documentation tasks which become more and more supported by information systems [1]. The use of the Electronic Patient Record (EPR) is increasing and has the potential to improve the quality of care [2].

Therefore health care professionals and computer specialists need knowledge about the management of health care information systems [3]. Already in the year 2000 the International Medical Informatics Association (IMIA) published recommendations on education in Health and Medical Informatics emphasizing on the management of information systems [4].

In the current curriculum for medical students in Münster there is only one compulsory subject in the domain of medical informatics including the main topics of hospital information systems, electronic patient records, information acquisition as well as classification and coding systems. At least in Germany, education concerning the management of information systems is not mandatory for medical students. On the other hand, due to the lifecycle of medical IT systems healthcare professionals are confronted with specification and implementation of information systems.

Haux et al. described programs for medical informatics students as well as for health information management students with a focus on system analysis and project management [3]. This training might be useful for healthcare professionals too. For example to conduct realistic case studies regarding the design and implementation of information systems the expertise both from medicine and computer science is beneficial.

Healthcare professionals, in particular physicians, need skills and knowledge regarding information systems, not only as end-users, but also regarding requirement specification and evaluation. On the other hand, computer scientists need to understand processes in hospitals, medical documentation and physicians' workflows in order to design and implement adequate systems.

Former course evaluations by medical students showed that the teaching in subjects like medical informatics can be improved through practical oriented inputs [5, 6]. It also became evident that the need for health informatics training is increasing [7]. Therefore, our main objective was to design a multidisciplinary course with practical training for medical and informatics students. This course should be integrated in the current curriculum of both medicine and informatics.

Materials and Methods

The design of the new course concept is mainly influenced by three factors:
At first it is based on the standard evaluation of an existing course in informatics for medical students. We reviewed the evaluation of this course from winter term 2007/2008 to summer term 2009.

Secondly we used experiences from a pilot course on management of medical information systems which was introduced in the last year.

Thirdly we analyzed literature concerning medical informatics education with a focus on multidisciplinary courses.

Results

Evaluation of the current course in medical informatics

In the respective terms more than 400 medical students attended the course and evaluated education in medical informatics on a scale from 0 (very good) to 100 (very bad). Table 1 shows the results. The average score is between 38.9 and 56.3 while the median ranges from 32.0 to 53.5.

Table 1 – Evaluation of the course in medical informatics

Term	n	Avg	Mdn	Std Dev	Min	Max
2007/2008	129	39.5	34.0	25.4	2	99
2008	108	56.3	53.5	25.2	4	100
2008/2009	107	41.8	38.0	26.5	3	98
2009	113	38.9	32.0	26.1	1	100

Evaluation of the course in medical informatics from winter term 2007/2008 to summer term 2009 on a scale from 0 (very good) to 100 (very bad). n = Number of students, Avg = Average score, Med = Median score, StdDev = Standard deviation, Min = Minimum, Max = Maximum.

We also assessed the free text comments to explain the big range in the students' evaluations. On the one hand, students evaluated the course as "*one of the most important courses for the working life*" and "*good to gain insight into hospital information systems*", but on the other hand they missed the "*practical relevance*" and evaluated it as being "*abstract without practical examples*".

Therefore we decided to focus on practical tasks in the new course.

Experiences from a pilot course

In the summer term 2009 we conducted a pilot course for the management of information systems for medical students. We combined lectures with a practical part based on a case study.
In the case study the students have to analyze an existing tumor documentation process that should be described and modeled in order to specify requirements for a new system.
In the free text evaluation at the end of the course the students stated that the "*course was good, because it followed a central theme*" and that it was "*informative to work in small groups*".

Due to this positive feedback we decided that a case study should be a central part of our new course concept.

Literature analysis

In the literature regarding medical informatics education we identified a trend towards multidisciplinarity. The Committee on Interdisciplinary Research (IDR) of the National Academy of Science, the National Academy of Engineering and the Institute of Medicine analyzed "problems whose solutions are beyond the scope of a single discipline" [8]. The IDR provided also recommendations for students and postulated that "students should seek out interdisciplinary experiences […] that address societal problems and research experiences that span more than one traditional discipline" [8].
In 2008 van Bemmel added that this interdisciplinarity begins in the classroom [9]. Current research in medical informatics shows that interdisciplinarity should be a considerable part in medical education [10]. Also in the domain of clinical research informatics there is a strong need for cross-discipline education [11].

Regarding the practical relevance of such a course it is shown by Stang et al. that the use of examples which are close to reality helps students to understand the clinical relevance [12].

Besides the multidisciplinarity the concept of cooperative learning itself is an important aspect in teaching sciences and should therefore be utilized [13].

New concept for the multidisciplinary course

The main idea was to have mixed teams of informatics and medical students who work on realistic case studies and benefit from each other. Domain knowledge and IT skills should complement each other but also communication and collaboration should be fostered.

In addition to an existing curricular course for medical students the multidisciplinary course "Health Care Information Systems" was introduced for both medical and informatics students.

The course comprises lecture parts to introduce the theoretical background and practical parts in which students work on a case study with respect to an information systems project.

The main contents which will be described in the following are:

- Project management
- System analysis
- System selection
- System implementation
- Project conclusion

The course starts with a case study based on the following objective: "Hospital department X needs new software for their electronic cancer documentation".

The course design is shown in Figure 1. In the middle part the main contents of the course are listed. In each phase the tasks vary for informatics students (on the left) and medical students (on the right). Only the first and last tasks are the same. In the project management phase both groups have to create a project plan. In the system analysis phase medical students have to search for information about documentation needs and workflow which is then transferred into process models by informatics students. Medical students have to specify their requirements as prospective healthcare professionals during the system selection phase while the informatics students provide the functional specification. During system implementation informatics students should program and implement a system that can be evaluated by the potential users. Finally both groups complete the project report in the conclusion phase.

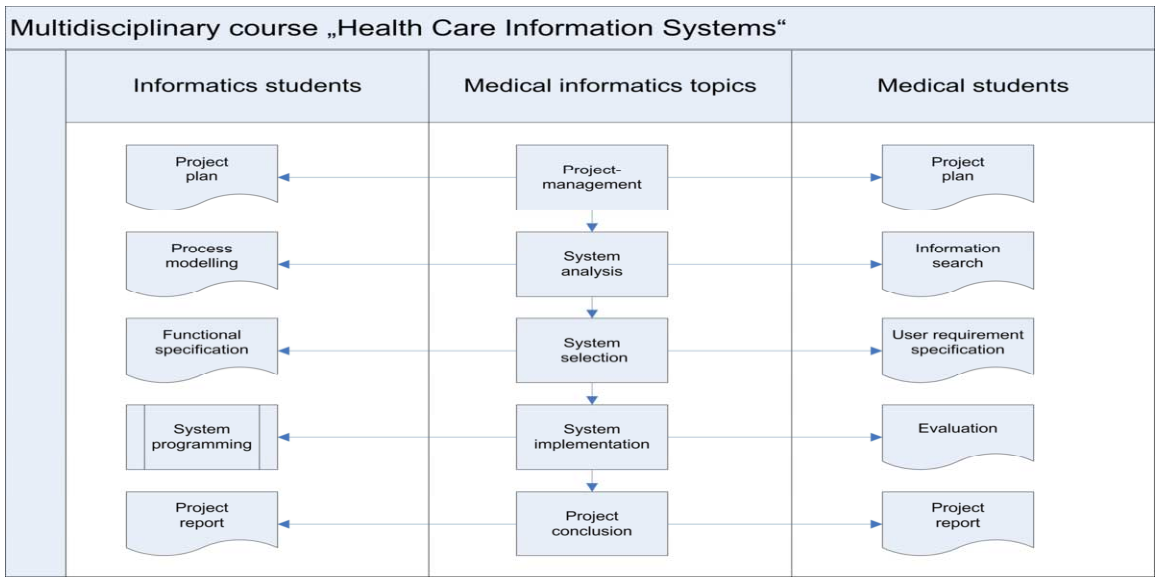

Figure 1-Multidisciplinary course contents.
The middle column shows the course contents. The external columns show the tasks of the informatics and medical students according to the single topics.

To avoid that poor contributions from one of the student groups affects the work of the other group we provided an individual feedback via Email, presented sample solutions according to the respective home-work and discussed the student solutions during classroom teaching.

Besides expert knowledge the students will also need to develop soft skills like communication abilities. Therefore the students work in small groups to enhance efficient conversation and teamwork. The course is integrated as an optional module in the curriculum of the medical students and as a compulsory elective module in the curriculum of the informatics students.

The course consists of 16 hours classroom teaching plus comprehensive project documentation and implementation tasks for the informatics students. In total there is a workload of 2 ETCS-Credits. The course is designed for 16 students per term (eight medical and eight informatics students).

Last term we started with 12 students (four medical and eight informatics students). A post course evaluation showed that the content and the integration of theory and practical tasks were in general good but there is still room for improvement. The overall rating was excellent.

Table 2 – Evaluation of the multidisciplinary course

	excellent	**good**	**fair**	**bad**
Course content	33 %	67 %	0 %	0 %
Integration of theory & praxis	33 %	59 %	8 %	0 %
Overall rating	87 %	17 %	0 %	0 %

Evaluation (in percent) of the multidisciplinary course from winter term 2009/2010 on a scale from 1 (excellent) to 4 (bad).

Discussion

With the course “Health Care Information Systems” informatics students gain insight into processes and documentation requirements of hospitals and can act as IT system providers while medical students learn about process description and modeling so that they can act as clients. Besides the domain knowledge students from both disciplines get experience in teamwork, presentations and communication which are important especially in cross-discipline projects. A critical aspect for establishing good communication is to create common theoretical foundations and a common terminology. The joined work on the case studies is designed to enhance communication between the two different domain groups.

Apart from the advantages for the students attending the course, also research in the domain of medical informatics will be fostered through the discussions between both domain

groups. As van Bemmel stated "interdisciplinary research can not be effective without interdisciplinary education" [9].
There are some discussions at what point in time in the curriculum a course in medical informatics should be placed and how such a course can be integrated in the education. Lungenau stated that after an introduction in the preclinical stage the problem-based-learning should be placed in the clinical part [13]. We agree with this and integrated the course as a compulsory elective module in the clinical stage to provide medical students with a possibility to extend their knowledge in medical informatics.

As a next step we plan to further extend the practical part by using videos - based on existing storyboards of clinical cases – in order to provide even more realistic clinical settings. Furthermore, we plan to complement the course by a seminar in which students can focus on specific topics from the course.

In addition further courses will be thoroughly evaluated by both student groups. Last year the University of Münster introduced the *Münster Audience Response System* (MARS) which is a system through that the students can use an electronic device to actively participate in lectures. We intend to use this technology to improve our multidisciplinary course.

Conclusion

Multidisciplinary education in healthcare information systems for medical and informatics students based on case studies is feasible and both disciplines can benefit from it.

Competing Interests

The authors declare that they have no competing interests.

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Training Software Developers for Electronic Medical Records in Rwanda

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Abstract

In many developing countries, electronic medical record (EMR) systems are being implemented in resource-poor settings. Essential to such implementations are software developers with a high technical capacity, a good understanding of medical informatics and an awareness of local clinical needs. This paper describes a training program which has been run in Rwanda to enable local computer science graduates to play a significant role in that country's forthcoming implementation of a national EMR system. Such a training program is unique in that region of Africa and we discuss the challenges inherent in such an undertaking. We describe the development of the curriculum and the evolution of the teaching methodologies over the course of the year and discuss its potential integration with academic institutions in Rwanda. Finally we propose that training programs of this nature which produce local software developers who are familiar with medical informatics are a requirement for successful and sustainable eHealth implementations in the developing world.

Keywords:

Rwanda, Education, Software, Electronic medical record

Introduction

In the last decade, electronic medical records have become increasingly central to healthcare in developed countries, and such systems are also now being used in many developing countries. This trend has increased markedly in recent years as large projects have been established to treat HIV, Multi-Drug Resistant Tuberculosis (MDR-TB) and Malaria. Funding for these projects, which comes from the Global Fund to Fight Aids, Tuberculosis and Malaria, the US PEPFAR program and others, has supported the development of a range of information systems in Africa, Latin America and the Caribbean. These systems range from spreadsheets and simple databases, to commercial software packages (which may be modified for the new purpose), to sophisticated, custom built software solutions. They are used for a wide variety of purposes from clinical care and telemedicine to reporting, supply chain, accounting and research.

There are many challenges to implementing such systems in resource-poor areas ranging from lack of stable electricity and communication systems to basic problems of heat, humidity and physical security. Additional to the hardware and software costs there are important human costs in terms of training of staff that will be using the system. However, training of local staff is normally limited to end-user training and does not include maintaining or extending the software itself. With the use of closed source propriety medical records software, this is usually not an option anyway. However, with the use of community developed open source software, it is not just an option but an important way of connecting developers with users, thus realizing the benefits of open source by enabling implementers to customize the software to their needs. Such training means that implementations are not dependent on ex-patriot software developers for all improvements and fixes, which improves sustainability and supports broader development goals.

Background

The OpenMRS project, which is co-lead by Partners in Health (PIH), the Regenstrief Institute in Indiana, USA and the South African Medical Research Council, is an open source initiative built by many collaborating groups around the world [1,2]. A key strength of this initiative is that the software is free and developed through the experience of a growing number of different parties, including many in resource-poor areas. To date, OpenMRS is implemented in at least 23 developing countries and is supporting the care of over 1 million patients, more than 150,000 of which are HIV/AIDS patients on antiretroviral treatment. An important aspect of OpenMRS, especially for a developing country, is its modular architecture. This allows developers to independently add their own functionality to the EMR without having to make changes to the main application. Developers in different countries can share and collaborate on such modules. For this reason, OpenMRS is more accurately an extensible platform rather than an application.

In 2006, the Rwandan Ministry of Health (MOH) decided to begin plans for a national roll-out of OpenMRS for the purpose of tracking patient medical information in all health centers and hospitals around Rwanda. The MOH requested that

PIH, who had already implemented the system in six health centers and one hospital in the country [3], provide expertise and support for the project. It also called on the Treatment and Research AIDS Center (TRAC), an institution within the Ministry of Health responsible for treatment and research related to infectious diseases including HIV, tuberculosis, and malaria, to lead the roll-out of such a system throughout the country. Since 2006, PIH has expanded its use of OpenMRS to 12 sites, and the Government of Rwanda has invested heavily in their telecommunications sector, to provide power and internet to hospitals and health centers around the country.

It was determined in 2007 that in order to support the large and ambitious endeavor of a national OpenMRS roll-out and to prepare Rwanda to sustain the system internally, many Rwandan software developers and IT staff would need a considerable amount of further training. Additionally there was the immediate need to fulfill additional functionality requirements that the government had identified for OpenMRS. The principle of Rwandans building and supporting such a national system is consistent with the government's plan to move to a predominantly knowledge-based economy by the year 2020, commonly referred to as "Vision 2020". Therefore, it was vital for Rwanda to build the necessary technical capacity to take ownership of its development agenda, and it was for these reasons that PIH developed the plan for a mentor-driven, software development training course.

Such a course may be unique in the developing world. There are several examples of less developed countries such as South Africa [5] and Brazil [6] where health informatics courses have been established for medical students and professionals. Currently the Government of Rwanda is working to establish a health informatics center of excellence which would provide access to such training in this region of Africa. It is a difficult task given the lack of academics with a suitable background and it will likely require the sharing of resources and curricula with other neighboring countries as proposed in [7]. This training course is however, quite different from those initiatives in that it aims to produce graduates capable of developing the system rather than using it. Despite extensive literature search in the biomedical (Pubmed) and computer science fields, no reports of similar courses were found.

A 3 month pilot training program was started in November 2007 in partnership with RDB-IT (Rwanda Development Board – Information Technology). This pilot consisted of one mentor and six students who were a mixture of recent computer science graduates and existing employees of RDB-IT. The course content consisted of web design, Java programming and some of the technologies used by OpenMRS, and culminated in the development of at least one module that was deployed and used at TRAC. The limited time of the course unfortunately meant that by the end of the course, most of the students were not able develop software for OpenMRS without significant supervision. However, the students did leave with a good understanding of the technologies involved from an implementation point-of-view. One of the students became the EMR manager at TRAC, and has now been tasked by the MOH with overseeing the OpenMRS rollout.

It was clear from this pilot that the level of experience with software development that most of the students had received at their universities was not sufficient to enable them to grasp the advanced programming skills required for developing a large enterprise level software platform such as OpenMRS with only a few months of additional training. This was finding was consistent with experience of other similar programs which considered the use of local software developers such as [4]. Thus plans were made for a more substantial training course which would have the resources and time to produce local software developers capable of independently contributing to the OpenMRS project. Based on the experiences of the pilot program it was decided that the course should:

- Be one year long to give sufficient time to cover all the necessary technologies.
- Have a thorough screening of applicants to ensure that only high quality students were recruited.
- Involve enough mentors to ensure all students received a practical "hands on" experience, with no more than 6 students per mentor.

In addition to these requirements for the actual training of students, it was important to develop a course which was relevant in the context of the government's plans for a national EMR, and adhered to a model that was sustainable and scalable. The following goals were decided:

- Create a cyclical course where some of the students become mentors in subsequent years.
- Develop a comprehensive curriculum which can be shared, peer-reviewed and refined by other institutions and organizations.
- Indentify health management needs within Rwanda, and develop and deploy customized OpenMRS software modules to meet those needs.
- Include teaching of core medical informatics principles and expose students to non-technical issues through site visits and other activities.
- Undertake an evaluation of the technical training program and the software tools developed to assess the effectiveness of the program.
- Document the experiences and lessons of the OpenMRS adaptation process and capacity building effort to provide policy guidance for the scaling up of the initiative beyond the pilot phase in Rwanda and for a wider application in Africa.

Methodology

Different training and academic course models were considered and it was decided that this training course should use the model of a sponsorship program where students receive salaries. This was important because in this initial year of the course, it would not be able to offer a qualification accredited by an academic institution, and so to attract strong candidates

there had to be a financial incentive. This model is also familiar to public institutions in Rwanda where employees are often sent on training courses whilst still receiving a salary. The employee is then contractually obliged to continue working for that public institution for a period of time proportional to the amount of training they received. Such a contract would be essential to meeting the goals of this course, as it would ensure that the training invested in the students benefit Rwanda's health sector. To facilitate such a model the students would be employed by RDB-IT and obliged to work for the MOH for 2 years after completing the course.

For practical reasons the course length was set at 11 months. The first 7 months were split into two teaching sections. The first would be 3 months long and used as a probation period, and thus an opportunity to drop any students who were not performing well enough. The final two months were set aside as a production stage to ensure that there would be sufficient time for students to develop software modules for OpenMRS.

Screening of candidates

One of short-comings of the pilot program was the lack of entrance qualifications of the students before they were accepted onto the course and so a screening exam was developed which would test the candidates':

- Understanding of basic IT concepts.
- Knowledge of the software development lifecycle.
- Ability to construct simple algorithms.
- Awareness of more advanced software development concepts such as object-oriented programming.

In October 2008, RDB-IT selected 40 computer science graduates from applications they had received, and facilitated them undertaking the screening exam. In addition to enabling the selection of the best students, the results also enabled the course mentors to begin creating a curriculum appropriate for the students' understanding of the relevant technologies. The results of the screening exam also showed that although students were generally familiar with theoretical IT concepts, most struggled to construct even basic algorithms. It was evident that students generally had little practical experience of software development, especially with modern object-oriented languages such as Java. From the 40 candidates who sat the screening exam, the top 19 were called for an oral interview. These interviews allowed mentors to examine non-technical criteria such as:

- Students interest in healthcare
- Communication skills
- Ability to mentor others

The final selection of 10 students was based on the combination of their screening exam scores (weighted at 70%) and oral interview scores (30%).

Development of the curriculum

The screening exam results showed that some topics which the students studied at university would have to be covered again in the new training course. So a curriculum was developed that would start with very little assumption about what the students already understand, and then throughout the teaching stages, introduce all of the core technologies required for OpenMRS development. Even where students were familiar with the topics, there would be a new emphasis on best practices. The curriculum was broken down into 8 units to ensure that all of the important topics would be covered (see Table 1), and each of these topics is described briefly in the following sections.

Table 1 – Course curriculum

Unit	Title	Weeks
1	Foundations	2
2	Basic Web Design	4
3	Basic Java Programming	5
4	Advanced Java Programming	7
5	OpenMRS Implementation	4
6	Enterprise Java Programming	6
7	OpenMRS Development	7
8	Medical Informatics	-

Foundations

This was a high level overview of many topics from IT and Medical Informatics. The intention of this short un-assessed unit was not so much to give the students an understanding of the topics, but rather

- To start building a common technical vocabulary for students and mentors. This proved to be very important given that *for most of the students, English was their third language*.
- To ensure that all of the students are familiar with the basic tasks of maintaining their computer, and using its software to make documents and presentations.
- To introduce the students to the broader ideas of eHealth and their role as software developers.

Basic web design

This was to build on the students' prior experience of HTML, introducing XHTML, CSS and JavaScript. It emphasized the importance of separating content from design and developing standards compliant web pages.

Basic Java programming

This was to give students a firm foundation in the Java language. It would cover all the syntax of the language, and introduced the students to object oriented concepts, with which many were not familiar.

Advanced Java programming

This covered more advanced topics in Java programming such as design patterns, multithreaded applications and unit testing.

OpenMRS implementation

A break from development in general, this unit covered OpenMRS from an implementer perspective. This included:

- Basic setup and maintenance of a Linux based server as well as how to manage the necessary server software such as Tomcat and MySQL.
- Infrastructure issues such as power and internet connectivity.
- Staffing and training issues.

Enterprise Java programming

This covered most of the Java Enterprise Edition (J2EE) technologies at the core of OpenMRS such as JSP, JSTL, MySQL and Hibernate.

OpenMRS development

This covered some J2EE technologies not covered in the previous unit (e.g. Spring), and teaches development of OpenMRS modules using the OpenMRS API.

Medical informatics

Unlike the other units of the course, this unit was taught throughout the year. The content was largely provided by guest lecturers, either in person, or through remote lectures using Skype. Topics covered included medical data and coding, EMR systems, decision support systems, pharmacy systems, evaluation of medical information systems. These were taught with a focus on developing country environments.

Course implementation

It was clear from the start that the course needed to emphasize practical experience over theoretical understanding. Each of the students was given a laptop for the duration of the course to ensure that they had an adequate machine for completing course exercises and projects (of the ten students, only a few had their own laptop). Typically each day, a mentor would give a lecture to introduce a new topic, and then set small exercises to reinforce the content of the lecture. At the end of each week, a project would be set which would involve many of the topics taught that week. Students were given a few hours each afternoon to work on these, and also expected to work on them at home.

Assessment

At the end of each unit (except the first), students were given a week long project which would incorporate many of the technologies from that unit. Most of these projects were related to eHealth, and included:

- An online health check website (Basic Web Design)
- A simple console based EMR (Basic Java Programming)
- A virtual OpenMRS server and deployment plan (OpenMRS Implementation)

Students were also given a written exam at the end of each module. Because students were encouraged to help each other with projects, the written exams were generally a more accurate indicator of an individual student's performance.

Module production

The last two months of the course were set aside for development of modules for OpenMRS sites in Rwanda. The EMR managers at TRAC (MOH) and Rwinkwavu hospital (PIH) were asked to compile a list of additional functionality they would like to have implemented at their sites. Course mentors then discussed these requests with some of the OpenMRS programmers, in order to determine which were the most suitable for implementation as modules by the students. A list of 5 potential modules was agreed upon, and then allocated to pairs of students, depending on the complexity and the students' ability (see Table 2). As much as possible these student projects were managed as real software projects. All are now in clinical use.

Table 2 – Modules developed by students

Name	Description
PMTCT	Registers mothers and their children on the Prevention of Mother To Child Transmission program
Patient Alerts	Alerts that notify clinicians of patient data indicating the need for immediate action
Drug Order Export	Allows drug order data and patient regimen histories to be exported
TRAC Data Quality	Produces lists of potential errors or omissions in data entered into the EMR
Data Entry Delay	Provides statistics about the time it takes for encounters between clinicians and patients to be entered into the EMR

Discussion

The curriculum described here and the teaching materials are all available online for other people to download[1]. It is hoped that this will lead to collaboration with other similar training programs around the world, and allow the materials to be peer reviewed and further developed by others. Much of the materials are not specific to OpenMRS and thus a suitable resource for any similar Java-based training course.

Teaching methodologies

One of the advantages of creating a new training course has been the freedom to explore different teaching methodologies, some of which would be difficult to incorporate into a traditional academic course. One method that was found to be particular effective and increasingly used as the course progressed, was asking stronger students to explain complex con-

[1] http://openmrs.org/wiki/EHSDI_Training_Course

cepts to the rest of the class in the language of their choice. This usually led to discussion amongst students - often involving those students who would be less inclined to ask a mentor for clarification. On other occasions all of the students would be assigned a different topic and required to give a presentation to the rest of the class. This had the added benefit of improving their presentation and communication skills.

Institutionalization

The creation of an independent training course was considered necessary in this first year, to satisfy the immediate need for local software developers capable of producing OpenMRS modules. Likewise the sponsorship model used was considered necessary to attract high quality students and to provide a mechanism for placing students in jobs with the MOH. However, moving forward it is important to explore ways of making the course more sustainable and scalable. We have already begun discussions with one of the universities in Rwanda about how this course could be integrated into their postgraduate programs. This presents a challenge because our emphasis on "hands on" mentoring is at odds with the requirements of most post-graduate academic courses. We would also need to reduce the overlap in topics covered by this course and the undergraduate computer science courses, perhaps by finding ways of assisting them in strengthening their courses. Even in an academic institution, it may be possible to maintain the sponsorship provision for some or all of the students. We must continue to partner with the MOH and other groups who are implementing OpenMRS in Rwanda, giving them the opportunity to invest in the training of their staff, and to ensure that the course continues to be relevant to their needs.

Collaborations

We believe that there is much that other organizations implementing eHealth solutions in the developing world can learn from this training course. First and foremost we hope that other organizations are encouraged to initiate similar programs, and can see that it is both possible and beneficial to train local software developers, rather than relying on ex-patriot staff. We are also keen to explore ways of collaborating with similar training programs that OpenMRS is involved in such as Google Summer of Code, which provides grants for students to spend several months working on an open source project and being mentored by a developer. It is hoped that this course will eventually integrate with the health informatics center of excellence that the Government of Rwanda is trying to develop with funding from IDRC and Rockefeller Foundation. It will link this developer training program with training in medical informatics for physicians, nurses and other clinical staff, data manager training, and also include research and evaluation. Another important collaboration linked to this course is the American Medical Informatics Association GPP program to create collaborative training programs in medical informatics in Africa (funded by the Gates Foundation).

Conclusion

This training course was created to provide high-quality Rwandan software developers with the necessary programming skills and grasp of medical informatics to contribute to the further development of OpenMRS in that country. The students developed OpenMRS modules which are being used at the TRAC and Rwinkwavu Hospital sites. They worked closely with the EMR managers from those sites, who were satisfied that the modules were of sufficiently high quality to be deployed on EMR servers. They graduated in October 2009, and in February 2010 the course was restarted with 12 new students. Clearly, it is difficult to objectively measure the success of the course without external assessment of the students, so it is intended that the students will sit exams for Sun certifications for J2EE development. We will also carry out a more detailed review of the modules in the near future.

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Strengthening Health Systems through training of Health Care Providers in the conduct of Routine Waiting Time and System Efficiency Surveys

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Abstract

The effective functioning of Health Systems is reliant on good quality information being available for decision-making. Routine surveys exemplify an under-utilised source of such information that could enable Health Departments to gain insights into the performance of health service provision, from both the stand-point of the providers and users. Amongst these, Waiting Time and System Efficiency Surveys (WTSES) directly responds to the commonest complaint of users of healthcare services. There is, however, little information on approaches to routinely implement robust and sustainable facility-based WTSES especially in resource-constrained settings. This paper describes the conceptual and methodological basis for implementing WTSES in health care facilities, using a method that places the conduct of the survey within the purview of the normal service activities of health care providers, and thus makes the routine assessment of Waiting Times possible at low cost and with high benefit. The authors aver that the universal implementation of the WTSES presents the potential for enriching patient and health facility information systems, particularly in resource-constrained settings, where efficient use of limited resources is critical.

Keywords:

Patient waiting times, Routine surveys, Health facility surveys

Introduction

The collection, processing, reporting and use of routine health information is ineluctable for the effective and efficient functioning of health delivery systems [1]. Routine health information systems (RHIS) are important to guide and improve decision making including *inter alia*, strategic planning and policy development, daily operational activities, and controlling resources such as finances and personnel [2]. It is for this reason that they are aptly described as *health management information systems*. Effective RHIS will also directly increase the staff and community's understanding of the functioning and outputs of the health delivery system; will help to identify problem areas and areas where health services need to be improved; will improve the motivation of staff by highlighting improvements where appropriate and advocate for changes to facilitate further improvements in the health service [2]. A number of health facility-based information systems such as public health surveillance, health system monitoring and mortality information systems exist, and to varying degrees have been successful in meeting some of the aforementioned potentials.

Routine large-scale surveys however, exemplify an under-utilized source of information that could enable Health Departments to gain insights into the performance of health service provision from both the stand-point of providers and users. Amongst these, the Waiting Time and System Efficiency Survey (WTSES) directly responds to the commonest complaint of users of health care services [3]. The WTSES primarily measures how long people wait for a service and the amount of service time they receive at health facilities. Importantly, in addition to identifying long waiting times, the survey identifies the reasons why these arose and suggests ways to reduce them. The survey also measures the workload of the staff, the efficiency of service provision and the percentage of time staff spend attending to patients. There is, however, little information on approaches to routinely implement robust and sustainable facility-based WTSESs especially in resource-constrained settings. This paper describes the conceptual and methodological basis for implementing WTSESs in health care facilities using a method which places the conduct of the survey within the purview of the normal service activities of health care providers and thus making routine assessment of Waiting Times possible at low cost and with high benefit.

Methods

The focus of the survey is to measure the time patients' spend at the health care facility for any service. This includes the amount of time that patients spend waiting for a service, and the time taken to provide the service. This requires that patients are tracked from their time of arrival at the health facility till the time they depart the health facility. The sample size required for a valid survey is typically quite large, so all patients seen at the facility in a time period (e.g. a session, a day, a week, or a month) are included in the sample. The more heterogeneous the services provided at the facility the longer the time period required and conversely the more homogenous the service the shorter the time period required. The starting point for the survey is therefore a decision on this time period. For

primary level care facilities where services rendered do not significantly change from day to day, an average day within an average week of the year should suffice. For secondary and tertiary level care facilities a longer time period is usually required in order to assess all services.

Data collection is done via a timesheet. As patients enter the health facility, they are handed a timesheet on which their arrival time is recorded. The patients are then asked some basic questions, such as their age, whether they have an appointment and how they travelled to the health facility. The timesheet has a list of every point or station in the facility at which the patient may receive a service (hereafter referred to as a "service point"). Each of the health workers (such as receptionist, doctor, pharmacist, nurse, etc) who attend to the patient on that day, then fill in the time they start seeing the patient and the time they finish seeing the patient, against their service point on the timesheets. When the patients leave the health facility, the departure time is recorded and they are asked questions about how long they are willing to wait at the health facility for the services which they had just received. See Figure 1.

The health workers also complete a personal timesheet. On their personal timesheet, they record the time that they commenced duty at the service points at which they worked and the time that they completed their duty at that service point. They may work in more than one service point through the day and are expected to document all of these on their timesheets. The health workers also fill in a short questionnaire on the amount of time that they think it is appropriate for patients to wait and on whether they have sufficient equipment and space to properly attend to the patients.

Both patient and staff timesheets are then captured using a customised database. Using a combination of data from the patients' timesheets, the patients' questionnaire, the health workers' timesheets and the health workers' questionnaire, the waiting times, service times and patient workload for every service point is then calculated.

Data Analysis

A database application has been developed to facilitate the capturing, cleaning, analysis and storing of data as well as the production of standardized reports. The simple individual patient calculation of waiting and service times is shown in Figure 1 and 2. These are then aggregated for all patients surveyed to develop composite tables and graphs on key indicators for the health facility.

The first primary table is a detailed service point table which reports descriptive statistics on the numbers of patients who attend the facility, the number of staff who work in the facility, the number of patients who visit individual service points, the daily full-time equivalent staff present at the facility, workload of staff per service point (calculated as the number of patients seen per full time equivalent staff per day), workload efficiency index (calculated as the percentage of available staff time spent providing services to the patients), percentiles (5^{th}, 25^{th}, 50^{th} and 95^{th}) of service and waiting times per service point and then overall for all service points.

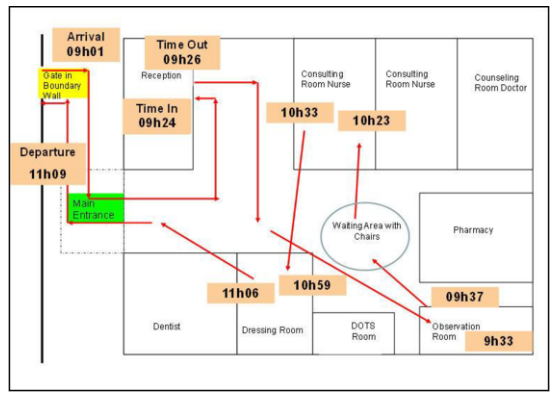

Figure 1 - Measuring Waiting and Service Time at a health centre by following a patient with a timesheet. The patient arrives at 9:00, waits 23 minutes before being attended to by the staff at reception at 9:24. Receives a service for 2 minutes until 9:26 and is then sent to the observation room. Similarly the patient waits at and is attended to at the other points.

Calculating Waiting and Service Times

Arrival Time 9:01

Service Point	Time In	Time Out	Service Time	Waiting Time
Reception	9:24	9:26	2 min	23 min
Observation Room	9:33	9:37	4 min	7 min
Consulting Room Nurse	10:23	10:33	10 min	46 min
Dressing Room	10:59	11:06	7 min	26 min
Complete ST			23 min	
Complete WT				102 min

Departure Time 11:09

Figure 2- Calculating the Waiting and Service Time of a patient

In addition, "arrival time graphs" are used to display the arrival times of patients and the median waiting and service times according to hour of arrival. This is done for every service point and then for the entire facility (i.e. all service points combined). Another set of graphs, the "snapshot graph" shows the waiting and service patterns for every service point in the facility in relation to the staff available to provide the service.

Results

To date, surveys have been implemented in over 200 primary level care facilities, 11 secondary level (regional hospitals) and 3 tertiary hospitals within 2 provinces of South Africa and three districts in the United Republic of Tanzania. Waiting and Service time calculations have been done for over 110 000 patient visits to health facilities.

For all of these health facilities, customised patient and staff timesheets have been developed together with customized database applications. From these, standardized reports for health facilities have been generated showing *inter alia*, the "detailed service point table", "arrival time graphs" and "snapshot graphs" (See Figures 3, 4 and 5).

Importantly, in all the surveys health workers themselves collected and interpreted the information as described earlier and this has translated into very enlightening information about their service points. Findings indicate that facilities and service points show a wide variation of waiting and service times. Overall, staff time usage efficiency ranged from low to modest, while waiting times ranged from minimal to excessive. Eight immediate causes of long waiting times have been identified. These are:

1. *High Workload*: if staff are overworked, then patients have to wait longer as staff have too many patients to attend to.
2. *Batching and inappropriate arrival patterns*: if many patients arrive at the same time then most of these patients would have to wait a long time to be seen, as the staff member would be busy seeing the patients who were first in the batch and the rest would be waiting.
3. *A lack of efficiency in attending to patients*: patients are waiting and yet staff members are present at the service point but they are busy doing something else instead of attending to the patients who are waiting.
4. *A mismatch*: a mismatch occurs when patients arrive to be seen but staff are not yet at that service point.
5. *A logistical problem*: patients are waiting to be seen and staff are available to see the patients but due to a lack of equipment, rooms or other logistical needs, staff are unable to attend to the patients.
6. *Flow problems:* Staff are available to see patients and patients are at the facility but they are being delayed at some other service point.
7. *Queuing problems:* This occurs when patients are attended to by staff in an illogical order, i.e. the patients are not attended to in the order that they arrive at the service point.
8. *High Service time:* An inappropriately high service time for a particular service point would result in higher waiting times for the other patients waiting in the queue.

Prior to the surveys, it was anecdotally believed that high waiting times were mainly due to high workloads. However, in all settings surveyed so far, high waiting times were rarely linked to high workloads but were consistently linked to lack of appointments and the resultant flood of patients arriving at facilities in large batches, especially in the early hours of the day [4].

Service Point	% Staff Time Spent Attending to patient	Median Service Time	Median Waiting Time	Logistics Problem
Surgical Intern	90%	20	50	N
Medical Doctor	52%	30	42	Y
Emergency Room Doctor	14%	28	9	N
Doctor Resuscitation Unit	63%	105	1	N

Figure 3- Detailed Service Point Table
The surgical intern is overworked with a resultant high waiting time. The high waiting time for the medical doctor is due to the logistical problem of awaiting laboratory results. The resuscitation doctor has an appropriately low waiting time.

Health Care Systems uptake of the Survey

Having successfully developed and piloted the WTSES in primary level clinics and health centres in Cape Town (South Africa), we were able to develop simple and efficient methods to analyze waiting times and identify the major causes of long waiting times using a robust methodology supported by a customised database. Based on the experiences of this first survey, we extended the methodology to allow for the identification of all the causes of excessive waiting times, and we standardized the methodology to enable the widespread roll-out of the survey. The methodological procedures were then tested by doing surveys of all clinics and health centres in Cape Town in 2007. It proved to be highly successful in measuring waiting times and identifying the causes of those that were excessively long. Solutions for these problems were then developed. Our success spurred replication of the survey in KwaZulu Natal Province, South Africa and further on to East Africa where we surveyed health facilities in 2 regions of the United Republic of Tanzania

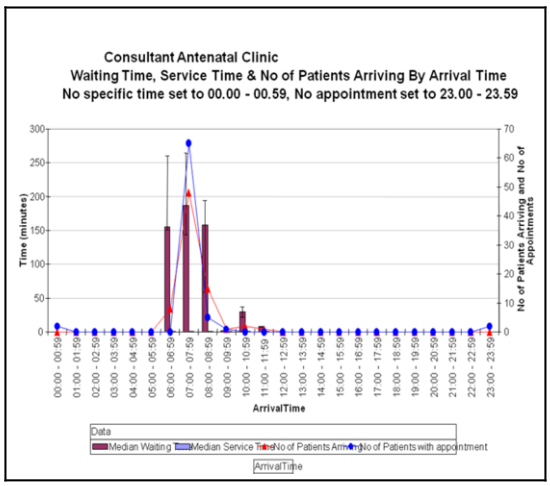

Figure 4- Arrival time graph of a service point in a health facility showing batching between (0700hrs-0800hrs) caused by inappropriate appointment times. Ninety-nine percent of the patients have arrived by 08.00 even though the clinic operates from 08.00 to 13.00.

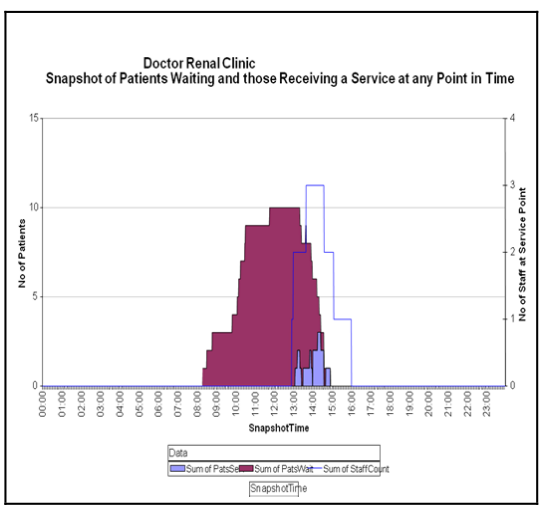

Figure 5- Snapshot graph of a service point in a health facility showing mismatch. Patients start arriving at 0800hrs for a service which starts at 1300hrs

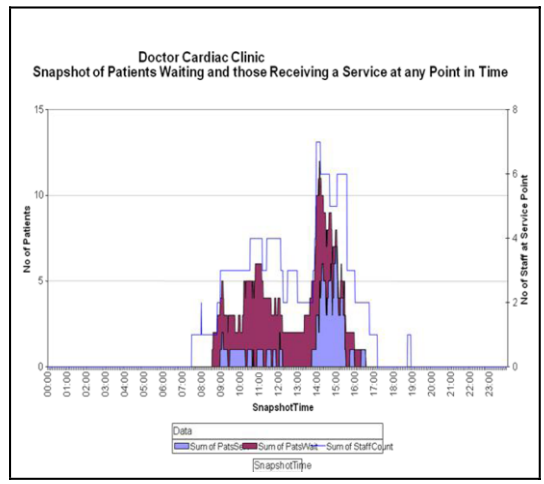

Figure 6- Snapshot graph of a service point showing relative inefficiency between 0900hrs-1200hr (3 Staff in the facility but only one patient is attended to at any point in time); absolute inefficiency between 1200hrs-1350hrs (staff present but no patients are attended to) and good efficiency between 1400hrs-1630hrs. Flow problem between 07.30 and 08.30 as staff are present but no patients have arrived yet.

By the second half of 2007, we had all the valid and necessary ingredients to allow the rollout of the WTSES: a robust methodology and a database had been developed, a training manual had been produced and we had demonstrated that it could be done in a very cost-effective, standardized manner. We had also successfully conducted repeat surveys in a total of 125 primary level care facilities in the Western Cape and supported several others in KwaZulu Natal. The only thing lacking was trained health workers and a desire by health managers to implement the survey routinely. It was also unclear whether the methods successfully used at primary level care facilities would be appropriate for larger and more complex secondary and tertiary level care facilities.

In 2008, we were asked to undertake surveys of regional and academic/tertiary level facilities in the Western Cape. This required that the survey took into account the complexities associated with the delivery of these higher level healthcare services and the vagaries in the process of service delivery in such sections as Trauma and Emergency units. Working with Quality Assurance Managers of the Department of Health we conducted surveys in 7 secondary and tertiary-level hospitals in the Western Cape Province.

Discussion

We have developed a robust method of measuring how long patients wait for services. Importantly in addition to determining the extent of long waiting times and the service points affected, our survey method identifies the reasons why the long waiting time arose and consequently suggests ways to reduce

them. The survey also measures the workload of the staff, the efficiency of service provision and the percentage of time staff spent attending to patients.

Beyond merely being a time measurement activity, our experience has espoused a wide scope of benefits of the WTSES in primary care, *inter alia*; it serves as a process evaluation tool of service time efficiency; a quality measurement tool; an epidemiological profiling tool; and has been successful in its primary aim of identifying and suggesting solutions to long waits for health care services.

The WTSES is quintessential of a routine large scale survey with universal applicability across the tiers of the health care delivery system (primary, secondary and tertiary). Our experience provides evidence that:

1. Regular monitoring and evaluation of health services via large scale routine surveys such as the WTSES is possible in health systems of developing countries
2. Such high benefit surveys can be undertaken using valid and robust methodologies and yet be conducted at a low cost.
3. Existing human resources within health systems can be used to implement the survey in its entirety – including planning, data collection, data cleaning, analysis, interpretation, presentation of results and then development of appropriate interventions based on the findings

Routine surveys must have sufficient depth to assess all the major contributing causes of the problem being investigated.
With the addition of routine large scale surveys such as the WTSES to their routine health information system, health departments would be in the envious position of having an unprecedented amount of high quality information to guide strategic and operational planning, as well as to assist with day to day decision making.

Conclusion

Given the current tools, it is possible for health facilities in developing countries to routinely conduct WTSESs. The benefits of increasing systems efficiency and reduction in waiting times allows increasing improvements in quality of services over a period of time. Because health workers undertake the survey themselves, not only is the survey conducted at a low cost, but also it imminently impacts high staff morale as service provision improves and staff assume the role of researchers in their own right. However, health delivery systems will need further support in modifying particular work environments and mode of service provisions and further training of staff to do this adequately.
Further research is needed to evaluate the success of interventions undertaken to reduce waiting times at facilities and to explore the integration of the survey database application with other large databases utilized by Health Departments.

Acknowledgments

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Learning of each other – online: On the division of labour between technology and supervisors

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Abstract

The article discuss challenges and solutions when an existing course programme, in which contributions from the group form an integral part, is to be converted into an online programme. The focus is on division of labour between technology and supervisors. The case is the Norwegian online version of Chronic Disease Self-Management Program from Stanford University. The interplay between humans and technology is discussed from a theoretical framework developed from the works of Latour and Nonaka. In special difference between human modelling and a technological systematic and rule-based approach is emphasised. By delegating parts of the role in classroom courses to the e-learning solution, it has been possible to create a solution where participants are learning from each other. This demands knowledge on the part of the supervisors so that they help to increase the effect of the technology and not work against it.

Keywords:

Patient education, Distance education, Educational technology, Man-machine systems, Lay knowledge.

Introduction

The volume of health related e-learning programmes is supposed to increase. Provided by public, voluntary and private sector. Many of those natural to offer online exist already as ordinary courses, which means that they must be transformed from classroom to online. This article discusses this transition, with an emphasis on how interaction between technology and human resources can facilitate good learning processes.

The case investigated is the Norwegian online version of Chronic Disease Self-Management Program from Stanford University [1]. This was transferred from classroom to online as a design-based research project [2, 3]. The transformation is discussed on the basis of learning theories and theories about the interaction between humans and technology.

As part of their final reflections, participants are asked to say what they felt to be most useful. It is quite obvious from these that participants have felt that they have been part of a group. Against this background we discuss challenges and solutions when an existing course programme, in which contributions from the group form an integral part, is to be converted into an online programme. The focus is on division of labour between technology and supervisors.

Background

In its traditional form Chronic Disease Self-Management Program is a 15-hour course spread over 6 weeks. The course intends to help participants manage their illness, carry out normal activities and tackle emotional challenges. The programme aims both to impart knowledge from a set syllabus and to enable the participants to share their experiences. The course has been translated to a number of languages, among others Spanish, Chinese, Australian English and Swedish. The course also forms the basis of The Expert Patient Programme that is offered by the Department of Health in Britain. The programme was translated into Norwegian in 2001.

Chronic Disease Self-Management Program is not linked to any specific diagnoses and is a supplement to normal treatment and education in managing specific illnesses, both for people with chronic illnesses or disabilities and their families. The course content and programme are set out in a detailed instructor handbook. The pedagogical foundation of the course is to be found in the work of Albert Bandura [4]. The programme has been developed and modified over a period of time through close cooperation between health professionals and users.

Among others the course has been tested on persons with heart and lung diseases, strokes and rheumatoid arthritis (e.g. [5, 6]. The results showed a significant increase in among other things training, mastering symptoms, improved communication with health professionals, own experienced health situation and exhaustion. It was registered that the participants also had fewer social inhibitions and a reduced use of health services. In the American health system the programme gives a cost/effect score of 1:10.

Method

The course was transformed from classroom to online within the framework of design-based research. Brown [2] and Collins [3] are regarded as portal figures for this type of research, but several directions exist, such as e.g. formative research [7], design research [8] and theory-based design [9, 10]. It is theory-based design that will be adopted in this project.

In design-based research the key feature is that the research aims and the developmental aims are closely interwoven [11]. In this project the aim is of developing a good learning environment coincides with the aim of developing an understanding of the connection between technological and human organisation for learning. Moreover, in design-based research it is essential that the development take place in iterative development processes. Here this has been solved through so-called extreme programming [12].

What is special about theory-based design [9, 10] is that it is based on the assumption that all learning environments consist of five elements that stand in a dialectic relationship to each other. These are: 1) psychology that forms how one understands learning and thinking, 2) pedagogy that dictates how to organise learning environments, 3) culture that reflect values appriciated, 4) technology which support, govern or make for a richer learning environment, and 5) pragmatism with regard to the availability of resources.

Thus the precondition for enacting a successful transformation from classroom to online is knowledge about the course and combined with knowledge about e-learning. With the aid of this knowledge the course is built up pragmatically within the framework provided by the culture and the technology in accordance with the fundamental psychological and pedagogical principles.

Norwegian Net School has developed PedIT, an online e-learning platform well suited to the course. In May and June 2004 the course was run as a pilot using this e-learning solution. The pilot had 18 participants and four supervisors, all of whom were experienced instructors from classroom courses. The pilot led to minor alterations in the online solution, which in accordance with extreme programming were implemented during the test period. Even so, the most important outcome was the experiences gained by the supervisors in how to organise this type of activity.

In the autumn of 2004 a trial programme was run, consisting of 2 courses with a total of 78 participants in 8 separate groups. The material presented here originates from this trial. The material contains 3200 utterances. 75% of these are related to action plans.

A similar model was tested in 2008 with 48 participants. From 2009 the project is part of the regular portfolio of the Norwegian Study Organization for Disabled.

Theory

In our discussion of e-learning as technology we shall make use of theories that in the main have been developed by the French sociologist Bruno Latour. An important point in his work is that both humans and technology are actors with agency [13]. Latour's colleague Madeleine Akrich [14] compares this agency with that of a film manuscript that defines the framework of the actors' actions.

In the remainder of the text we will discuss the interaction between the e-learning tool and the supervisors. In this discussion we shall make use of the terms delegation, programme and anti-programme. Delegation involves leaving control of action to others, programme is what one is steering towards, and anti-programme refers to others' actions with the aim of neutralising control. Since it is Latour's work that is a basis for our discussion, these 'others' may be both human and non-human actors.

In one article Latour [15] discusses strategies used by hotels in order to keep possession of their keys. Three of these are: 1) the staff remind the guests to hand in their keys before they leave the building, 2) display notices that politely request the guests to hand over their keys, and 3) attach heavy key-rings to the keys. All of these are delegation, but whereas the first two involve describing a desired action, the third action is inscribed in the key.

Reminding the guests to hand in their keys convinces one group of guests, putting up a sign a larger group, and attaching heavy weights to the keys an even larger group. It is easy to imagine that hotel guests are very keen to take their keys with them, which mean that they remove the key from the key-ring. In that case this is an anti-programme to the hotel's programme. If the hotel chooses to weld or nail the key-ring to the key to avoid this happening, this would be a case of an anti-anti-programme.

Where the balance between programme, anti-programme and anti-anti-programme goes is a matter of opinion, especially when one delegates things to technology, since technology does make judgements. In what follows, we shall discuss how technology can and must take over part of the supervisor's tasks on an online course, and what responsibilities are best left to the supervisor. But first we ought to look at learning.

Learning

The aim of an educational programme is learning, but this is a difficult concept to define, which explains why so many pedagogical theories and approaches exist. Here we shall make use of an approach developed by Nonaka et al (e.g. [16, 17]). This approach focuses on how the surroundings must facilitate four types of transformation of knowledge if learning is to be effective:

Socialization: this involves experiencing things together. Here individual tacit knowledge is shared, and becomes common tacit knowledge. In this process, shared experience and empathy are important.

Externalization: This is the process by which tacit knowledge becomes explicit knowledge. In this process a key feature is to articulate the joint tacit knowledge from the socialising process.

Combination: In this process, 'old' and 'new' knowledge is combined to form more complex knowledge structures. In this process reflection is essential in order to achieve this combination of new and 'old' knowledge.

Internalization: This is the process during which what one thinks in the combination phase becomes practice, and thus where explicit knowledge forms the basis for tacit knowledge by its becoming part of our behaviour.

Nonaka combines these transformations into what he calls an SECI model. In what follows we shall discuss in more detail how technology can be designed to support these processes.

In the model below (Figure 1) we see in the dark part of the diagram what can be included in the course, and in the lighter part what must be done by the participants as part of their daily lives / routine. In other words, the content of the lighter part must be delegated to the participants in the form of 'homework', while the content of the dark part can be delegated to the course.

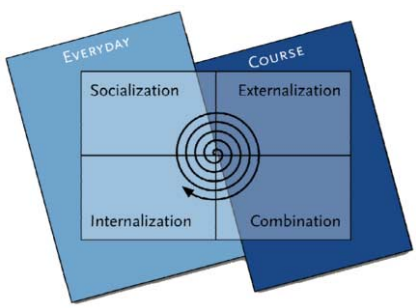

Figure 1- Didactic model based upon Nonaka [16]

Furthermore, we shall look more closely at the interplay between humans and technology in four areas of the online Chronic Disease Self-Management Program.

Group pages

When one meets in a room, one shares time and place. This is not the case when one meets online. At the same time all the participants comment on the fact that they have felt that they belong to a group. Essential to this experience are the group pages, which are the first thing the participants meet when they log in.

In addition to presenting the group, the group pages also serve as an entrance to action plans, course sections, forum and the large group. The fact that the group pages act as an entry page is an important signal that the group is a key component.

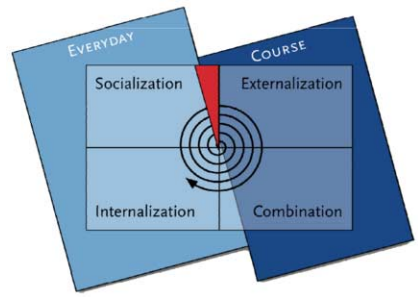

Figure 2- Socialization

In the programme, training in presenting yourself as a person with a problem is a key element, since it is represents an important opportunity to involve the course members more actively. Facilitating socialization (Figure 2) is therefore important. Parts of this function are delegated to the technology, and are thus independent of whether or not participants has logged in. In this context, weeding out those have signed up for the course but not joined has an important contribution to make. This has been delegated to the technology. The supervisors present themselves and thereby provide a model for the participants as to how they should do the same.

Course items

On traditional courses there are short lectures delivered by the instructors from a detailed manuscript. In the online version these are known as course items and take the form of texts that are to be read. On the traditional courses the short lectures are followed up by questions and group exercises. These have two different forms: brainstorming and problem-solving.

In brainstorming the question is defined by the course, and the participants offer their thoughts in relation to this. In the problem-solving the participants contribute by mentioning what they personally experience as difficult, and the other course members are challenged to help them find workable solutions. Both the brainstorming and problem-solving activities serve to incorporate the experiences of and suggestions from the participants in the course items. In this process, the supervisors are also important contributors, but most of all as equals as well as role models who demonstrate how one is expected to 'behave'.

In the SECI model [16], brainstorming and problem-solving activities are placed in the transition between dialogue and systemizing, while the course items are to be found under systemizing, where syllabus meets existing knowledge (Figure 3). The result of this meeting must be put into practice in one's daily life for it to become active.

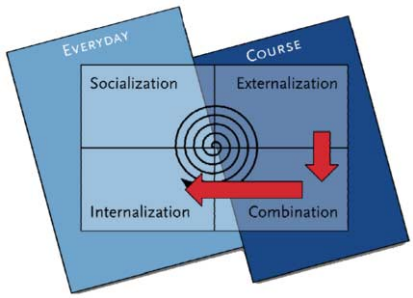

Figure 3- Brainstorming and problem solving

Action plans

An action plan can be described as a New Year's resolution meant for a week. An action plan starts with a set of targets such as, e.g. that you plan to walk a kilometre three times a week. You tell the group that you intend to do this, and when you come back a week later, you tell them about your experiences.

Moreover, the comments show that the action plans represent an important link between course and everyday life. The background for the high level of activity and positive comments with regard to the action plan is that it facilitates activity on all the four contexts indicated by Nonaka [16] (Figure 4). This is incorporated in the technology in a way which puts a focus on the group.

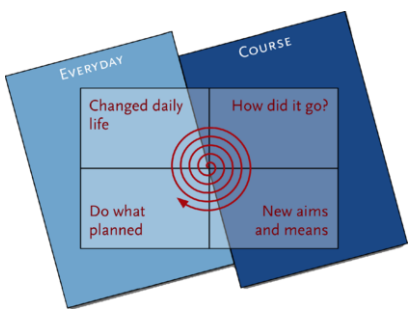

Figure 4- Action plans

Sharing the action plans in written form both emphasizes the obligatory nature of the task and offers the chance of a shared group experience. Here the technology makes a contribution in a number of ways. If the participant has written his or her action plan or their own evaluation without having received any feedback, the text 'I need comments' appears automatically on the group page. When you click on this sentence, you will be directed to the person's action plan. Moreover, 'I am proud of myself' appears if the participant checks this choice when he or she writes their own evaluation.

'I am proud of myself' and 'I need comments' are programmed into the software to focus attention on the participants' processes. This compensates for the reduced human presence in the case of e-learning, and replaces something of what is lost by the absence of body language and oral communication. Delegating this function to automatic programming and technology also has a normalizing effect.

Forum

The idea behind the forum is to provide a place where everyday experiences can be freely exchanged. In the forum it is possible to communicate in the same way as one would normally do during the breaks between classes on ordinary classroom courses. In other words, the discussion forum is an unstructured part of the dialogue and systemizing in the SECI model [16] (Figure 5), and creates a place for everything that does not fit in naturally elsewhere.

The discussion forum has little or no structure or control, with the exception of a desire to offer support to good discussions and put a stop to or give a twist to those that might seem unfortunate.

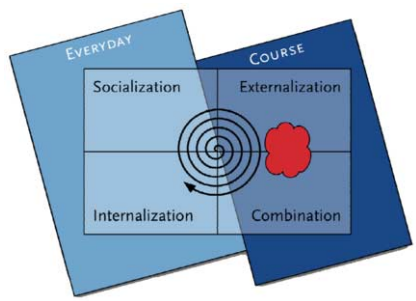

Figure 5- Forum

Supervisors can post messages from the forum onto the group page. Even though the course leaders themselves decide what is to be posted on the front page, the incorporating of the messages into the group pages has been delegated to the technology.

Discussion

In developing the online version the choice was made to emphasize those areas in which the Internet can provide added quality, while feeling free to tone down those parts where classroom sessions offer their special qualities. One example is supervisor-guided dialogues whose strength lies in immediate responses, body language and the opportunity for explanatory follow-up questions. Tools and methods more appropriate to online communication have replaced some of these dialogues.

Using the four main features group, action plan, course items and forum, it has been possible to create a number of arenas for interaction between individual understanding and social

practice, and to locate these in various parts of Nonaka's SECI model [16] (Figure 6). This contributes to what has been experienced to be a successful project. In the diagram below the four features have been put together to form one single model.

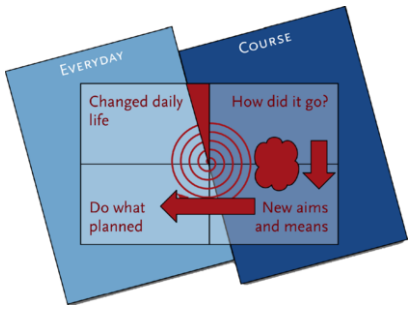

Figure 6-Single model combining the four features

Being able to claim that the development of the programme has been successful is due to a large extent to the high degree of correspondence between the course in the classroom version and the technology that has been applied. Chronic Disease Self-Management Program is by nature rigid and based on a cognitive understanding of knowledge and learning.

By delegating parts of the role of the supervisor in various ways to the e-learning solution, it has been possible to make sure that the participants feel that they are both seen and respected by other participants, at the same time as they are learning from each other. Moreover, this demands knowledge on the part of the supervisors so that they help to increase the effect of the technology and not work against it. Only then will the technology become an integrated part of a well-functioning course team.

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eBug – teaching children hygiene principles using educational games

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Abstract

Technology enhanced education has been recently established as a new approach for all stages of education. However, among these new IT media it is computer games playing the central role in delivering education in particular to children and teenagers, however, real world sound evaluation is often given little attention. The EU funded e-Bug project developed web games aimed at children to teach basic principles of prudent antibiotics use, hand and respiratory hygiene and aims to reinforces an awareness of microbes, hand and respiratory hygiene among junior and senior school children in 10 countries in Europe. An educational pack implemented in schools across Europe is complemented by Internet web games for two age groups teaching a set of learning objectives (LOs) using a fast and interactive platform game design for junior children and investigate detective games based on PBL principles for senior children. In this paper, we present the design of e-Bug junior and senior games and evaluation results.

Keywords:

Infectious disease, Educational games, Platform game, Detective game, Antibiotic resistance, Microbes, Hand and respiratory hygiene

Introduction

E-learning has been widely established as the use of Internet technologies to enhance knowledge and educational performance [1]. The value of e-learning tools and packages in supporting medical education is now well-documented [1,2], however little attention has been given to the use of web games that are particularly suitable teaching media for the e-native generation of children.

There are a few health education programmes targeting children (e.g, Do Bugs Need Drugs [3], Bugs Investigators [4]), however, this target group is often omitted in public campaigns. Raising the awareness of antibiotic resistance and improving hand and respiratory hygiene among children has proven to have strong impact on children health and school absences [5, 6].

In this paper, we describe e-Bug games developed in a DG SANCO-funded Europe wide project aiming to fill this gap by developing web games to teach children basic principles of microbes, hygiene and antibiotic resistance and translate into 10 EU languages and implement across Europe.

e-Bug Project

The reason EC branch DG SANCO funded this large EU educational project was that antimicrobial resistance remains one of the key problems within community and hospital settings within Europe. Increasing antibiotic resistance is related to increasing antibiotic use and lack of awareness of this phenomena among parents and children is contributing to the problem [5].

Many EU countries have public educational campaigns to encourage prudent antibiotic use, however, children are not the typical target group. Research has shown that respiratory and gastrointestinal infections have been identified as a major cause of childhood illness in schools and that the implementation of proper hand hygiene practices has reduced absenteeism within the school environment.

e-Bug (www.e-bug.eu) is a DG SANCO funded antibiotic and hygiene teaching resource aiming to reinforces an awareness of basic knowledge of microbes, hand and respiratory hygiene and the benefits of prudent antibiotics use among junior and senior school children across Europe. There are 17 countries involved in e-Bug covering 62% of European population.

There are two complementary products for both age groups – en educational pack taught at school science lessons and online games, currently launched in 10 EU countries. Education packs, covering the appropriate part of the learning curriculum, are complemented by web-based interactive games teaching the same e-Bug learning outcomes (LOs). Therefore, e-Bug combines traditional methods of classroom delivery with online, web-based games to teach a set of agreed Learning Outcomes. Education games teaching through the mechanics of the game have been successfully evaluated as effective educational intervention [7].

e-Bug Project Aims

The set of LOs were derived, implemented through the games, from the e-Bug project aims:

- To compliment national antibiotic and hygiene educational campaigns
- Develop an antibiotic and hygiene teaching pack & website with online games for both junior and senior schools
- Translate and implement the pack across associated countries in close collaboration with local Ministries of Health and Education
- Evaluation of use and impact of pack and website
- Disseminate and market the e-Bug resource to collaborating partner countries

The project is aimed at two age groups, for each a different style of games was developed to better suite the playing needs and cognitive abilities of children. Therefore, the first game style, aimed at junior children, is a fast engaging platform game while the senior children game design is rather a cognitive detective game. In each of the game the learning outcomes were taught through games mechanics and seamlessly tested.

The e-Bug Junior Game

The junior platform games (designed for the age group of 9-12 year olds) consists of a number of "levels" each teaching a set of learning outcomes. Player, shrunken inside human body, interacts with useful and harmful cartoon microbes and antibiotics and viruses. Teaching the LOs is implemented through the way the player interacts with microbes. Children knowledge is tested seamlessly before and after each level in a Game Show style similar to the popular TV game "Do you want to be a Millionaire?"

The game was designed to incorporates elements of platform games (similar to the Mario series), fast-reaction games (similar to Whackamole) and quiz games. These types were identified through focus groups and market research as being popular with this age group.

In the platform game elements, the player is shrunken to the size of a bacterium and uses a hoverboard to navigate environments that microbes inhabit. Learning outcomes are implemented through the way the player interacts with microbes. For example, the player throws soap at bad microbes to wash them off skin.

The quiz elements are used to assess player knowledge gain in a seamless fashion. For evaluation purposes, we use a pre and post questionnaires which will be changed to post-questionnaires for the real version. Immediately prior to each section of the game, the player is asked a series of questions in the quiz that assess their knowledge of the content of the coming section. The same questions are asked immediately following the section. By comparing the player's response before and after each section, we are able to determine the effectiveness of the game mechanics used to teach each learning outcomes.

The game is split into 5 sections, each of which is designed to teach one set of learning outcomes. Figure 1 illustrates the process of the junior game.

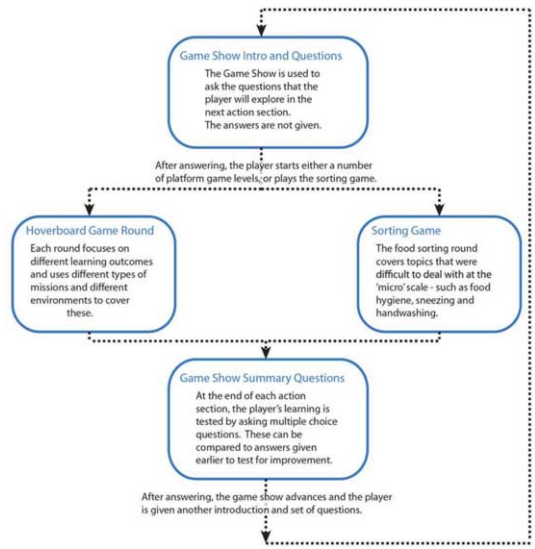

Figure 1 - Junior games process

Implementation of Levels

The first section of the game covers basic information about microbes. To teach the difference between the tree main types of microbes (bacteria, viruses and fungi), the player is tasked with using a camera phone to take photographs of one type at a time. In the game, the three types of microbe are visually designed to show the differences in size and shape, as illustrated in Figure 2.

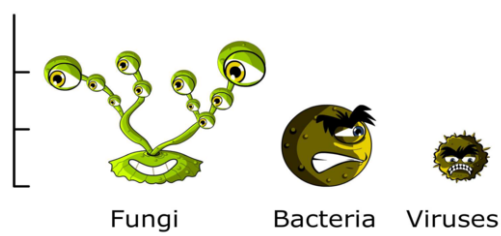

Figure 2 - LO: Bugs are different sizes

The second section of the game introduces the idea that some microbes can be harmful. The player is damaged through contact with bad microbes. Additionally, the player uses soap to wash harmful microbes off skin and uses white blood cells to destroy microbes that have infected a body (see Figure 3).

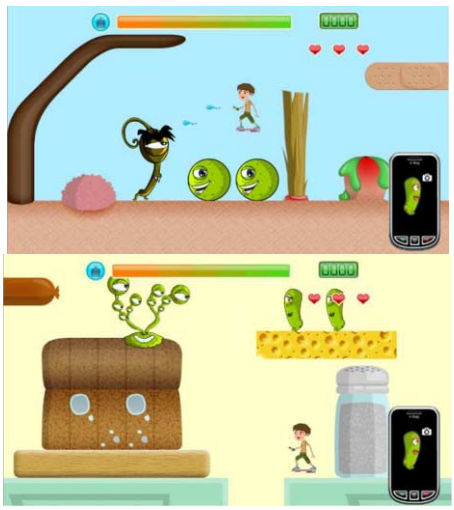

Figure 3 - Bugs are shown in different locations – on the skin and in the kitchen

The third section of the game seeks to demonstrate the usefulness of some microbes. The player has to push lactobacillus microbes into glasses of milk in order to turn the milk into yoghurt; as illustrated in Figure 4.

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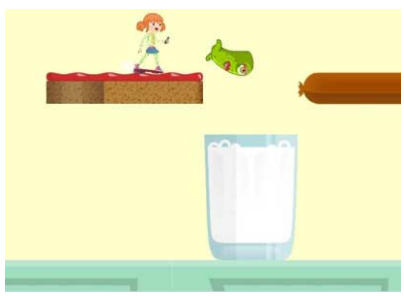

Figure 4 - Player transports lactobacillus to make yogurt

The fourth section of the game covers appropriate food storage guidelines. The player aims to put shopping away in a fridge and cupboards, making sure to wash hands after handling meat and to put each item in an appropriate place to prevent contamination and use a tissue when sneezing to test appropriate respiratory hygiene skills. This is illustrated in Figure 5.

Figure 5 - The food sorting game is used to show hand and respiratory hygiene.

The final section tackles appropriate antibiotic use. Seeking to show that antibiotics kill good and bad bacteria but no viruses, we implemented a 'smart bomb' effect for antibiotics. To show the importance of finishing a full course of antibiotics, the player is shown an infection grow back after initially appearing dead following a partial antibiotic course. By using the remainder of the course, the infection is fully eliminated. This level is illustrated in Figure 6.

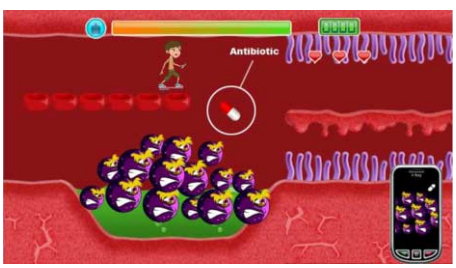

Figure 6 - Player delivers full course of antibiotics to infection

The player pre and post knowledge responses gathered during the quiz show elements are used to assess the effectiveness of each of the above game mechanics.

Evaluation and Results

In addition to the pre and post knowledge gain evaluation, from February until March 2009, a beta-version of the game [8] was evaluated for playability and user-friendliness using a questionnaire to assess user satisfaction and focus groups with a number of primary schools in the UK.

29 pupils took part in the focus groups (and fully completed the pre and post questionnaire) from three schools. Whilst this is a small number of participants, the results were promising. Before playing the game, only 4 pupils "agreed" that fungi were microbes. After playing, 18 agreed. Smaller improvements were seen in other questions including: "We use microbes to make things like bread and yogurt" (11 correct before, 23 correct after playing), "Soap can be used to wash away bad bugs" (20 before vs 24 after) and "Bacteria and Vi-

bugs" (20 before vs 24 after) and "Bacteria and Viruses are the same" (19 correct before vs 23 after playing).

The main evaluation of the games took place in the period of May – August 2009. Each of the completed level (many users dropped out during the game) was evaluated for statistical significance of knowledge change of the LOs. As many questions were correct before and after the game, the statistically significant improved responses were measured (using McNemar's test), for the following questions: "if you cannot see a microbe it is not there", "most coughs and colds get better without medicine" and in particular "we use good microbes to make things like bread and yogurt". There was a trend towards improved knowledge however in other questions did not reach statistic significance. The full report of this study can be found in [9]. Therefore those particular game mechanics seem to teach the LOs very well. Further study would need to be conducted to evaluate an impact on behaviour change.

The e-Bug Senior Game

Senior games, aimed at age group 12-14 year olds, use a detective style investigating a series of infectious related cases or outbreaks in Europe where the player has to discover the source of infection or contamination to successfully solve a puzzle. The game design is similar to that of Phoenix Wright [10], a popular detective game available on the Nintendo DS.
In order to avoid what Habgood calls "Chocolate Covered Broccoli" [11] where the game offers no educational benefit beyond extrinsic motivation, it is necessary to integrate learning through game mechanics. Problem Based Learning (PBL), "any learning environment in which the problem drives the Learning", is a natural approach to games based learning [12]. That is, before students learn some knowledge they are given a problem." [13]. The stages of PBL vary between implementations. For e-Bug, the Queens University definition of 5 stages of learning was used [14]. The full description of the 5 stages implementation on eBug could be found in [15]. The player explores a crime scene narrative, interviewing characters and finding evidence that illuminates their understanding of microbes, hygiene and antibiotics and learning the given set of LOs. The player is presented with a scene, talks to characters, collects evidence, investigates evidence in a laboratory and presents an answer to "puzzle" – the cause of infection or reason for an illness to the boss of e-Bug ("Big C" character).

Figure 7 - Big C character

There are three puzzles to solve, each testing several LOs. First puzzle is based around hand hygiene LOs, 2nd and 3rd teach appropriate use of antibiotics and the issue of antibiotic resistance. For better illustration of the PBL concept we present an example from the first puzzle. A famous actor gets sick by infection transmitted as a result of poor hygiene at a bathroom but poisoning food and insufficient hygiene in the kitchen must be eliminated by collecting and testing evidence samples. Figure 8 illustrates so called "micro-vision" feature allowing users to see microbes on the scene, collect samples and test them.

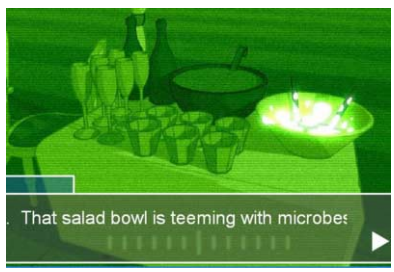

Figure 8 - Microvision of the barbecue scene – microbes visible in the salad bowl

The evidence is being collected into a PDA-like device, tested and hypothesis about the cause of the infection either proved or disproved. These are testing the learning objectives in a seamless way throughout the game while at the end of the game user reports to the Big C summarizing the findings.

Evaluation and Results

The game is complete and an evaluation has taken place with 346 pupils. Evidence for knowledge and attitude change has been collected through an online pre and post game questionnaire. Qualitative feedback has also been collected through focus groups and an open ended questionnaire. The results demonstrated a statistically significant knowledge improvement in puzzle 2 and 3 (puzzle 1 was found too complicated by children). Over 55% children would play the game again. The full results set will be presented at the conference.

Implementation and International Dimension

E-Bug is implemented in Flash 6 and supports all common browsers (IE6, IE7 and Firefox). The multi-lingual e-Bug web site is hosted at IBM Lotus Domino 6 web server and provides full access to the complementary pack sections for both junior and senior schools. E-Bug involves 17 European countries; 10 of those are currently translating the pack and the games and will be implementing the resources in their school systems. These include, UK, Denmark, Czech Republic, France, Poland, Italy, Portugal, Spain, Belgium and Greece.

Monthly web server logs evaluation demonstrates that the user base is steadily growing[1]. In particular, the importance of the resource was highlighted around the peak of the wine flu epi-

[1] http://www.e-bug.eu/ebug_secret.nsf/England-Project-General/eng_eng_p_wp_gn_stats

demics in April-May 2009 when the number of visitors quadrupled, as illustrated in Figure 9.

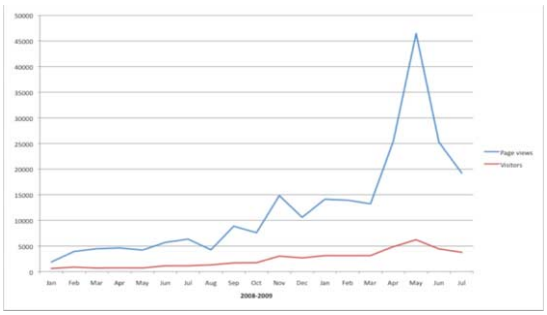

Figure 9 – Traffic on e-Bug web site

International interest in e-Bug is growing. The ease and cost-effectiveness of translation of the games to other languages and localisation to serve as education tools for children in other countries could help to bridge the financial divide and assist in effective and playful healthcare education in less-wealthy countries like Uganda where we received interest in a partnership with local NGOs. Technology transfer of e-Bug games engines can allow successful hosting of any similar kind of platform and puzzle games from any medical or other domains.

Conclusions

e-Bug project a unique example of hygiene and AMR intervention aimed at children implemented and evaluated across Europe. In this paper we described the development and evaluation of e-Bug web games complementing an educational pack aiming to teach junior and senior children basic principles of hand and respiratory hygiene and antibiotic resistance e-Bug games were translated to 9 European languages, after being developed in the UK. Games evaluation investigating players' knowledge gain demonstrated effectiveness of teaching given LOs through the game mechanics for both age groups. International user base is steadily growing and the support to non-UK users, in particular from other EU countries, ECDC, WHO as well as from developing countries.

Acknowledgments

We acknowledge DG SANCO for providing funding for this EU project and all partners who contributed to the development or the pack and games (http://www.e-bug.eu/ebug.nsf/Home?OpenPage). We also acknowledge all schools taking part in evaluation and children playing first versions of the games. We also acknowledge an invaluable input from the e-Bug artists: Nancy Lai and Sandy Beveridge.

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Ambulatory Orthopaedic Surgery Patients Knowledge with Internet-Based Education

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Abstract

There is a growing need for patient education and evaluation of the outcomes of it. The aim of this study was to compare the ambulatory orthopaedic surgery patients' knowledge with Internet-based education and face to face education with a nurse. The following hypothesis was set: Internet-based patient education (experiment) is as effective as face to face education with a nurse (control) in increasing patients' level of knowledge and sufficiency of knowledge. In addition the correlations of demographic variables were tested. The patients were randomised to either the experiment (n=72) or to a control group (n=75). Empirical data were collected with two instruments. Patients in both groups showed improvement in their knowledge during their care. Patients in experiment group improved their knowledge level significantly more in total than those patients in control group. There were no differences in patients' sufficiency of knowledge between the groups. Knowledge was correlated especially with patients' age, gender and earlier ambulatory surgery. As a conclusion, with the Internet-based education could achieve positive results on patients' knowledge. Internet is usable method in ambulatory care.

Keywords:

Patient education, Internet, Outcome assessment

Introduction

There is growing interest on the effectiveness of patient education with Internet. Internet interventions is a concept that encompasses various types of web programs, including behaviorally-based and empirically validated web-based treatment programs as well as patient education sites [1]. There is evidence of the effectiveness of the Internet –based education on patients' health-related behavior [2, 3]. In addition there are reviews about Internet –based education effects on patients' knowledge [3-11]. However, there is scarcity of studies made with surgery patients and especially with ambulatory surgery patients.

In this study wanted to focus on Internet-based intervention studies with ambulatory orthopaedic surgery. This limitation was made because patient education with ambulatory orthopaedic surgery patients is a different than for example long term care patients. The content of education and the knowledge differs with different patients. Ambulatory orthopaedic surgery patients are usually young and health patients. They need a lot of knowledge about their care and they have to handle quite independently in their care. There are some studies about the use of Internet in patients education with ambulatory orthopaedic surgery patients [12,13]. Hering et al. [13] studied the impact of a website on patient knowledge with a randomized controlled trial (n = 164) with a control intervention of nurse based-education (standardized verbal instructions). They found that, the use of a website was more effective in improving patients' knowledge of anaesthesia. However there is no research about the effect of demographic variables on patients' knowledge.

The aim of this study was to compare the ambulatory orthopaedic surgery patients' knowledge with Internet-based education (experiment) and face to face education with a nurse (control). The following hypothesis was set: Internet-based patient education (experiment) is as effective as face to face education with a nurse (control) in increasing patients' level of knowledge and sufficiency of knowledge. In addition the correlations of demographic variables were tested.

Materials and Methods

Study design

Study design was a randomised controlled study. This clinical trial has not been registered, since at the time when we started we did not have a trial register in Finland for this kind of studies. All ambulatory orthopaedic surgery patients (n=173) in one of the five university hospitals in Finland, between July 2005 and September 2006, were eligible for inclusion in this study. The final response rate was 86% (149/173). Patients fulfilling the inclusion criteria got an invitation to participate in our study via a letter of invitation they received for the ambulatory surgery operation. At the same time, they got the first instrument (baseline). The inclusion criteria were that a patient needed to be over 18 years of age, Finnish-speaking, have access to the Internet at home and the capability to use it, have no cognitive disabilities, and have the capability of completing the instruments and informed consent. The exclusion criteria were an ASA-classification over II (ASA). (Figure 1.)

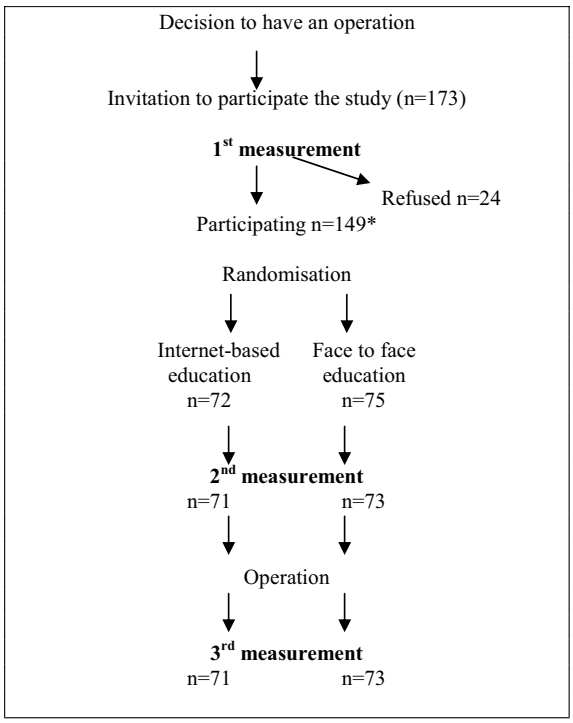

*Figure 1- Study design and flow of patients; *two patients of these were randomised to control group, but they were excluded from the study because they did not come to patient education*

Randomisation and stratification

The patients were randomly assigned (based on: gender, age, and the location of the operation) to either the experiment group (n=72) that received patient education through Internet-based education or to a control group receiving oral education by nurses (n=77). Two patients in the control group were excluded from the study because they did not come to the patient education sessions. Neither the patients nor the study coordinator were aware of the educational assignment until after everyone had been randomly assigned to their groups.

Patients in the experiment group participated in the Internet-based patient education designed for this study. The educational programme was structured based on six areas of knowledge: bio-physiological, functional, experiential, ethical, social and financial [14, 15], which are defined as being important in the cognitive empowerment process [16]. The website consisted of knowledge about nine topics on surgery (i.e. instructions for preparing for the operation, the schedule of events on the operation day, follow-up care, financial aspects, and frequently asked questions by patients). Patients visited the website 1–121 days (mean=14, SD 19.1) before the operation. Patients were asked about their usage and the application time on the website. Patients used the website four to six times (mean 2.3). The application time for the website ranged from 10-300 minutes (mean=81, SD 66.7).

Patients in the control group participated individually in face-to-face patient education with a nurse (in total eight nurses) in a separate room in the ambulatory surgery unit. The theoretical base for the patient education with a nurse is the same as the Internet-based education. Patients were given a leaflet about the content of the session. Nurses were trained for this study and they knew the content of the website (Internet–based education) and they had the printed version of the website available. The face-to-face education session took place on average 9 days before the operation (range 1–55 days, s.d. 7.1) and lasted on average 22 min (range 10–40 min, s.d. 7.0).

Instruments and data collection

The data were collected using two structured instruments: the Knowledge Test (KT) and the Sufficiency of Knowledge (SoK). These two instruments were used before the preoperative education session (baseline), after preoperative education (2nd measurement) and two weeks after the operation (3rd measurement).

KT has 27 items and six subscales: the bio-physiological (8 items; e.g. knowledge about symptoms, treatment, complications), functional (4; e.g. mobility, rest, nutrition, body hygiene), experiential (3; e.g. emotions, hospital experiences), ethical (5; e.g. rights, duties, participation in decision-making, confidentiality), social (3; e.g. families, other patients, patient unions) and financial (4; e.g. costs, financial benefits) dimensions of knowledge. The KT-instrument has a three point scale: correct, incorrect and do not know. The patients were asked, for example, if it is correct or incorrect that they can eat before the operation that they can drive home after operation or that they can see all their care documents. The proportion of the patients' correct answers in each dimension and in total was calculated. The respondent received a score in each dimension and in total calculated by adding the correct answers (max 27) and calculating the mean. For example, the bio-physiological dimension consisted of eight items, so the correct answers were proportioned to eight items. Thus the maximum score was 1 (correct answer) and the minimum was zero (incorrect or do not know answer) in all dimensions and in total.

The SoK has 32-items (plus 13 sub items =45 in total). It includes the same six subscales as "KT": bio-physiological (7items + 13 sub items), functional (7 items), experiential (3 items), ethical (9 items), social (2 items) and financial (4 items). The patients were asked, for example, if the patients had enough knowledge about pain, symptoms and costs of care. The SoK has a four-point scale (1 = strongly disagree to 4 = strongly agree), with a higher score indicating higher levels of sufficiency of knowledge. The SoK was constructed on six dimensions of knowledge by calculating the means for the sum variables. The sum variable was accepted if the patient had answered at least 50% of the items. The total indexes of sufficiency of knowledge were calculated by using the means of the six sum variables.

The following demographic characteristics were asked from the patients at baseline: gender, age, basic and vocational education, and the amount of ambulatory surgery operations.

Statistical analysis

The data were analyzed statistically using SPSS for Windows (version 16.0). Results are shown in frequencies, percentages, means and standard deviations. The Pearson Chi-Square test was used for the comparison of the sample demographic characteristics between the groups.

The effect of sociodemographic variables (age, gender, basic education, professional education and earlier ambulatory surgery) from the pre- to postoperative phases on knowledge level and sufficiency of knowledge was tested using one way analysis of variance.

Ethical considerations

Ethical approval for the study was obtained from the ethical research committee of the hospital district. Patients were informed and they agreed to participate in the study on a voluntary basis and gave written informed consent.

Results

Demographic variables

A total of 147 (=n) ambulatory orthopaedic surgery patients were enrolled: 72 in the experiment group and 75 in the control group. There was no statistically significant differences between the groups in the demographic variables (p = 0.189-0.976). The average age of participants in the Internet –based education group was 44.2 years (range 18-69, SD = 12.73) and 43.5 years (range 18-67, SD = 12.74) in the face to face education group. (Table 1)

Table 1- Patients' demographic variables

Variables	Experiment group (n=72)	Control group (n=75)
Gender		
*male	46	44
*female	54	56
Basic education		
*six years schooling	20	16
*nine years schooling	41	55
*twelve years schooling	39	29
Professional education		
*no education	16	18
*secondary level	29	36
*upper secondary/college	32	29
*polytechnic/university	22	17
Earlier ambulatory surgery		
*yes	58	57
*no	42	43

Results

Knowledge level and sufficiency of knowledge

Patients in both groups showed improvement in their knowledge during their care (Table 2). Patients who received Internet-based education improved their knowledge level significantly more (p = 0.033) than those patients who underwent face to face education with a nurse. There were no differences in patients' sufficiency of knowledge (p>0.05) between the experiment and control group.

Table 2-Patients knowledge level and sufficiency of knowledge in three different phases of care (A=experiment group; B=control group)

Knowledge	Before education mean A/B	After education mean A/B	Two weeks after operation mean A/B
Knowledge level	0.48 / 0.48	0.63 / 0.57	0.65 / 0.62
Sufficiency of knowledge	2.73 / 2.73	3.29 / 3.05	3.40 / 3.22

Relationship between knowledge level and sufficiency of knowledge and demographic variables

Knowledge level was related to the patients' professional education in the experiment group. After education patients who had no professional education evaluated their knowledge level lower (0.53) than those who had secondary (0.59) or upper secondary (0.66) or polytechnic or university (0.70) education. The age, gender, basic education and earlier ambulatory surgery were not related to the patient's knowledge level

In the control group age and earlier ambulatory surgery experience were related to patients' knowledge level. Two weeks after operation youngest (18-34 years old) experienced their knowledge level lower than the older ones (0.53-0.63). Knowledge level was related to the patients' experience of earlier ambulatory surgery in the control group. Patients' who had had earlier ambulatory surgery, experienced higher knowledge level than those who had not (0.55-0.39) before education, (0.62-051) after education before operation and two weeks after operation (0.66-0.56). The gender, or basic and professional education were not related to knowledge **level** in the control group. (Table 3)

Table 3- The relationship between patients knowledge level and demographic variables (A=experiment group; B=control group)

Object	Before education A/B	After education A/B	Two weeks after operation A/B
Age	0.080/0.172	0.570/0.157	0.927/**0.028**
Gender	0.643/0.374	0.654/0.079	0.079/0.500
Basic education	0.902/0.668	0.155/0.786	0.574/0.764
Professional education	0.472/0.612	**0.007**/0.865	0.130/0.641
Earlier ambulatory surgery	0.116/**0.001**	0.953/**0.002**	0.919/**0.006**

Sufficiency of knowledge was related to the patients' age, gender and earlier ambulatory surgery experience in the experiment group. Before education youngest (18-34 years old) experienced their sufficiency of knowledge lower than the older one (2.43-2.90). Women's sufficiency of knowledge was higher than men's after education (3.39-3.03) and two weeks postoperatively (3.53-3.28). In addition before education the patients who had had earlier ambulatory surgery experienced their sufficiency of knowledge higher than those who had not had (2.90-2.50).

In the control group patients' sufficiency of knowledge was related to the patients' earlier ambulatory surgery experience. Two weeks after operation patients who have had earlier ambulatory surgery experienced their sufficiency of knowledge higher than those who have not had (3.34-3.07). The other demographic variables did not differ significantly. (Table 4)

Table 4-The relationship between patients sufficiency of knowledge and demographic variables (A=experiment group; B=control group)

Object	Before education A/B	After education A/B	Two weeks after operation A/B
Age	**0.045**/0.399	0.293/0.369	0.118/0.711
Gender	0.566/0.296	**0.001**/0.806	**0.010**/0.694
Basic education	0.914/0.829	0.728/0.331	0.368/0.432
Professional education	0.974/0.815	0.371/0.943	0.272/0.868
Earlier ambulatory surgery	**0.006**/0.117	0.961/0.074	0.938/**0.030**

Discussion

We hypothesized that Internet-based patient education (experiment) is as effective as face to face education with a nurse (control) in increasing patients' level of knowledge and sufficiency of knowledge. In addition the correlations of demographic variables, level of knowledge and sufficiency of knowledge were tested. The hypothesis was confirmed Patients having Internet –based education had higher knowledge levels than patients receiving face-to face education with a nurse. However there were no differences between educations in patients' experience of sufficiency of knowledge. In addition some correlations between patients' knowledge and demographic variables were found.

There are only a few earlier studies about the cognitive outcomes of Internet –based education [3-11]. This is surprising because it is known that the use of Internet is growing and more and more people are also searching the knowledge from the Internet for their health problems. According to this thus [see also 13] the Internet is usable method in patients' education.

Patients' demographic variables were slightly related with patients' knowledge. However the related variables were different in experiment and control group. It seems that in the experiment group patients who had no professional education experienced their knowledge level lower than those who had. This difference was not significant in the control group. It might be that the more educated patients are also more used to use the internet. In the control group the youngest patients experienced their knowledge level lower than the older ones (two weeks after operation). The earlier ambulatory surgery experience was related to the patients' knowledge level in the control group in all phases of care. There were not similar differences in the knowledge level of the experiment group. It seems that face to face education can not improve patients' knowledge level equally if the patient has had earlier ambulatory surgery. Could it be that nurse assumes too much about the patients' knowledge level and the content of the education is not sufficient. This problem is avoided in the internet education since the content of education is the same for all.

Patients' sufficiency of knowledge was related to the patients' age, gender and earlier ambulatory surgery experience in the experiment group. Internet-based education improved especially the sufficiency of knowledge of the youngest patients' and patients with no earlier ambulatory surgery experience. These patients might also benefit most from Internet –based education. In addition sufficiency of knowledge was highest among women after the education in the experiment group. In the control group, only earlier ambulatory surgery experience was related to the patients' higher sufficiency of knowledge two weeks after surgery.

Conclusion

Internet–based education could be used with the ambulatory orthopaedic surgery patients. Internet is a successful method in

patients' education and it improved patients' knowledge even more than face to face education.

The relation of patients' demographic variables on patients' knowledge varied. It seems that Internet is a successful method especially with young people, women and patients with no earlier ambulatory surgery experience. Face to face education could not improve patients' knowledge level equally, well if the patient had had a previous ambulatory surgery. This issue calls further research.

Acknowledgments

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An open repositories network development for medical teaching resources

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Abstract

The lack of interoperability between repositories of heterogeneous and geographically widespread data is an obstacle to the diffusion, sharing and reutilization of those data. We present the development of an open repositories network taking into account both the syntactic and semantic interoperability of the different repositories and based on international standards in this field. The network is used by the medical community in France for the diffusion and sharing of digital teaching resources. The syntactic interoperability of the repositories is managed using the OAI-PMH protocol for the exchange of metadata describing the resources. Semantic interoperability is based, on one hand, on the LOM standard for the description of resources and on MESH for the indexing of the latter and, on the other hand, on semantic interoperability management designed to optimize compliance with standards and the quality of the metadata.

Keywords:

Open Access, Open Archives Initiative, Open repositories, Interoperability, Metadata, Teaching resource.

Introduction

In view of the quality and cost of production of digital resources, reuse of digital resources is a major issue for producers wishing to enhance their digital heritage and for the bodies of players wishing to share them. Reuse of digital resources runs up against two major difficulties: the geographical dispersion of the data and their heterogeneity.

The open repositories approach offers some elements of response. The approach is based on two complementary initiatives:

- The Open Access (OA) initiative,
- The Open Archives Initiative (OAI).

The Open Access initiative [1] is at once a commitment to a principle, to a strategy and to a financial involvement which has laid down the rules of free access to the resources.

The Open Archive Initiative [2] has specified an interoperability technique for heterogeneous and widespread repositories. This technique defines the modes of exchange of the metadata files describing the resources. It thus deals exclusively with aspects of syntactic interoperability. On the other hand, it does not manage the semantic interoperability of the metadata and the added value services related to these metadata.

The techniques formulated by the OAI have been widely used in numerous projects [3]. However, the setting up of open repositories involves more than technology alone [4] and the research performed into the role, design and management of digital libraries falls within in the scope of this problem.

Research has evolved from a narrower view emphasizing enabling technology to one that encompasses the social, behavioral and economic context in which digital libraries are used. As suggested by Borgman [5], digital libraries should be much more than search engine portals. Search and access over a set of resources, while important to any digital library, are not sufficient. Digital libraries should provide advanced services that facilitate use of resources by their target community.

Lagoze [6] proposed that this added value consists of establishing context around those resources, enriching them with new information and relationships that express the usage patterns and knowledge of the library community. The digital library becomes a context for information collaboration and accumulation and much more than just a place to find information and access it.

Digital libraries are not static and require management and long-term evaluations to determine their quality and to identify new directions for growth. Zuccala's approach [7] is to carry out evaluation using a set of qualitative and quantitative research techniques, including webometric analyses and an online survey of repository users.

This paper describes the process we used to develop an open repositories network for the diffusion and sharing of digital teaching resources created by teachers at French-language Schools of Medicine.

The architecture and management of the open repositories network are described with emphasis on syntactic and semantic interoperability. The main results are presented and the benefits and limits of the system are discussed.

Objectives

The widespread adoption of digital technology in universities and, in France, an incentives policy adopted by the Ministry of Higher Education and Research has triggered a considerable increase in the number of teaching resources. These resources are easy to consult via digital workspaces located in universities. However, availability at national and international level raises frequent problems in the absence of interoperability between the different systems

In the medical field, the CISMeF team [8] set up a centralized system for the inventory and indexing of, and access to teaching resources in French.

This efficacious system is nevertheless faced with two constraints:

- It is based upon centralized indexing which takes no account of the ever greater autonomy of the different institutions regarding indexing,
- It uses proprietary standards and technologies which greatly hinder interoperability.

With the support of the UMVF, the French Virtual Medical University [9], we have been led to rethink the overall referencing, indexing and accessing model.

Our project is focussed on the creation of an open repositories network designed to enhance the visibility, accessibility and sharing of the teaching resources produced by medical faculty.

This new model takes account of the pooling of documents produced by different institutions while avoiding centralization of the indexing system.

The orientation of the project towards an Open Access approach has led us to define a number of priority objectives:

- Establishment of a network of interoperable repositories,
- Compliance with international standards in order to ensure syntactic and semantic interoperability between the different repositories,
- Strong management, at national level, in order to optimize compliance with semantic interoperability.

The open repositories network

The metadata providers and service providers-based architecture

The architecture of the environment (Figure 1) is based on a set of shared protocols and interoperability standards aimed, firstly, at using shared metadata to describe the resources and, secondly, to allow exchange of these metadata.

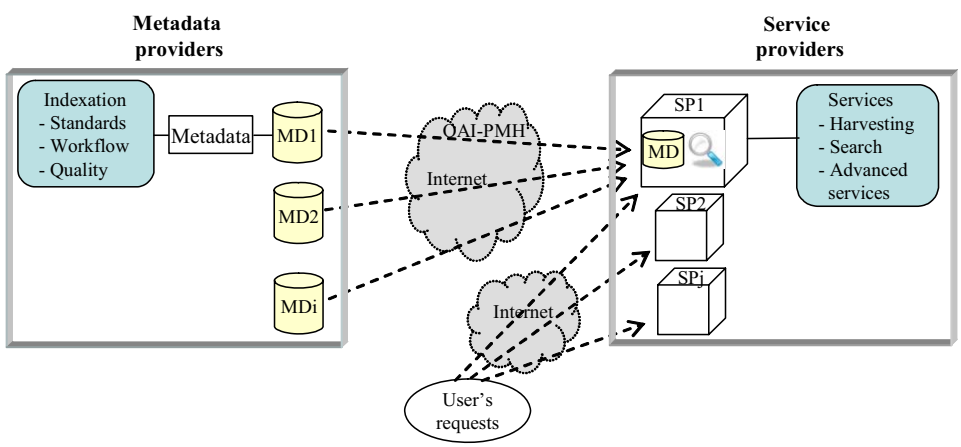

Figure 1 - Open repositories network architecture

The urbanization of this system calls on two types of players:

- The metadata providers who expose metadata passively in standardized repositories and which can be queried by service providers,
- The service providers who first harvest metadata actively by querying the metadata providers before providing services using these metadata.

Any structure can serve as a metadata provider or a service provider, or both simultaneously.

Successful implementation of this environment centered on metadata exchanges is dependent on the syntactic and semantic interoperability of the metadata.

Syntactic metadata interoperability

Syntactic interoperability is provided by the OAI-PMH protocol (Protocol for Metadata Harvesting). OAI-PMH [10] is a simple and powerful framework for metadata harvesting. With OAI-PMH, metadata providers are never directly accessed by end-users. Service-providers harvest metadata-providers and the result is used to create services covering the content of several metadata repositories. OAI-PMH specifies the syntax of 6 query verbs (Identify, ListSets, ListMetadataFormats, ListIdentifiers, ListRecords, GetRecord) used for metadata harvesting. Queries via HTTP allow recovery of metadata XML files.

Semantic metadata interoperability

The quality of the environment is conditioned upstream by the semantic interoperability of the metadata. We chose to describe the teaching resources using the LOM (Learning Object Metadata) standard proposed by the IEEE Learning Technology Standards Committee [11]. The purpose of the LOM standard is to facilitate search, evaluation, acquisition and use of learning objects, for instance, by learners or instructors or automated software processes. This multi-part standard also facilitates the sharing and exchange of learning objects, by enabling the development of catalogs and inventories while taking into account the diversity of cultural and lingual contexts in which the learning objects and their metadata are reused.

LOM defines a hierarchy of data elements for learning object metadata. At the top level of the hierarchy are nine categories: General, Lifecycle, Meta-metadata, Technical, Educational, Rights, Relation, Annotation and Classification. Each category contains sub-elements which, in turn, contain elements or sub-elements. The LOM standard includes more than 80 data elements and it was established as an extension of the Dublin Core metadata element set (15 elements) [12].

Implementations of the LOM are normally based on application profiles to meet community context-specific needs, without losing interoperability. Despite its many elements, the LOM conceptual data schema may be extended by adding new vocabularies and by adding new elements. We used this possibility and, to meet the specific needs of medical teaching resources, we defined an LOM application profile integrating the MeSH thesaurus. Each medical teaching resource is indexed in MeSH using the Describer/Qualifier/Major-Minor triplet. We used the classification category for the MeSH extension. Figure 2 is an example of an LOM XML MeSH integration.

```
<lom:taxonPath>
  <lom:taxon>
  <lom:id>D008581/Q000150/N</lom:id>
  <lom:entry>
    <lom:string language="fre"> méningite/complications/N
    </lom:string>
    <lom:string language="eng"> meningitis/complications/N
    </lom:string>
   </lom:entry>
  </lom:taxon>
</lom:taxonPath>
```

Figure 2 – Example of LOM MeSH integration

Adoption of a standard such as LOM is an essential, but insufficient, precondition. To achieve optimum metadata quality, it is vital that all players share the same understanding of the semantics of the items in the LOM and use the same vocabularies. In France, the SupLOMFR group, set up by the Ministry, is the reference providing guidance in the use of the LOM. The number of items defined in the LOM standard is very large and SupLOMFR specifies whether LOM data elements are optional, recommended or obligatory. SupLOMFR also:

- Provides information on how elements are interpreted in the French teaching context,
- Specifies the use of vocabularies and of taxonomies,
- Specifies the classification schemes.

SupLOMFR is making a major contribution to the management of semantic interoperability.

Services

The function of the service providers is to trigger relevant harvesting of metadata, i.e. to target metadata providers according to the profile of potential users. Each service provider offers users a search engine to exploit the harvested metadata.

Results

Technical implementation

Under the aegis of the Ministry, the French ORI-OAI [13] consortium is assisting in the technical deployment of the open repositories network by integrating open source tools (Orbeon form builder, OSWorkflow, LIUS, Nuxeo). Seven packaged modules are available: document storage, OAI repository, OAI harvester, workflow manager, vocabulary manager, indexing engine and search engine. These modules dialogue with one another using web services. Each module is highly configurable to meet specific contexts.

Metadata production workflow

Good quality metadata are a key component in the successful implementation of an open repositories network. The need for good quality metadata must be fully understood by the community.

A solely teacher-generated metadata model has many limitations. Teachers may lack knowledge of indexing principles and are more likely to generate insufficient and poor quality metadata. Both teachers and metadata specialists play important roles in the metadata production process. This collaborative approach needs to specify the metadata production workflow.

Metadata creation should be identified as an incremental process and as a shared responsibility. This responsibility should be distributed in a practical and reasonable way within the institution. The creation and refinement of a workflow is dependent on operational and strategic factors. Several more or less complex workflows can be established. The main difference between workflow models is in the number and the roles of the players involved in the process.

A four-level workflow model including the teacher, information and communication technology specialist, librarian and legal department seems to fit the French university context. Each player produces metadata in his/her area of competence. This workflow can be represented using a state transition diagram as in Figure 3.

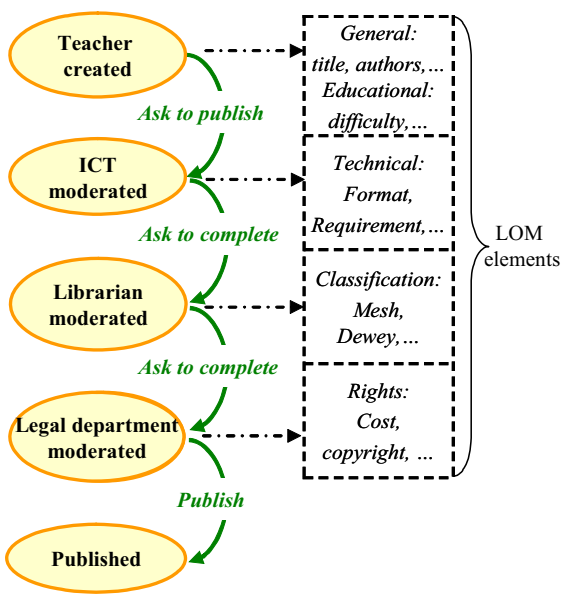

Figure 3 - A four level workflow model

Metadata creation comprises five successive states from the teacher-created state to the published state. The Metadata creation workflow starts with a teacher initiative in which general elements are produced. ICT and librarian complete the metadata. The Metadata creation workflow ends with a legal department decision after validation of the rights aspects.

Operational providers

Today, the network is based on several operational metadata providers and service providers.

During the last quarter of 2008, 4200 resources indexed by CISMef and 2000 resources indexed by Canal U, the French Higher Education and Research Web TV channel, were integrated into the first repositories.

To allow integration of the CISMeF 4200 teaching resources in the ORI-OAI repository, the CISMeF team developed a mapping function to restructure the original XML files according to the LOM metadata schema. CISMeF information about indexations (MeSH keywords, MeSH qualifiers and CISMeF resources types) and CISMeF metaterms for categorization are mapped to LOM metadata elements. The transformation from one metadata schema to another is ensured by XSLT processing. Figure 4 shows an example of mapping.

In 2009, other universities (Aix-Marseille, Paris, Rennes,…) joined the project. The CISMeF ORI-OAI repository will now receive an additional 4000 teaching resources.

An overall picture, at national level, of the network deployment covering all the themes, is provided by the French thematic digital universities portal [14]. The 12300 resources listed in July 2009 reflect the deployment status of the two themes involving medicine (4200) and science and techniques (8100). All the other themes (law, economy,…) will gradually be added to the network.

```
<CISMeF:learningresourcetype>
  <CISMeF:descriptionRessType>
    educationalcourses
  </CISMeF:descriptionRessType>
</CISMeF:learningresourcetype>
```

```
<lom:educational>
  <lom:learningResourceType>
    <lom:value>
      lecture
  </lom:value>
  </lom:learningResourceType>
</lom:educational>
```

Figure 4 – An example of mapping from CISMeF schema to LOM schema

Discussion

The choice of the open repositories approach for the diffusion and sharing of medical teaching resources has provided us with elements of response towards a solution of the heterogeneity issue.

The OAI-PMH protocol has enabled us to achieve complete control of syntactic interoperability. On the other hand, semantic interoperability is more difficult to ensure. Despite the adoption of a standard such as the LOM, the players in the community are not all equally demanding regarding observance of standards and control of the quality of the metadata. The increase in the number of players and indexing facilities raises the issue of indexing quality. Improvements in quality should be attainable by defining a supervised workflow designed to harmonize indexing practices. The management of semantic interoperability is a key factor in the creation of a high quality open repositories network.

For users, one of the added values is the search engines integrated in the service providers. These search engines are often general in scope and do not take sufficient account of user profiles. This partly explains the utilization rate which fails to match the efforts devoted to the system [15]. One avenue of research is to establish connexions between the resources in order to take account of the context [16]. The OAI-ORE (Object Reuse and Exchange) [17] aims to describe and exchange compound and semantically linked objects and is working in that direction.

Conclusion

This paper described an open repositories network development for the diffusion and sharing of medical teaching resources.

Driven by the Ministry and thanks to the efforts of the ORI-OAI consortium, the open resources approach is being rolled out in France, and in all sectors, and not only in medicine.

The next steps will seek to extend the network of players, develop services which take into account user profiles and evaluate usage.

The open repositories approach can be applied to documents other than teaching resources such as theses, training curriculum, or scientific publications. The aim is thus to enhance a whole digital heritage backed by high-quality semantic interoperability management.

Acknowledgments

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Using the Virtual Reality World of Second Life to Teach Nursing Faculty Simulation Management

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Abstract

Healthcare faculty members have come to depend on the advantages of teaching with clinical simulation, but not all faculty are competent in their ability to manage students during the simulation experience. This federally funded proposal provided the opportunity for nursing faculty to participate in a synchronous learning event using the virtual reality world of Second Life (SL). Based on competencies, faculty participants were guided through the simulation process by a "Master Teacher." Participants then became the teacher and chose the settings, objectives, and clinical data to manage their own simulation using avatar role assignments. Feedback populated the participant informatics dashboard, so that progress towards their competencies was recorded. Another unique informatics application was the use of the Synthetic Derivative project to use de-identified patient data to promote better clinical realism. Additional evaluation activities regarding content, appropriate use of the technology, and design features were assessed. The development of the SL environment for this educational study provides the setting in which to pilot test the provision of actual clinical care that does not require "hands-on" interventions.

Keywords:

Computer simulation, User-computer interface, Nursing education, Nursing faculty.

Introduction

Despite the fact that the US is beginning a documented nursing shortage, nursing schools across the nation turned away an unprecedented 49,948 qualified applicants to baccalaureate and graduate programs primarily due to insufficient numbers of faculty [1]. For the faculty members who remain, they must be able to rely on efficient teaching strategies that promote more independent student learning and critical thinking. For those nurses who are preparing for faculty roles, they must be able to select appropriate teaching strategies for the goals they wish to accomplish. Both groups must become competent and confident in their abilities to use technology in order to impart these skills into the learning of today's students.

Clinical simulations have the potential to provide such solutions, but only if nursing faculty are competent in simulation management. As part of a Robert Wood Johnson Partners Investing in Nursing's Future Grant, the Tennessee researchers surveyed nursing programs across the state. Results revealed that although 100% have some sort of simulation equipment, 74% state they are not using simulation at 100% of capacity. The reason cited for not using simulation technology by 72% of the respondents was a lack of trained faculty.

The virtual reality world of Second Life (SL) provides an environment that allows users from around the world to "log on" to this web-based platform. Second Life is a 3D virtual world, created by its residents. The world is driven by the interactions of real-world individuals and their "inworld" residents or "avatars" [2]. Thus, for every avatar one encounters in SL, there is a live person somewhere in the world who is dictating that avatar's actions, emotions, words, dress, etc. SL provides the place for interactions with people, businesses, and organizations in a 3D environment but requires only an Internet connection and working computer rather than extensive travel arrangements. Hansen notes that the major strengths of virtual worlds are one's ability to design and construct unique environments and then share them with others in a collaborative fashion [3]. A pilot postgraduate medical education program was delivered in SL. All participants (12 of 12) agreed that this experience was an effective method of medical education, that the virtual world was superior to other methods of online continuing medical education, and that they would enroll again as well as recommend this format to others [4].

The purpose of this project was to provide a computer application for nursing faculty that would allow them the opportunity to manage clinical simulations while advancing in their own competency and proficiency levels of simulation management. The virtual world of SL was chosen for the delivery of the geriatric cases because it could be used as an educational meeting place that requires no travel arrangements. Although the educational session took place in a synchronous fashion similar to a face-to-face meeting, it required much more effort to build the virtual environment according to user needs. In addition, planning was also necessary to design the learner experience. A unique complication of our development efforts was the fact that the learners were also faculty members. Their purpose in attending the event was to learn to provide the appropriate faculty guidance in simulation rather than to learn the details of the simulation itself. Prior to attending the learn-

ing session, participants were required to complete an orientation session to SL that has been specifically designed for our use. Competencies provided the structure for both the orientation and educational simulation sessions and were presented graphically using a color-coded dashboard.

Materials and Methods

Competency Development

Most faculty required orientation activities to the SL platform. One of the negative implications of using the SL platform is that most users start their experience on "Orientation Island." Many times there are other avatars on the Orientation Island who are predators and are there only to harass new users either verbally or through the use of nudity or sexual innuendos. It was possible to bypass this island by providing participants with the specific island location for the intended education session via a SLURL (Second Life Universal Resource Locator). In doing so, however, participants do not learn how to manipulate their avatars. As a result, orientation activities specific to this project were required.

Video sessions and one-on-one orientation sessions ensured that all participants reached pre-determined competency levels in this environment. Competencies included the following:

1. *Getting Started Tasks* (setting up an account in SL, selecting a name and password; installing the SL client; creating an avatar, alter appearance, alter clothing; learning how to walk, run, fly, land, sit, turn around, teleport, alter your viewpoint, use gestures; learning how to use the various maps; bringing up chat bar, chat window; acquiring and managing inventory);

2. *Intermediate Tasks* (using search tool; adding a "friend"; instant message a friend; going to a SL URL; selecting and configuring of headset; bringing up and using audio chat; acquiring and spending Linden dollars; uploading and playing a PowerPoint presentation); and

3. *Social Tasks* (awareness of how to teach and learn within this environment; how to identify and report abuse; how to document care in this environment; how to get technical help).

Competencies for faculty in simulation management do not currently exist and thus had to be developed by the project faculty. Rather than an extensive Delphi technique with content experts that takes valuable time, project faculty drafted proposed competencies and received feedback from two consultants recognized for their international expertise in nursing simulation development. [1] Informal focus groups were then conducted using members of the International Nursing Association for Clinical Simulation and Learning (INACSL). Although it is not within the scope of this paper to list every developed competency, general categories for the nurse educator were as follows: plans simulations, participates in simulations, provides debriefing and reflection, and evaluates simulation. In addition, competencies for the simulation coordinator/specialist were developed (although not used for our SL experience).

[1] Consultants were Dr. Pamela Jeffries and Dr. Sharon Decker

Informatics can be applied to the competency process with the development of visual dashboards that illustrate at a glance the progress users have made in meeting the identified competencies. The use of dashboards in the clinical setting has been validated as an effective measure of quality improvement in Vanderbilt's fight against ventilator acquired pneumonia [5]. With the use of dashboards designed by evidence-based care parameters, the number of ventilator acquired pneumonia cases dropped from over 300 a year to 140 a year. The impact of this project was prevention of 16 deaths per year, more than $4 million in savings per year, more than 100 hospital days per year avoided and more than 400 ICU days per year avoided. The project illustrated the behavioral implications of visually seeing progress in the clinical domain, and the SL project team sought to replicate this positive behavior in their project environment.

Second Life Development

The first priority for beginning the development in SL was the leasing of the island itself. In order to do this, the project team had to determine a name for the island. Because this project is a collaboration between the Vanderbilt University School of Nursing and the University of Kentucky College of Nursing, it was determined that the name of the island should not reflect either institution. Instead, the name "NURSIM4U" was chosen and a welcome sign was designed that contained the logos from both institutions (see Figure 1 below).

Figure 1 – Welcome to Conference Center

Because the team wanted to provide nursing participants with a variety of choices, it was determined that there would be an outpatient facility, a nursing home facility, an acute care facility, and a variety of homes on the island. A conference center was planned for the center of the island, and would be the place in which all participants would start after entering the NURSIM4U SLURL. All of these locations were mapped onto a graph of the island to determine both size and location of the buildings. It was also determined that two new facilities (outpatient diabetes clinic and acute care critical bed tower) would be replicated in the SL environment, allowing for the use of existing plans to dictate the room dimensions and layouts.

Simulation Development and Populating the Electronic Medical Record

Content experts were faced with the challenge of ensuring that the clinical data they used for simulated patients resembled reality. After determining the types of patients to be included in the case scenarios, clinical data were accessed using the unique database at Vanderbilt University called the Synthetic Derivative (SD). The Synthetic Derivative is a database containing clinical information derived from Vanderbilt's electronic medical record, labeled with a unique research ID, and stripped of personal identifiers [6]. Thus, the SD is a set of records that is no longer linked to the identified medical record from which it is derived and has been altered to the point that it no longer closely resembles the original record. The SD interface allows the user to search data extracted from most of the major health information databases at Vanderbilt. The database contains records for over 1.7 million unique individuals. The search interface allows the user to input basic clinical and demographic information, such as ICD9 codes, medication, lab values, age and gender and returns de-identified data to the user for review and selection.

Use of the SD requires approval from the Institutional Review Board as well as completion of a data request form by the SD administrators. Both approvals were received by the project investigators so that the clinical simulation cases could be population with realistic data values that had actually been demonstrated by an individual at some point in time.

Several simulation design issues surfaced during scripting. How much of the simulation should be scripted versus depending on knowledgeable participants who were assigned roles with descriptive parameters for behaviors? How much choice should faculty participants have in the selection of singular objectives versus groups of objectives? How do you teach faculty while they are also playing roles in the simulation? How do you make certain that the experience allows the "Master Teacher" to role model behavior but at the same time critique the teaching behaviors of the faculty participants? These issues were frequently discussed by the project team before final decisions were made as to how to guide the simulation experience.

Evaluation Tools

There is a need for more empirical research in order to unearth the pedagogical outcomes and advantages associated with this type of e-learning technology. The relevance of this innovation on a large scale is yet to be demonstrated and requires empirical research [7].

Many of the original evaluation tools selected for use in this study were developed by the National League for Nursing in conjunction with Laerdal who funded a national, multi-method project with the following purposes: 1) To develop and test models that nursing faculty can implement when using simulation to promote student learning, 2) To develop a cadre of nursing faculty who can use simulation in innovative ways to enhance student learning, 3) To contribute to the refinement of the body of knowledge related to the use of simulation in nursing education, and 4) To demonstrate the value of collaboration between the corporate and not-for-profit worlds [8]. The research goals were to explore how to design simulations, implement simulations as a teaching strategy, and evaluate selected learning outcomes using simulations. The study was designed with eight project coordinators and one Project Director (Jeffries).

Selected tools for this SL project included the Simulation Design Scale and the Student Satisfaction and Self-Confidence in Learning. The Simulation Design Scale, a 20-item instrument using a five-point scale, was designed to evaluate the five design features of the instructor-developed simulations used in the NLN/Laerdal study [9]. The five design features include: 1) objectives/information; 2) support; 3) problem solving; 4) feedback; and 5) fidelity. The instrument has two parts: one asks about the presence of specific features in the simulation, the other asks about the importance of those features to the learner. Content validity was established by ten content experts in simulation development and testing. The instrument's reliability was tested using Cronbach's alpha, which was found to be 0.92 for presence of features, and 0.96 for the importance of features. The second tool was the Student Satisfaction and Self-Confidence in Learning, a 13-item instrument designed to measure students' satisfaction (five items) with the simulation activity and self-confidence in learning (eight items) using a five-point scale. Reliability was tested using Cronbach's alpha satisfaction = 0.94, self-confidence = 0.87.

Additional evaluation tools designed specific to this SL project included a content evaluation tool (effectiveness of teaching/learning methods, whether program met the stated objectives, whether the content was relative to their work, whether the online environment was conducive to learning, whether the participant was able to achieve own personal objectives, whether attending the event was an appropriate use of time, and whether the participant would recommend this workshop to others). Scales ranged from A (Strongly Agree) to E (Strongly Disagree) or A (Very Effective) to E (Very Ineffective). Furthermore, an Instructor Feedback tool was designed by the project team in order for the faculty participants to receive feedback from both the "Master Teacher" and the other faculty participants.

Pilot Testing

Pilot testing is just beginning as of the writing of this paper. By the time of paper presentation, results will be available for not only the pilot testing for the first six months of the continuing education offerings for nurse educators. Nursing faculty members from both schools constituted the 20 pilot testers in five different groups.

Results

Content experts had no familiarity with the SL environment and were unsure of the potential capabilities of providing a simulation experience in this world. They continued to want to rely on video production rather than graphic representation of situations. A standardized scripting format including the "props" for the simulation was helpful in moving the project forward. Scripts were developed for each setting (outpatient,

in-patient, nursing home, and home) that included three different sets of objectives with three matching scripts. This provided the faculty participants with choices and allowed the "Master Teacher" to role model teaching behavior in one of the scripts while allowing two student teachers to guide the remaining two scripts. Practicing these scripts and providing the appropriate feedback was a crucial development activity for the project team.

Much was learned in the development of the SL environment. Using the plans of real buildings resulted in a claustrophobic effect when using an avatar to navigate. This was because of the camera angle being above the head of the avatar. Hallways and rooms were widened to accommodate this problem. Figure 2 illustrates the expanded hallways.

Figure 2 – Expansion of Hallways

In addition, once a group of avatars were clustered within one room for a simulated experience, the room became crowded and difficult for the designated caregiver to navigate. Early attempts at having the "observer" avatars either suspend themselves in the air or sit on an observation wall were dropped when it was determined that the inexperienced faculty participants had too much difficulty with these maneuvers. Assigning the observers places to stand in the rooms provided a more viable alternative, as well as enlarging the actual square footage of each room (see Figure 3).

Figure 3 – Nursing Home Room

At the current writing of this paper, the project has completed nine months of a 36 month project period. After pilot testing has been completed, it is planned to offer the simulation modules as continuing education sessions for nursing educators in the states of Kentucky and Tennessee. The final year of the project will offer the sessions as continuing education for nurses in the Southern region of the United States.

Discussion

The environment of SL is one creative solution to synchronous learning that is only beginning to be used in nursing education. A more popular application of SL has been to meet within the SL world in order to present information to one another, usually using a typical Power Point presentation. Another popular use of SL is to have information resources available for a variety of support groups. Several universities have replicated their physical campus within the SL world, and the Duke University School of Nursing has created a popular You-Tube video that demonstrates their SL use [10].

It was never the original intent for this project to build a simulated environment that could be used for both education and clinical care. Because the SL clinical environment has already been created for this educational application, it now becomes feasible to also use the facilities for the provision of actual care that does not require a "hands-on" approach. Faculty at the Vanderbilt University Schools of Nursing and Medicine are partnering to pilot test the delivery of maintenance care to diabetic patients in the outpatient environment (which is a replica of the current Eskind Diabetes Center). It is postulated that these virtual visits will require less time and expense while providing a resource rich environment for those patients willing to enter the SL world for their care

Early in the development efforts the issue of privacy was of monumental concern for the provision of patient care. Anyone on the island that was within 65 meters could hear conversations that were intended to be private between a patient and healthcare provider. In order to ensure that the audio portion of care delivery could not be overheard by others, selected patient care rooms were elevated to levels that could not be accessed by other avatars who were "flying" on the island. In other words, avatars in SL can only fly at 200 meters, but buildings can be built as high as 300 meters. Private patient interactions thus required teleporting by the healthcare providers and patients from within designated privacy protected rooms. A privacy button placed within the room required the avatars to touch the button in order to be teleported to the elevated private room which was suspended above avatar flying levels. Once the visit was completed, the privacy "off" button teleported participants back down to the original building in order to complete any post visit activities and exit the facility. A recent feature added to the SL world now allows for point-to-point discussion between two avatars so that this elevation feature is no longer necessary.

Conclusion

It is feasible to use SL as an environment for nursing faculty to learn how to manage clinical simulations. Although currently

in pilot testing, early results indicate that a "Master Teacher" can provide enough structure and coaching to provide "student teaching" experiences when a cadre of seasoned nursing faculty is not available to all. Using SL does require orientation to that environment for those learners who are not familiar with its features, but it remains a viable choice for those willing to take on the challenge. At the same time, production of various clinical facilities allows for them to be used with groups of students (nursing and interdisciplinary). Perhaps the most important contribution to this project will be the use of constructed facilities to provide an alternative choice for the provision of patient care in an era when computer usage is ever increasing.

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Teaching During a Pandemic Event: Are Universities Prepared?

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Abstract

As the threat of pandemic events streaks across the planet, the question then becomes can universities, particularly health science centers charged with producing the next generation of health care providers, continue their teaching and educational mission by offering classes in a distance environment, completely uncentralized, away from the traditional centralized campus? A sampling of campus websites were reviewed to gather a sense of how well prepared we are, followed up with a survey administered to faculty and staff in the School of Nursing at Vanderbilt University. The concern being that if a technology rich environment such as Vanderbilt is not fully prepared to continue teaching in a pandemic event, what concerns should we have for other institutions providing health care provider education that may not have access to the resources a Vanderbilt has? Finally, a set of recommendations to schools is presented, based on the findings.

Keywords:

Educational technology, Audiovisual aids, Multimedia, Education distance, Videoconferencing, Education nursing.

Introduction

This is an interesting time to be teaching. The threats of a pandemic event on the mission critical functions of a teaching university can be overwhelming. With the threats of pathogens and natural and man-made disasters impacting schools and businesses around the world, it is important that universities, (particularly with health care programs producing the disaster responders) be prepared to carry on their academic mission through the event. Lim et al [1] clearly describe the problems associated with closing professional schools with a healthcare orientation. While it may very well be accepted practice to close schools and give credit to students for work covered (as what happened in many institutions in the United States during the Kent State University event in 1970 [2]) it is inappropriate to extend that practice in today's world, particularly to those training to enter the field of healthcare. This means it is important that schools of nursing, medicine, dentistry, and pharmacy be prepared to continue the instructional process even while a school closure and suspension of teaching activities is happening all around them.

The question then becomes how well prepared are institutions and the faculty and staff in those institutions to continue educating during a pandemic or disaster event? If a pandemic event, perhaps caused by H1N1 swept across an institution, would that institution be able to quickly implement new teaching environments to replace the traditional face to face lecture presentations currently in place now?

Materials and Methods

A quick perusal of institutional websites around the world show that colleges and universities are giving this issue real thought. A number of institutions have posted websites outlining various features faculty should consider using in the event of an official or unofficial closing. [3-8]. For purposes here we will define an "official closing" as one in which the school administration has told students and faculty to stay home. They may dismiss students from the dormitories. Of course the problem about what to do with students who are too sick to travel home, or have no place to get to quickly is a confounding factor. But precedent for official closings does exist. Probably the most well known were the closing across the United States that took place after the Kent State University incident where national guardsman open fired upon student protest demonstrators resulting in four deaths. [2] However, that was a different situation as students, and faculty were angry, but not sick. While over 4 million university students "struck" by refusing to go to classes nationwide after the event, they could, if they so desired, continue to read, organize and meet face to face. Also at that time there were few options for continuing collective education when the students were suddenly dispersed across the country. While the current situation with regard to H1N1 may result in some official school closings, it is far more probable that we will begin to see large numbers of "unofficial school closings". For the purposes here an "unofficial school closing" is one in which the faculty member and/or large numbers of students are too sick to come to class. The university does not officially close the institution, rather people are just too sick to show up for work, either as a faculty member, staff person supporting the academic environment, or the students themselves.

As one examines this problem of continuing the educational process in the face of a pandemic event, it is clear that there are three stakeholders in this problem. Obviously there are the students themselves. While many students would briefly relish the time off, most students in professional schools recognize that this creates a direct hit on the quality of their education. There are knowledge, skills, and content they know they need to know, and simply giving students "time off" will not ac-

complish their goals. Many spend a lot of money on their tuition and they have a reasonable expectation to be taught.

The second stakeholder is the faculty member. They have defined content they know they need to get through so that the student may advance in the program. They have spent considerable time and effort refining their course syllabus and providing the right types of lectures and presentations, typically in a face to face traditional classroom environment. They have assignments that make and papers that need to be submitted for grading and evaluation. Finally, of course there is the typical sit down examination at various points in the course. Even if students are able to meet for a test, these exams would have to be completely rewritten to account for the fact that significant content may have been missing because of lost lectures. Included in this group are deans and associate deans who not only teach courses in their academic programs, they make sure the correct policy decisions are implemented and enforced. If closing decisions are made at the college level, these administrators need to have a significant presence during the entire decision making process, even if they too are home sick.

Lastly there is the academic support staff that many faculty members rely on to accomplish the more mundane tasks of collecting papers, duplicating handouts, typing exams, and providing library materials on reserve. Without these people the academic mission can grind to a halt. In addition, support staff members provide the administrative support needed to continue the infrastructure of the school such as making sure that people are paid correctly and on time, tracking work time, and paying the bills the school incurs. Finally there is the technology support staff to be concerned about. If the people maintaining the servers, software, and network become ill what happens when their efforts are needed to provide support to the faculty, staff, and students of the institution?

Reviewing the academic plans institutions are providing their people is an interesting exercise. While none reviewed made reference to any type of data collection process to see what is needed, they did, instead, focus on what their institution can provide currently for their stakeholders. Some websites were very specific, dealing with the applications and services they can provide. Others were more general and dealt with why one should use various approaches rather than the specifics of how to use a specific application.

Four assumptions seem to dominate the discussion online. First, there is the assumption that institutions "know" what is best for their stakeholders and have no need for data collection. Secondly, there is the assumption that the institutions already have in place the correct technology in terms of mission and quantity to address the problem. Third, there is the assumption that the stakeholders have the right type of technology at home to deal with any type of work from home situation (whether they are faculty, staff, administrators, or students). Finally there is the assumption that the stakeholders will be able to train themselves quickly and just in time on any technologies needed to work from home. These assumptions are very short sighted. Let us deal with each of these assumptions in sequence.

Assumption 1: Institutions know what is best for their stakeholders. The problem with this approach is that the decision makers typically are not "in the trenches" and have very little knowledge about what is really needed. These decision makers often have no teaching responsibilities and typically do not interact with faculty, support staff, and students regarding the act of teaching. While they may know in general terms, the devil really is in the details and they never have a real opportunity to learn the details from an instructional point of view.

Assumption 2: Institutions already have in place everything they need. Academic budgets are eclectic. When money is available a product or two may be acquired, but typically this happens with little planning and lots of penny pinching. Hardware and software licenses are frequently underestimated (or overestimated) with little effort to build the environment to capacity correctly. For example, at Vanderbilt University, which would be regarded as a rather typical institution using a course management system, such as Blackboard, less than half of the classes have a significant Blackboard presence. If suddenly the other 50% decided to use the course management system extensively, could it handle the sudden increase in load? Often it is one or two vocal stakeholders who decide what should be purchased and implemented, often times at cross purposes with the rest of the institution. If the products are acquired with grant monies, they may not meet the direct needs of the institution because of grant limitations. Furthermore the grant investigator gets to decide what he will spend his resources on. Finally, grants are typically not cross disciplinary. This means they acquire software specific for their situation and often mount it on servers they are directly involved with and not shared with the rest of the institution. Universities are often "silos" fostering this behavior.

Assumption 3: Stakeholders have the right technology at home. Do they and what are the consequences if they do not? Later we will report survey data at our own institution that clearly belies the opinion that even in 2009 our faculty and staff are appropriately configured at home. Failure to have the right setup at home means they cannot function as they do at work. Furthermore, as the data that follows shows, there is a strong reliance in the Vanderbilt University School of Nursing, for example, on the use of administrative assistants (secretaries) who, for a variety of reasons are less configured at home than the faculty. Finally, none of the technology does any good if the students are inadequately prepared at home.

Assumption 4: Stakeholders will train themselves in what they need to do just in time to do it. Will they? Some of this technology is complex with a significant learning curve. Most institutional websites we reviewed offered little in the way of real training, opting instead to let the users train themselves as best they can once they have identified what technology they wanted to use for their classes.

The question then becomes how well prepared is the health sciences academic area, to provide real education to our students in the event of a pandemic closure? The answer appears to be "not very." The Vanderbilt School of Nursing (VUSN) has one of the premiere informatics support areas of any school of nursing in the world. With 18 faculty and staff members in informatics, out of a total of 242 employees, with

expertise in educational informatics, software development and design, use of interactive communication tools such as web and video conferencing, and with extensive course management system experience (two of the faculty actually developed an early prototype of a CMS in the mid 1990s), VUSN is well positioned to help faculty and staff use technology extensively in their teaching. In addition, 7 of the 9 masters specialties have a significant distance education component as part of a blended program that has the students show up on campus only one or two long weekends per semester. In short, the faculty are very well versed in the tools of distance education (the exact set of tools they will use if their students cannot come in at all) and do just about everything on Blackboard including administering exams, even if the program is not a distance specialty. Therefore, it was natural to assume that the faculty and staff would be exceptionally well prepared to continue the educational mission of the school, even in the event of a pandemic closing.

A careful review of institutional websites about teaching in a pandemic situation is rather enlightening, more in what it does not say than what it does say. First of all very few institutions have program specific websites related to this issue, opting instead to have a general university approach to the problem. This "one size fits all" approach may play well in the press, but in practice, with a myriad of programs and needs it is doomed to fail many times. Most likely individual schools within a university do not have the support personal, hardware, and software to go it alone and must rely on an institutional response to succeed. Clearly some things must be institutionally based. (It makes little sense for individual colleges in a university to have their own course management systems for example) but the tools that are promoted in a specific program (even down to the specific tools and features in a course management system) must be college and program identified and supported. For example, the instructional technology needs teaching statistics in a Doctor of Nursing Practice (DNP) program are far different than the technology needs of an English Professor in an undergraduate Arts and Sciences program. A statistics professor needs presentation programs that demonstrate statistical techniques to his students, whereas the English professor needs tools to allow students to engage in more real time discussions. What universities typically do is provide a collection of tools hoping the individual faculty members will find an appropriate tool in this smorgasbord and learn how to use it, and then learn how to use it effectively, all within a very short period of time.

In order to determine where the Vanderbilt School of Nursing is, in terms of faculty and staff technology capabilities at work and at home, a brief survey asking them about their capabilities was prepared and electronically distributed through Survey Monkey. A small number reported themselves as administrator, but administrators were asked to report themselves as faculty if they do a reasonable amount of teaching during the year. The thinking here is that the focus of the effort for the relatively brief closure time needs to be the direct support of the instructional mission. Most likely software required for teaching would be a superset of software access required for administration. The survey was divided into two components. The first component was filled out by everyone and dealt with infrastructure capabilities at home. The second component dealt entirely with teaching needs. This second section was filtered by role so that only those reporting as doing a significant amount of instruction, either didactic or clinical, were asked these questions. The faculty and staff were given 10 days to complete the survey. The students were not surveyed because the students need to have the correct hardware and software, as a prerequisite for admission into the program, to function in a distance environment (even if their academic program is not a distance program). All of Vanderbilt's nursing students have contemporary PCs (including some Macintoshes) and broadband connectivity. The only area where students appear to be deficient is in the number of systems with webcams for video conferencing, but in the event of a closure, because of class size, video conferencing would probably not be used outside of the PhD program anyway, and those students already have webcams. Furthermore, the costs of webcams and their ease of use means they could quickly acquire one should the need arise. Interestingly, students rarely complain about the technology requirement. While that could be the type of student Vanderbilt attracts, more likely it is that today's students in the health professions just know that personal ownership of contemporary technology is an important component of their educational responsibilities.

Results

Based on the survey results and follow up interviews with faculty and staff the following competencies were identified but everybody does not need to know everything:
Competencies (infrastructure):

1. Installing/using Virtual Private Network
2. Creating drive mappings/transferring files
3. Using Remote desktop
4. Checking bandwidth
5. Configuring headset and/or webcam

Competencies (applications):

1. Posting documents and hyperlinks
2. Creating/administering a test
3. Using discussion board/wikis/blogs/social networking
4. Using web/video/text conferencing tools
5. Creating/posting narrations (Powerpoint/screen recordings)
6. Using assignment submission

The following tables show the response rate to the survey as well as the areas that are deficient.

Table 1 – Overall Response Level

	Faculty	**Support Staff**
Total. Number	109	78
Reporting (%)	87 (80%)	63 (81%)

Table 2 – Strengths and Deficiencies at Home

Capability at home:	Faculty	Support Staff
Computer	85 (98%)	60 (95%)
Broadband	85 (98%)	53 (84%)
VPN	25 (29%)	20 (32%)
Narrated Powerpoint	33 (38%)	N/A
Headset	33 (38%)	N/A
Other software needs	30 (34%)	N/A
Assignments in Blackboard (Bb)	66 (76%)	N/A
Post Material in Bb	59 (68%)	N/A
Test in Bb	18 (21%)	N/A

Faculty members teach extensively with Powerpoint, yet have learned to use Powerpoint to provide "talking points". Simply providing the students their slides without any audio narration to accompany the slides renders the presentation essentially useless. Currently only 38% of our faculty know how to narrate a Powerpoint presentation for posting in the course management system. Audio quality is a significant issue. Built in microphones in laptops provide a hollow sound making the narration difficult to understand. The solution is to narrate Powerpoint slides using a microphone headset, yet less than 40% of the faculty have such a device. 34% of the faculty want to show things other than Powerpoint slides, yet only two have the ability to create screen recordings and convert them into a format that can be posted in Blackboard. While 76% of the faculty know how to receive assignments from students in Blackboard, only 21% have the personal ability to create and administer an exam in Blackboard. However, since almost all the faculty use the Blackboard examination feature, how can this be explained? It turns out, upon further questioning that faculty rely heavily on administrative assistants to do this type of work for them. They provide the assistant with test, in Word format, and the assistant then puts that effort in the Blackboard utility. The implications for this are significant if the school becomes involved in a pandemic event. The question then becomes if a faculty member creates an exam or wants to post content to Blackboard, and they typically have their administrative assistant complete the effort, is the administrative assistant going to be able to work with this from home? The answer, even in a technology rich environment such as Vanderbilt University, is equivocal. While 84% of the administrative staff can reach the internet from home, that includes all 15 information technology (IT). support people as well. It appears that only 46 of the 63 true administrative assistants reporting have that capability. That means 1/3 of the support staff either do not have that ability or haven't indicated that they have that ability. Preparing for a worst case scenario requires the assumption that no response likely means they cannot do it. In short, faculty are relying on personnel who will not have the ability to do this ,from home. The problem is compounded by the fact that only 32% of the administrative assistants have true Virtual Private network (VPN) knowledge and connectivity to be able to carry out the complete academic mission from home. VPN software allows the user to access IP restricted resources on the campus. The situation regarding administrative assistants is very serious when it comes to broadband connectivilty. Only 84% of the administrative assistants have some form of broadband connectivity from home. This means some do not have the infrastructure to their homes to provide real service to the faculty, even if they have the correct software and are trained in its use.

The faculty situation is appreciably better. 98% have a functional home computer (either desktop or laptop) to work from and 98% have broadband capabilities to their home. One concern is that only 29% of the faculty have the VPN client installed on their home computers. Lack of VPN capabilities mean they will not be able to get to their office desktop machines, through remote desktop nor will they be able to get to files stored on departmental servers.

Implications

The implications for what this means in terms of carrying out the educational mission of the school of nursing are profound. On the staff side, the administrative assistants need to acquire broadband services at home. Part of the problem is that some of these individuals live in locations where broadband connectivity is either unavailable or prohibitively expensive. Their personal resources may be low and they may have to be financially incentivized to do this. At the very least those without capability at home need to be identified with what responsibilities they are in charge of, and develop methods for shifting those responsibilities either back to the faculty member or to other administrative assistants who have capability from home. As the data show, currently faculty are very reliant on administrative support personnel to do a lot of the work related to technology, for them. Relying on individuals who, in much larger measure, do not have the capabilities at home to carry out the task makes little sense.

Specifically what do institutions need to do to be able to continue the educational mission of these professional schools during the pandemic event? First, the faculty need to become aware of what technology teaching solutions are available, both inside their institution and what can be acquired from outside the university. They need to conceptualize how they would teach their courses from a distance and what software they need to do this. Trangenstein [10] has created a toolkit set that explains the various options available to the faculty in schools of Nursing. There are perhaps some course content that cannot be taught through distance education techniques. This content will have to be put on hold until face to face classes reconvene after the pandemic event is over.

Secondly, software needs to be acquired in sufficient license quantities so that faculty can continue the teaching mission of the institution. At Vanderbilt School of Nursing we have Blackboard as the course management system, Camtasia to record narrated Powerpoint presentations, Centra for synchro-

nous web conferencing, and Scopia for small group video conferencing with webcams. Vanderbilt also provides servers to store video files to be viewed in classes asynchronously.

Third, support materials need to be created to teach faculty and staff the tools they need quickly and in a timely manner. Production of PDF brief training manuals, quick reference guides, and brief (3-7 minutes in length) narrated screen recordings can all be posted online. Break longer videos into shorter segments each centering around a specific technique or concept. Faculty and staff will not listen to long winded presentations when they are attempting to get a class up and running quickly. Examples from Kent State University [6] and Vanderbilt School of Nursing[10] are demonstrations of ways of doing this effectively. Avoid generalized approaches that do not get specific quickly. In an emergency, faculty do not have the time or patience to wade through pages of general explanations. They want to learn how to do what they want to do quickly and immediately. Avoid wasting time by discussing features they have little chance of acquiring or using.

Fourth, give the faculty the opportunity to try these techniques before they need them and strongly encourage them to do so. At Vanderbilt a new server was installed to use with narrated Powerpoint presentations. The use of this server is now required even though it really would not be technically necessary until a closing. Attempting to learn how to use new software applications or hardware in a crisis is often just not successful.

Fifth, make certain that the IT support people are philosophically on board and realize it is their responsibility to keep the technology running during the pandemic event. Give them the tools they need to manage servers, networks, and software licenses from home. They may not be allowed on campus either.

Sixth, determine what prerequisite hardware and software are required to manage each application. Faculty may need headsets, webcams, robust network connections, and expensive software, all in their home environments.

On the school side, training materials (consisting of online printable manuals and screen recordings of the actual application) will have to be created, aggregated onto a website, and made available to staff and faculty well in advance of the need. Convincing faculty and staff to learn this material well in advance of the need is an interesting training challenge but one we are overcoming. In the past 72 hours since this article was outlined, traffic to our website has dramatically increased, two faculty have requested additional one on one help, and three administrative assistants have asked for additional work in this area. Faculty are transitioning to taking charge of their own technology and the administrative assistants are recasting their role from what has traditionally been highly secretarial to one of technology support. This shows people are ready to make the move if given the correct tools, training, and resources.

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An approach to simulate and visualize intraoperative scattered radiation exposure to improve radiation protection training

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Abstract

Intraoperative radiography based on mobile image intensifier systems (C-arms) is widely used during the treatment of trauma and emergency patients. These devices produce scattered radiation, potential hazardous for surgeon and operation room personal (ORP). The propagation and intensity of scattered radiation is not intuitive, is not perceivable by human senses and depends on many variables. At courses on radiation protection the knowledge of the behavior of scattered radiation and the modus operandi to minimize the radiation exposure should be taught to ORP and surgeons. Currently this can only be done theoretically using fixed pictures and precalculated videos. This paper presents an approach to interactively simulate and visualize scattered radiation with a computer based training system for mobile image intensifier systems. The simulation depicts radiation propagation and intensity for arbitrary C-arm adjustments and different irradiated materials. This teaching component focuses on improving the current radiation protection training with interactive visual and practical aspects.

Keywords:

Scattering, Radiation, Computer simulation, Imaging, Three-Dimensional, Education, Radiation protection, Radiography, Interventional

Introduction

During surgical treatment of human and veterinary trauma and emergency patients or in catheterization laboratories mobile image intensifier systems (so called C-arms) are widely deployed to produce intraoperative radiographs. These radiographs are used for controlling, monitoring or documentation purposes during the intervention. Using C-arms the surgical outcome can be enhanced and by this the number of follow-up operations can be reduced. Due to the mobility of a C-arm, achieved by mounting the radiation source and the image intensifier on a freely movable C-construction (see Figure 1), one can create radiographs from every point and viewing angle around the narcotized patient. But this freedom in movement leads to the problem that radiation shielding arrangements, well known from stationary X-ray devices, are very hard or even impossible to install. Beyond that the surgeon, respectively the operation room personal (ORP) cannot leave the operation theatre (OR) during the radiograph generation process, as it is mandatory for stationary X-ray devices. Hence the staff in the OR is frequently exposed to radiation. The biggest amount of this exposure for surgeon and ORP is caused by scattered or so called stray radiation [1, 2]. The scattered radiation is emitted by the irradiated area of the patient every time a radiograph is generated and spreads in all spatial directions. The propagation and intensity of this radiation depends on many variables, for example the intensity and direction of the primary beam, the density values of the irradiated materials and the positioning and type of different objects in the OR [3]. Therefore the prediction and understanding of scattered radiation behavior is not intuitive. In spite of mandatory radiation protection clothes there is still a permanent stochastic risk for the staff regarding radiation injuries through the frequent radiation exposure. Thus to minimize the radiation exposure for all persons in the OR it is necessary that the surgeon and the ORP are able to position and adjust the mobile image intensifier correctly to get a meaningful radiograph with a minimum of scattered radiation. This implies that they understand the behavior of scattered radiation and that they know where regions of high radiation doses for certain adjustment situations are located, so they can take the safest position during the radiograph generation process. This knowledge about scattered radiation is usually presented to ORP and surgeons in courses on radiation protection. In Germany and other countries ORP have to visit these courses by law. Due to the fact that training with real radiation is potentially dangerous, which makes it prohibitive, and that radiation itself could not be perceived by any human sense presentation and education of the knowledge on how to diminish scattered radiation exposure during these courses is only done in a very theoretical way with images, textbooks or precomputed videos. Here the question arises if it is possible to enhance the radiation protection courses with interactive simulation and visualization of scattered radiation embedded in a computer based training system to be able to

demonstrate the complex correlations in a practical and visual way.

This paper demonstrates an approach to simulate and visualize scattered radiation for the mentioned training purposes during radiation protection courses.

Materials and Methods

The computer based training system virtX

In order to improve the teaching and training of the correct adjustment of mobile image intensifier systems the computer based training (CBT) system virtX was developed at the Peter L. Reichertz Institute for Medical Informatics in cooperation with the Georg-August-University Goettingen and the University of Applied Sciences and Arts, Hannover. This CBT system (see figure 1) offers exercise based training of the correct positioning of the C-arm for routine adjustments. A trainee can move three-dimensional virtual representatives of the C-arm, the patient and the operation table in a virtual operation theatre by using mouse and keyboard or by moving a tracked real C-arm and patient manikin which control their virtual pendants. During an exercise the trainee can generate a digitally reconstructed radiograph (DRR) at any time based on real CT-datasets and gets feedback via a traffic light, if the correct positioning is achieved. For detailed description of the system see [4-7]. Different prototypical versions of scattered radiation simulation and visualization have already been integrated in the virtX system and described and evaluated in [7] and [8]. The new simulation and visualization approach described in this paper uses the results of [8] as a foundation.

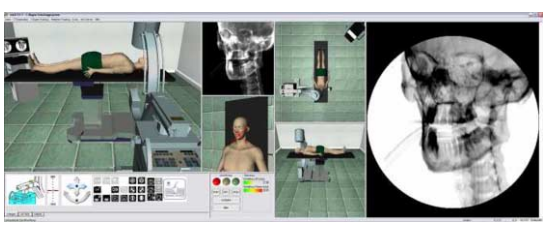

Figure 1 – Graphical user interface of the computer based training system virtX

Simulating scattered radiation using GEANT4

To calculate the physically correct behavior of radiation Monte Carlo simulation methods are a widely used and accepted procedure [9]. For the new approach of scattered radiation simulation which was integrated in the virtX training system we used the GEANT4 (*Geometry And Tracking*) toolkit in the version 4.9.3 Beta 1 [10] which uses such Monte Carlo methods to simulate the passage of particles through matter. This toolkit which uses the *Class Library for High Energy Physics* (CLHEP) is written in C++ and was developed at the European Organization for Nuclear Research (CERN). With GEANT4 a virtual environment can be constructed in which the physical interactions between a specific number of particles or photons with different objects are simulated. The user can create these objects using different geometries in the GEANT4 simulation world and specify their material properties and electromagnetic fields. For these geometries sensitive detector areas can be defined, which protocol every hit of a photon or particle. Furthermore it is possible to create primary generators in the simulation world, which emit a specific number of primary particles or photons with a discrete energy and moving direction. During one run GEANT4 simulates for every primary its way through the simulation setup until it is absorbed or it has left the simulation world.

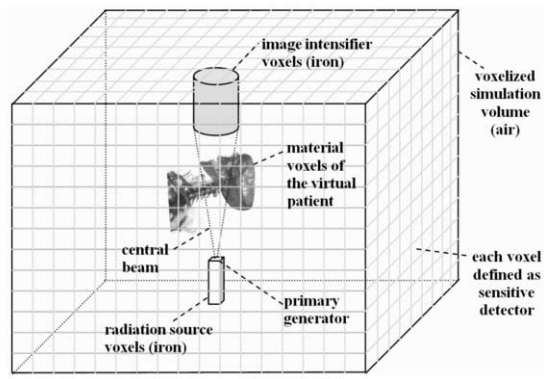

Figure 2 – Schematic description of the simulation setup in GEANT4

Similar to [8] the GEANT4 Toolkit was ported into the Visual Studio 2009 IDE so it could be integrated in the virtX project. In contrast to the simulation setup described in [8] the new approach uses a complete voxelization of the simulation environment. The simulation world, which was set to the size of 3m x 3m x 3m, was divided into 27 million voxels (300 x 300 x 300) of equal size. Each voxel was defined as a sensitive detector which protocols, depending on the simulation settings, either the energy deposit (respectively dose) in this voxel or the photons with their energies that are entering the voxel. During the initialization phase of the simulation first of all each voxel is set to the material *air* to briefly represent the operation theatre. Subsequently voxels for the C-arm are set to material *iron* depending on the geometrical properties of the simulated image intensifier (e.g. tube-image intensifier distance, image intensifier diameter).

For every simulation step the materials of the virtual patient are integrated in the corresponding voxels in the simulation setup depending on how the C-arm and the primary beam are adjusted over the patient. This is done by using the CT-datasets from the virtX system which are utilized to generate the DRR (comp. [4] and [7]). These datasets contain scaled Hounsfield values and are matched to the 3D patient model. To get the different materials for the patient-voxels in the simulation these scaled Hounsfield values are mapped to different types of tissue and their material compositions. Afterwards the indices of the voxels (where the material values have to be

set) are calculated using the rotation and location differences between the primary beam and the movable CT-datasets of the virtual patient. Similar to the simulation setup described in [8] a primary photon generator was defined next to the voxels, which represents the radiation source of the C-arm. This primary generator produces a user defined number of gamma photons with an energy which could be adjusted by the tube voltage parameter in the virtX training system. The moving direction of these photons is set randomly in the area of the central beam of the C-arm, which is defined by the tube-image intensifier distance and the image intensifier diameter. The schematic simulation setup is depicted in Figure 2.

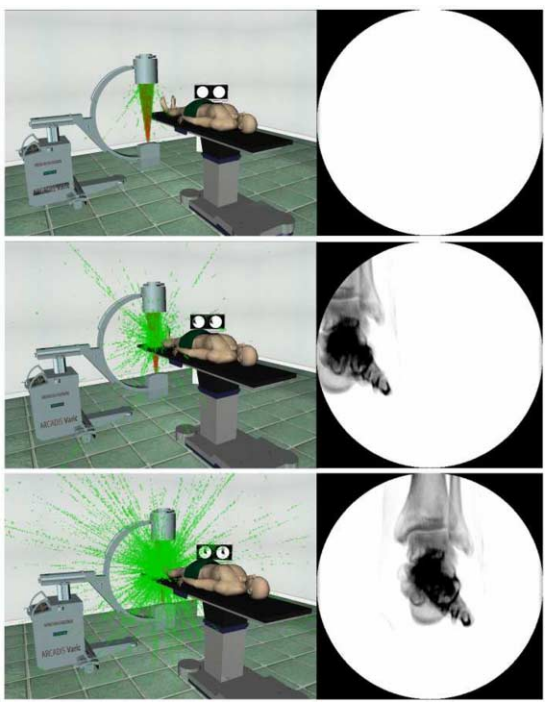

Figure 3 – Visualization of the scattered radiation simulation results in virtX

To visualize the simulation results of the GEANT4 toolkit a volume with the same voxel count and dimension as the simulation volume was integrated in the existing virtual operation theatre of the virtX CBT-system. This volume was coupled with the movement of the virtual C-arm and each voxel was set in correspondence with the sensitive detector voxel of the simulation volume. A transfer function was implemented which maps the resulting values (for example energy deposit or photon flux of the voxel) to semitransparent color values. In this way the color of every voxel in the visualization volume depicts the simulation values. In the current visualization version the colors green, orange and red are used to illustrate low, medium and high resulting energy deposit respectively photon flux for a voxel. The threshold values for the mapping of the calculated values to the colors can be adjusted over a graphical user interface in virtX. Figure 3 depicts the scattered radiation visualization results for three different C-arm adjustments over an ankle joint with the DRR and the corresponding photon flux for a tube voltage of 80kV. In these examples 5000 photons were simulated and the values represent the sum of the energy of passing photons (threshold values: green 0.1 MeV, orange 1 MeV, red 10 MeV).

Table 1 – Calculation times for the scattered radiation simulation for different numbers of simulated photons and irradiated materials

number of photons	Calculation time in seconds		
	only air	half ankle joint irradiated	full ankle joint irradiated
1000	6.1	9.9	11.4
2500	10.7	17.7	22.6
5000	17.8	30.8	41.6
10000	32.8	57.3	80.7
15000	47.2	85.8	116.7
20000	60.4	113.7	157.3

Results

Comparing the simulation results with isodose curves, which were measured during the operation of a real mobile image intensifier system, the presented simulation and visualization method represents the same information in a more interactive and spatial way for the teaching purposes during courses on radiation protection. A problem calculating physically correct behavior of scattered radiation for varying setups using Monte Carlo simulation methods is calculation time. The approach described in [8] already showed that it is possible to simulate and visualize the propagation of scattered radiation in an acceptable time for the mentioned training purposes with a certain abstraction layer. The new approach presented in this paper decreases this abstraction by integrating density values of a real CT-dataset into the simulation, cutting the simulation volume into voxels and visualizing the simulated results on every point in the virtual operation theatre. This offers a more realistic simulation and a more intuitive visualization than the previous approach. But this improvement increases the calculation time for every simulation step. In table 1 the calculation time for different numbers of photons and irradiated areas is listed (calculated on a standard PC: Intel Core2 Quad Q9000 CPU at 2.00GHz, 3GB RAM, Nvidia GeForce 9800M GS). Caused by the simulation algorithm of GEANT4 the calculation time gets bigger the more different materials are irradiated respectively gets smaller the more similar materials are irradiated. So the resulting calculation time only seems to be appro-

priate for a use during teaching courses for a small number of photons.

Discussion

Summarizing the aspects of this new simulation and visualization concept integrated in the virtX CBT-system one can say that it is possible to demonstrate the behavior of scattered radiation for different C-arm adjustments and irradiated materials in a virtual environment. However a faster calculation time and a more intuitive visualization (like isodose or risk curves) would be preferable. Currently the calculation for the simulation is done sequential. A speedup of the simulation by using multithreading or General-Purpose Computation on Graphics Hardware (GPGPU) methods for example with the CUDA architecture and programming API [11] has to be analyzed in future work. Furthermore not all objects in the operation theatre are currently taken into account for simulation. It would be preferable to simulate the effects on the scattered radiation behavior when using different types of operation tables, different positioning of surgical or anesthetic equipment or the different position of the surgeon and the ORP.

It would also be helpful for teaching and training during the radiation protection courses, if the virtual operation theatre in the virtX system contains movable avatars of the surgeon and ORP, which measure and visualize their individual body part radiation exposure. Through this trainees could test different C-arm adjustments and personal locations and instantly get a feedback over the specific radiation exposures and areas with high radiation risks. Also a correct modeling of the radiation source for better simulating radiation leakage or the X-ray spectrum of the central beam and an integration of the aperture functionalities of the mobile image intensifier in the simulation setup would additionally increase the level of realism of the whole scattered radiation simulation. Further research has to be done to evaluate the learning effect of this new teaching tool and to improve the level of realism and physically correctness at an acceptable amount of calculation time.

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A Compositional Personalization Approach for Designing Personalized Patient Educational Interventions for Cardiovascular Risk Management

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Abstract

Providing patients with personalized educational messages can improve self-management of Cardiovascular Disease (CVD) risk factors. We present our compositional personalization approach that generates personalized educational material by dynamically selecting fine-grained information snippets, as per the patient profile, and then synthesizing them in a educational template to yield personalized patient education interventions. We apply our personalization approach in the PULSE system—Personalization Using Linkages of SCORE and behavior change readiness to web-based Education—that generates personalized patient education for CVD risk management. The PULSE framework involves the calculation of CVD risk assessment using the Systematic COronary Risk Evaluation (SCORE) algorithm, the estimation of readiness to change using the Transtheoretical Model (TTM) of intentional behavior change. The educational interventions were derived from evidence-based staged lifestyle modification materials and Canadian guidelines for CVD risk management.

Keywords:

Patient education, Self-management, Risk assessment, Cardiovascular, Information personalization

Introduction

Patient education, especially for chronic health conditions, is an integral component of disease management, especially in a self-management context. Patient empowerment through education is geared towards encouraging patients to take increasingly responsibility for the management of their own health and wellness, whilst the role of the healthcare providers is the medical management of the disease [1]. Lately, there have been a number of programs that aim to empower individuals through educational programs to help them make informed choices about therapeutic options, risk assessments and lifestyle modification to ensure healthy lives. Such patient education programs offer evidence guided interventions, disease-specific care plans/maps and access to healthcare resources to improve patients' health status by influencing changes in patients' health behaviors and/or attitudes.

In general, patient education is practiced through the provision of 'generic' health educational material in the form of print materials (pamphlets or booklets) and/or Internet based health portals. Despite the benefits of patient education the rate of uptake of the educational material by patients is always a major factor in determining the impact of the educational program towards meeting the desired self-management targets. Typical educational material is designed to cover general issues pertinent to the needs a patient population, and from a patient's perspective they provide useful information but the information is not customized to the patient's specific needs. Lately, in an attempt to engage patients to self-manage their health and risk factors, patient education researchers have developed various approaches to personalize the rather generic patient education material towards the specific needs of individual patients [2, 3]. Personalized recommendations are more likely to be acted upon by patients since they can relate it to their own health targets. Lately, computer-based personalized patient education programs have made significant changes in the health and behavior of their targeted audience [4, 5].

Personalized patient educational programs can be made more impacting if we take into account the patient's underlying (a) perceptions and attitudes towards his/her health risks; and (b) behavioral disposition towards the uptake of any risk modification information [6]. If the patient is not fully prepared to accept the educational interventions to make lifestyle modifications, then even a personalized education program may be rendered ineffective in achieving the desired health outcomes. Therefore, we argue that the personalization of patient education material should be guided by patient's behavioral readiness to uptake educational interventions (in addition to the patient's health profile). Our strategy to personalize patient education is: (a) *determine* the patient's attitude towards his/her health condition and the associated risks and then establish their readiness level to make lifestyle changes; (b) *educate* the patient so that he/she contemplates lifestyle changes; and (c) *modify* the patient's lifestyle through personalized educational material that targets both the patient's behavior and health conditions.

In this paper we present a computer-based system to personalize patient education programs for the CVD risk management. The PULSE system—Personalization Using Linkages of SCORE and behaviour change readiness to web-based Education—personalizes educational material based on the patient's (a) ten-year CVD risk assessment calculated using the Systematic COronary Risk Evaluation (SCORE) algorithm [7]; and

(b) readiness to change risky behavior, which is determined using the Transtheoretical Model (TTM) of intentional behavior change [8]. We present a compositional information personalization method that involves the dynamic composition of a personalized educational package by (i) systematically selecting multiple, topic-specific, individual *snippets* of information based on the patient's behavioral and health profile; and (ii) synthesizing the selected snippets based on a patient-specific presentation template. The personalization logic was derived from Canadian clinical guidelines and behavior change literature, and was represented using Medical Logic Modules (MLM). The educational material covers both medical and psychosocial aspects of CVD risk management, derived from a combination of staged lifestyle modification and non-staged messages based on Canadian clinical guidelines. A web-based interface was developed for PULSE to interact with and to present a personalized educational package to the patient. We also report a small pilot user-study involving patients with CVD risks—the results highlight the efficacy of PULSE.

Materials and Methods

The key aspect of the technical design of PULSE is our compositional information personalization method [9]. The entire educational material is decomposed into multiple individual educational messages, called *snippets*, where each snippet addresses a particular health issue, targets a specific set of patient parameters and is relevant to a specific stage of change. Our strategy is to dynamically construct a document by systematically (a) selecting a set of snippets that are directly related to the patient's health conditions and behavioral stage of change; (b) synthesizing the selected patient-specific snippets to yield a seamless personalized educational package. Our compositional information personalization strategy accounts for fine-grained distinction between patients along multiple dimensions, and hence generates highly personalized educational packages [10]. In the forthcoming discussion we discuss the main components of PULSE—i.e. (a) a behavioral change model; (b) a patient data capture template; (c) a patient profile; (c) a message library storing the educational material as snippets; (d) the personalization logic that maps the patient profile to relevant snippets; (e) a presentation template to synthesize the snippets; and (f) a delivery medium to present the personalized educational package to the patient.

Behavior Change Model

For CVD risk management, we leverage behavioral models to explain and predict the patient's adoption of health-promoting behaviours or elimination of health-damaging behaviours. We use the Transtheoretical Model (TTM) of intentional behavior change as it guides the patient through the process of modifying problem behavior(s) and acquiring positive behaviors [9]. TTM consists of three key constructs: (i) Stage of Change - a characterization of a person's readiness to take and sustain action; (ii) The behavioral processes of change, representing how change occurs from one stage to another; and (iii) The decisional balance measures that indicate the patient's progress through the stages. In PULSE, we designed educational interventions that correspond to patient's needs at different stages of change. Table 1 shows our abstraction of the integrated TTM variables as used in personalizing interventions for CVD risk management.

Table 1 – Transtheoretical Model for CVD risk management

Stage of Change	Behaviourial Change Process	Decisional Measures	Pros Vs. Cons
Stage 1: Pre-Contemplation	Consciousness Raising, Dramatic relief	Confidence low Temptation high	Pros < Cons
Stage 2: Contemplation	Self Reevaluation, Self Liberation	Confidence low Temptation moderate	Pros <= Cons
Stage 3: Preparation	Social Liberation	Confidence moderate Temptation moderate	Pros >= Cons
Stage 4: Action	Stimulus control, Counter conditioning	Confidence moderate, Temptation low	Pros > Cons
Stage 5: Maintenance	Contingency management, Helping relationship	Confidence high, Temptation low	Pros > Cons
Habit	No message needed	Confidence very high, Temptation very low	Pros >> Cons

Patient Data Capture Template

The patient Data Capture Template (DCT) systematically records patient information—i.e. demographics, behaviour and clinical risk factors—needed to generate personalized educational material. We used the commercially available Wellsource Coronary Risk Profile that assesses CVD risk based on the FHS risk calculator. We made some modifications to it to meet (a) SCORE requirements; and (b) Canadian healthcare standards—in particular target levels for risk factors suggested by the Canadian Association of Cardiac Rehabilitation report.

We divided the DCT into four distinct sections: *(1) Demographic Data; (2) Health History Data; (3) Clinical Data; and (4) Risk Behaviour Data*. The first two DCT sections collect data describing the patient's characteristics and his/her non-modifiable risk conditions, whereas the last two DCT sections collect clinical and behavioural data relating to CVD risk factors (such as smoking, dietary choices, alcohol consumption, stress, depression), which can potentially be modified through lifestyle changes. In total the DCT collects 28 parameters that cover a range of risk conditions and risk factors, such as age, smoking status, amount of regular exercise, eating practices, alcohol consumption, stress, depression, blood pressure, glycemic control values, and behaviour change readiness. The patient data for all the parameters is used to design a patient profile.

A feature of the DCT is that it automatically prompts lifestyle change readiness questions whenever the patient's response is not in accordance with the accepted targets as suggested by Canadian guidelines. Figure 1 shows the readiness question posed to the patient after he/she confirms a smoking habit.

Behavioural Data: Smoking	Indicate your present smoking practices. ___ never smoked ___ quit smoking more than a year ago ___ quit smoking more than 6 months ago ___ quit smoking within the last 6 months √ currently smoke cigarettes
Behavioural Data: Readiness to Change	Are you ready to make lifestyle changes to improve your health by stopping to smoke ? ___ no interest in making any lifestyle change *(Stage 1)* ___ thinking about making a lifestyle change *(Stage 2)* ___ making plans to achieve a change *(Stage 3)*

Figure 1 - DCT for checking on smoking and then based on the patient's response we ask the readiness to change.

Patient Profile

The patient profile characterizes the patient along multiple dimensions in order to guide the selection of patient-specific snippets. It includes: (a) patient information collected via the DCT, (b) new patient information calculated using the DCT data, e.g. patient's body mass index, (c) the patient's computed SCORE value, and (d) the patient's stage of change for each risk behaviour, as illustrated in Table 1. The patient profile comprises three components as follows:

CVD Risk Profile describes the patient's absolute risk of CVD death and co-morbid conditions using the SCORE algorithm [8], which estimates the 10-year total cardiovascular risk of death. SCORE uses patient data on age, gender, smoking, systolic blood pressure (SBP), and total cholesterol (TC) and HDL cholesterol ratio to calculate the patient's risk category as percentages that lead to tertiles of risk as follows: ≤1% (low risk); 1 - 5% (moderate risk); and >5% (high risk). For example, a 60 year-old, non-smoking female patient with a SBP of 140 mmHg and TC:HDL ratio of 6.2 mmol/L would have a 10-yr CVD death risk of 2%, which means moderate risk.

The *Staged Risk Factor Profile* contains the patient's behavioural information and stage of change for specific modifiable CVD risk factor behaviours, such as smoking. We use the TTM to determine the patient's stage of change, for all potential risk behaviours, based on his/her response to questions relating to her/his readiness to modify the risk behaviour. We ask a readiness question—e.g. are you ready to make lifestyle changes to improve your health? The patient's response is used to determine the readiness to change along the five stages shown in Table 1—i.e. No present interest in making any lifestyle change infers *Stage 1*; Thinking about making a lifestyle change infers *Stage 2*; Making plans to achieve this change infers *Stage 3*; Recently started implementing this change infers *Stage 4*; and Have been doing this for six months or more infers *Stage 5*.

Non-staged Risk Factor Profile comprises additional information pertaining to other risk factors and conditions that are not integrated with TTM, for instance risk factors concerning eating practices, blood cholesterol levels, blood pressure, etc. This information is used to select educational messages for all non-staged risk factors and risk conditions.

Message Library

The message library contains a large volume of topic-specific educational interventions represented as fine-grained *snippets* of information. Each snippet addresses a specific aspect of a risk factor pertaining to specific patient feature. Snippets form the building blocks for a detailed and personalized educational package. Snippets vary in information coverage, ranging from a single sentence to a number of paragraphs and they collectively cover the range of potential variations of patient characteristics. Their sources were (a) staged lifestyle modification materials, based on the TTM, for the risk factors—i.e. smoking, overweight, stress, depression, and physical inactivity; and (b) non-staged educational resources for other risk factors—i.e. BP, lipids, eating practices, glycemic control, and alcohol. This material originated from the these Canadian sources: (a) "The Healthy Heart Kit" from the Public Health Agency; (2) Cardiovascular & Pulmonary Health in Motion Cardiac Rehabilitation Program at the QE II Health Sciences Centre in Halifax; (3) The Heart Disease: Prevention section of the Heart & Stroke Foundation website; and (4) Health Canada's "Food Guide to Healthy Eating" and "Physical Activity Guide to Healthy Active Living."

In the message library, at the first-level the educational material was categorized in terms of staged and non-staged. At the next-level, the staged material was categorized into five snippets categories, corresponding to the five Stages of Change. And, the non-staged material was categorized into six snippet categories—i.e. introductory (opening statements), informational (suitable action), definitional (meaning), motivational (incentive), factual (evidence), and gender-specific (suitable for one gender). In each case, the key educational information was selected from the original material to form a risk factor's snippet. For example, information from the cholesterol brochure was used to create snippets as follows. An initial sentence containing "Cholesterol is …" was converted to a *definitional snippet*. Information following the heading "Get the Facts …" was converted to a *factual snippet*. The sentence "What you eat plays an important role..." led to an *introductory snippet*. Discussion of cause and effect such as "Decreasing your blood cholesterol level by 1% …", led to a *motivational snippet*. Statements such as "If you want to lower your risk of heart disease try…" formed *informational snippets*. Gender-specific information, such as "Women tend to …", resulted in a *gender-specific snippet*. Local experts in CVD prevention and rehabilitation were engaged to verify the information content and coverage contained within each snippet.

Personalization Decision Logic

The personalization decision logic determines the selection of the relevant snippets based on a given patient profile. To establish the decision logic, we first developed a mapping matrix that contained the 14 risk conditions identified in the DCT and potential messages targeting these risk conditions. Next, the matrix was translated into symbolic decision rules—i.e. if-then statements—that map the profile elements in the IF part of the rule to specific messages listed in the THEN part of the rule. Figure 2 shows exemplar personalization decision logic. We developed around 300 rules that are executed by a rule-based engine employing forward reasoning.

```
If Gender = female and Exercise = no regular exercise
   Then <GenderF link> and <GenderF premenopause&exercise link>
If Gender = female and Exercise=five or more days per week
   Then <GenderF link>
If Gender = postmenopausal female and Depression=yes
   Then <GenderF link> and <GenderF post menopause> and
          <GenderF post menopause&depression>
If Gender = postmenopausal female and Depression=no
   Then <GenderF link> and <GenderF post menopause>
```

Figure 2 - Sample personalization decision logic

Information Presentation Template

The function of the information presentation template is to organize the selected snippets in a meaningful manner. The presentation template was divided into four sections: (1) The *Introductory* section provides a brief description about the document title, patient's name, date, clinic name (site) and the contents of the personalized document; (2) The *CVD Risk Profile* section provides both textual information and a graphical display of the patient's absolute risk of CVD death as computed by the SCORE algorithm. We present (a) a bar-chart displaying the 10-year risk of CVD death with comparison to a patient with an ideal risk profile; and (b) a pie chart displaying the contribution of a patient's modifiable risk factors to her/his total risk (see Figure 3ab); (3) The *Progress* section provides a graphical display of changes in a patient's modifiable risk factor values over time; and (4) The *Risk Factor Management* section provides information on each risk factor relevant to the patient. Each risk factor has its own sub-section complete with an introductory brief, the patient's current results, evidence-based target values, and lifestyle modification and risk management education. We recognize that managing risk factors may require lengthy educational messages leading to information overload. Therefore, the template contains 'expandable' segments that can be accessed by clicking a hyperlink that leads to detailed information.

Delivery Method

In PULSE, the educational material can be viewed online (in a web browser) or printed as a PDF document. Interaction with the PULSE system is initiated by a healthcare professional in a primary care setting. The practitioner enters the patient data into the DCT and then PULSE generates the personalized educational package.

Working Example

To demonstrate the working of PULSE we generate educational material for two patients. Through a comparison between the education packages generated for each patient we will be able to demonstrate the efficacy of PULSE. The two hypothetical patients are: Ms. Adams, aged 48 years, with a SCORE value of 1% (moderate CVD risk) and Mr. Brown, aged 60, has a SCORE value of 8% (high CVD risk). Figure 3ab displays the CVD risk profile presented to Mr. Brown.

Table 2 shows for each patient their data used to calculate risk assessment, the stage of change for their risk factors and the messages selected by the personalization logic. The personalization effect is illustrated by viewing the diversity of the number and type of messages received by each patient. Ms. Adams receives 25 snippets in comparison to Mr. Brown receiving 42 snippets. Overlap is their profiles results in the selection of some similar snippets. Yet, differences between their profiles results in selection of different snippets—Mr. Brown receives 3 BP messages as his BP levels are not normal, whereas Ms. Adams does not get any messages as her BP level was normal; Mr. Brown receives 2 additional lipids messages as his LDL and TG levels are higher than accepted targets, whereas Ms. Adams' values for these variables were normal; Ms. Adams receives an additional gender-specific exercise message at Stage 2 (Contemplation), whereas Mr. Brown receives at Stage 1 (Pre-contemplation). In summary, the diversity of snippets selected for each patient illustrates fine-grained personalization of their educational packages.

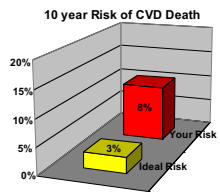

Figure 3a-Risk profile

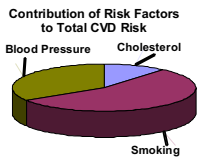

Figure 3b-Risk factors

Evaluation Study

We conducted a survey-based pilot study to evaluate (A) patients' willingness to follow the suggestions offered by PULSE, and (B) the quality of the information being presented with respect to the patient's profile. The survey presented 22 questions using 5-point Likert scales. The survey evaluated patient's intention to follow treatment suggestions in part A, and their impression of the quality of the information in part B. Six (6) patients with CVD risk factors were recruited at a medical clinic where they were under treatment for those cardiovascular risks. 83% of the responses to part A were positive, and 91% responding positively to part B (Table 3). For part A the survey comprised 10 questions, such as "Do you intend to try any of the suggestions to manage your cholesterol levels within the next 30 days"; "Do you intend to try the suggestions to healthy eating within the next 30 days", and so on. For part B the survey comprised 12 questions, such as "How useful would the information be in helping you manage your cardiovascular risk"; "The information on each of the topics was individualized"; "The information on each of the topics was new"; "The information on each of the topics was personally relevant", etc.

Table 3- Survey results for part A and B

	Positive	Neutral	Negative
Part A	34	7	1
Part B	61	6	0

A patient's readiness to change behavior, based on PULSE educational messages, was as follows: Stage1-No present interest in making a change (1); Stage2-Thinking about make a lifestyle change (3); Stage3-Making plans to make a change (5); Stage4-Recently started making a change (8); Stage5-Have been doing this for 6 months or more (1). The responses show that PULSE is having a positive influence on the behavior of the patients, as Stage 3 and 4 (for their different

Table 2 – Comparison of personalization results for two patients. The underlined snippets are common between both patients

Risk Factor	Patient 1	SoC	# of Msgs	Message ID	Patient 2	SoC	# of Msgs	Message ID
Age	48 years				60 years			
Gender	Female				Male			
Health Problems	None		3	<GenderF_link> <GenderF_menoLink_Ex> <BP_fh>	Hypertension		4	<BP_ph> <EP_bpLink_EP> <CVD_fh> <BP_fh>
Family History	Hypertension				CVD and high blood cholesterol			
Blood Pressure	138/88 mmHg		0		144/96 mmHg	***Stage 3***	3	<BP_info> <SBP_mot> <BP_gmlink>
Lipid Profile	TC 6.8 mmol/L, HDL 1.0 mmol/L, LDL 2.3 mmol/L, TG 1.6 mmol/L	***Stage 4***	4	<LP_info> <LP_TCHDL> <LP_mot> <LP_Link>	TC 5.1 mmol/L, HDL 1.1 mmol/L, LDL 2.5 mmol/L, TG 1.8 mmol/L	***Stage 2***	6	<LP_info> <LP_TCHDL> <LP_mot> <LP_LDL> <LP_TG> <LP_link>
Glycemic Control	FPG 6.9 mmol/L, HbA1c 6.8%		2	<GC_info> <GC_link>	FPG 5.9 mmol/L, HbA1c 5.8%		**0**	
Weight Control	weight (62kg), height (1.58m), waist (87cm)		0		weight (96kg), height (1.84m), waist (103cm)	***Stage 2***	6	<WM_info> <WM_wc> <WM_mot> <WM_Stage2> <WM_link1> <WM_link2>
Smoking	Quit smoking > 1 year ago		0		Smoker	***Stage 2***	4	<Sm_Stage2> <Sm_info> <Sm_link1> <Sm_link2>
Exercise	1 day/ week	***Stage 2***	5	<Ex_Stage2> <Ex_gf> <Ex_mot> <Ex_link1> <Ex_link2>	0 days/ week	***Stage 1***	4	<Ex_Stage1> <Ex_mot> <Ex_link1> <Ex_link2>
Alcohol	2/day and not > 9/week		0		2/day and not > 14/week		**0**	
Depression	No		0		Yes	***Stage 4***	2	<De_Stage4> <De_info>
Stress	Yes	***Stage 3***	3	<St_Stage3> <St_link> <St_info>	No		0	
Dietary Habits			8	<EP_intro> <EP_fibre> <EP_fat> <EP_fruitvege> …..			13	<EP_intro> <EP_grains> <EP_salt> <EP_meat&alt> …...
Total Msgs			**25**				**42**	

conditions) are the most prevalent. The results conclude that the educational interventions by PULSE is not only accepted by patients but is also deemed by patients as personalized.

Conclusion

Human behaviour is a key determinant of health improvement, yet its importance has not been fully appreciated in designing patient-specific educational interventions. Notwithstanding the effective organization, usability and relevance of healthcare information prescribed to patients, it can still not be guaranteed that the information will have the desired impact if it does not take into account the patient's behavioral attitudes towards self-management and self-improvement. The PULSE approach presented here is grounded in the belief that the efficacy of any patient educational intervention is contingent on the patient's readiness to change their behaviour. We presented a personalized patient education system that purports a unique synergy between evidence-guided CVD risk assessment—i.e. the SCORE algorithm—and the TTM for assessing the stage of change for risk behaviours, such that their combination leads to a rich patient profile. We have developed a novel compositional personalization method that maps the fine details of the patient profile to specialized educational messages—i.e. snippets. We dynamically compose an educational package that comprises interventions that correspond to the patient's physiological data, risk category and behavioral predisposition to lifestyle modifications. We addressed the challenge of transforming a wide range of evidence based guidelines and recommendations to a set of discrete messages, where each message needs to satisfy three inclusion criteria—i.e. medical, risk and behavioral. The feature of our work is that it purports a pragmatic methodology for designing personalized educational material for other medical problems. In conclusion, this project is a step towards empowering patients with accessible, up-to-date and pertinent information about CVD risk factors, lifestyle modifications and behavior change strategies.

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Augmented notebooks for pervasive learning in medical practice

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Abstract

Medical e-learning can benefit from the new technologies, and pervasive learning resources and tools worth to be introduced in the medical context. Micro-learning seems to be an interesting way for pervasive learning. But it is still difficult to propose pedagogical resources that are built by learners, from meaningful experiments. We conducted an analysis of the exchanges performed by Health care professionals in the hospital in order to understand where and when educational exchanges appear. We analyzed the type of documents exchanged. The residents' paper notebooks caught our attention first because it answers some clinician-needs and second because the computerization of such a notebook could add a collaborative dimension to the pedagogical resources. We propose a model of an augmented resident's notebook and we briefly describe an implementation using Content Management System and WIKI, before setting the discussion and the conclusion sections.

Keywords:

Medical Informatics, Pervasive learning, Health, Education.

Introduction

Aim of the work

Because of the diversity of situations of care, and since numerous learning resources exist in the field of medicine, we are interested in digital educational materials that health professionals are able to use in their care activities and that could offer contextualized knowledge. We wanted to know more about the pedagogical exchanges during care activity. We have analyzed where and when health care professionals use documents in learning situation. We identified the learning activities; and then how people do communicate to teach or to learn. When analyzing the documents used by the residents, we found the ones which have educational purpose, A paper notebook retains out attention because it is often used to gather useful pieces of knowledge and expertise during care activity.

Currently, everyone can easily use embedded technology through smart devices such as PDA, microPC, SmartPhone, an so on. We can thus consider electronic assistants for mobile learning. The second step of our work was then to propose a computerization of the notebook.

These researches take place in a national research program ANR-TELECOM-p LearNet[1]. It focuses on the design and the prototyping of new infrastructure for pervasive learning which is studying how the new technology (TEL: Technology Enhanced Learning) can support learning. "P-LearNet is particularly focused on the integration of technology, on providing easy use interfaces, on the possibility of contextualisation and adaptation to users, on the individual and collective training for formal and informal teaching, in relationship with the work and with the systemic and the training organizations". (our translation) [1].

Rational

Mobile tools are still rarely used in everyday health care practice. Their introduction still raises a number of basic problems e.g. size, battery life, not enough user-friendly interfaces. But thanks to the introduction of such devices, the health care professionals can avoid to switch from the place where he/she provides care to the place where he/she may consult informative resources. Moreover, ubiquitous environment could provide relevant information according to the context of use. In order to improve the dissemination of such devices, these tools must be therefore integrated into the activity. The quality and the accessibility of digital information, its nature, its structure, its granularity and its objectives are essential especially in the health care environment which is often stressful and urgent.

Scientific studies on the integration of mobile tools in the medical community are encouraging. Recent researches focus on the introduction of mobile tools such as PDA (Personal Digital Assistant) in the medical world. There is thus a quite abundant literature in this area with, for example, more than 200 articles from the raw research "Healthcare PDA" on Pubmed[2]. In a recent review [2] 48 articles describing the use of PDAs in the medical world were selected and analyzed. The results of this medical study are quite encouraging: access to databases seems to satisfy the users of such tools; access to drug information seems to be very popular as well. Another review covering articles from 1993 to 2004 proposed by Kho et al [3]

[1] http://p-learnet.univ-lille1.fr
[2] http://www.ncbi.nlm.nih.gov/pubmed/

stress the interest of practitioners for learning tools: " At the bedside, they[the PDA] can be used for clinical education by facilitating calculation of clinical prediction rules, checking for drug interactions, and consulting references to expand differential diagnoses. Handheld computers are also becoming an important part of patient care and documentation through electronic order entry and patient tracking applications".

The health educational materials are often traditional teachings resources such as slides or PDF documents, re-organized to be easily accessible on the Internet. Major projects are aiming at integrating and/or facilitating access to such electronic courses. For example, the UMVF[3] (Francophone Virtual Medical University), or the IVIMEDS[4] (International Virtual Medical School) are internet portals that gather respectively French and English educational resources. Moreover, new teaching materials are developed [4]. The design of new e-learning tools uses teaching engineering methods, organizes educational contents and takes into account interactions between learners and tutors. Most courses are however designed to be read and consulted over a period which is dedicated for learning, rather than during care activity. The learning resources consulted by the health professionals during their activity must be accurate and concise, so that information is fast and efficiently reached. Pervasive learning as defined by Thomas [5]:« Pervasive learning is a social process that connects learners to communities of devices, people, and situations so that learners can construct relevant and meaningful learning experiences that they author themselves in locations and at times they find meaningful and relevant » or micro-learning as reported in the conclusion of a 2008 conference pp121[5] "A new digital micromedia ecology, and with it new learning strategies, are emerging. The shift to fragmented digital communication and information flows affects all aspects of daily work and daily lifelong learning. This calls for innovative experiences, processes and technologies: ubiquitous, personal and dynamic, casual and volatile, but still complex and effective" worth to be carefully studied.

Materials and Methods

In general

Basic computers such as desktop PCs and mobile devices such as laptop or smart phone allow a dematerialization of information as well as a high availability of information. Different users can share some information and even collaborate to build collectively some information.

Identifying the needs for technological innovations is a difficult task. Indeed, it is very tough to project user's current activity in a technical future that in addition to being unknown could partly change their way of thinking and their way of acting. It is particularly true for pervasive devices which are taking into account the application settings. Therefore it is necessary to analyze the technical possibilities allowed by new technologies and to take into account the specificities of the user's activities. The comparison of these two aspects leads to the development of scenarios of future activity. We first decided to analyze where, when and what kind of pedagogical exchanges happen during the care. Then we focused on the identification of some learning materials whose computerization could help the caregivers.

Identification of the pedagogical exchanges

The objective was to identify the information exchanged between the caregivers in the department. We chose to observe the activity of the residents. This observation was conducted in the department of Gastroenterology at the University Hospital of Lille, where three half-days of observations were made. The following items were measured: - where were located the caregivers during pedagogical exchanges; what was the nature of the information provided; from whom or where did they obtain the learning information. An observation grid was elaborated, then implemented and completed in the software Studiocode ®.

Observers have characterized real-time information exchanged between the residents and the other people in the service. Residents spent over 51% of time in the corridor or in the patient bedroom. Residents communicate most information orally. An important part of it concerns encyclopedic knowledge and procedural knowledge. Most of the information that they received comes from the seniors and few from the other residents. They provide some information to the patients, but also to the nurses and other interns.

We inquired about the residents' needs concerning the improvement of their researches of information. They told us they have no special needs. When they haven't got the knowledge to provide the care, if the latter is beyond the scope of their specialty, they make a request to a specialist. If the knowledge is linked to their specialty, they would ask a senior, or quietly make a research on a desk computer when they have time. However, this lack of needs is also due to the difficulty they have to build a vision of the future management information (very different from the current mode). We noticed that almost all of them have a paper notebook on which they noted all information that they judge useful for their activity.

Identification of educational materials and analysis of the residents' notebooks

We made a second analysis to identify the learning materials used. In particular, we wanted to know more about the information contained in the notebook, as if it was identified as very important by the residents. The activity analysis was performed with the residents of the pediatric surgery department of Lille University Hospital. Four analysis methods were used:

Interviews which help to clarify about the nature of the residents's activity

Observations: ethnographic observations were conducted in the department of pediatric surgery.

Questionnaire: Following the initial interviews and observations, a questionnaire was done, asking about their habits and dealing with the communication tools they

[3] www.umvf.prd.fr
[4] www.ivimeds.org

used and the research information they performed. It was sent to the residents of all the departments of the hospital, in order to generalize the study. One hundred questionnaires were distributed; thirty-two were completed and returned.

Trace analysis: in addition to observation and interviews, the paper documents used by interns were analyzed. Thus, three books from three residents in anesthesia were photocopied and analyzed. By studying these traces we can identify the type of information that the caregivers are using while carrying out their tasks and we can identify the operative vocabulary they are using.

The main results of this analyze are then the following:

In order to search information, the residents have access to a computer in the medicine room or in the office. In these places the desktop computers are connected both to the information system of the hospital and to the Internet. A printer is usually also available. In these rooms, they work on the patient records and they perform their Internet researches. These researches are mainly focused on medical protocols or guidelines, on the pharmaceutical properties of drugs, on the prescription and the analysis of biological data and the detailed descriptions of diseases.

The anesthesiologists have access to a computer in the operating room. Some of them have pocket pc or smart phones.

Most of the residents also have a paper notebook. This document, pretty small, is placed in the pocket of the coat. In this notebook, they note important information for their medical practice. This document has the advantage of being accessible at any time and easily usable. In our observations, they rarely used it. However, all of them wanted to keep it with them, in case to retrieve the information it contains, if necessary.

The analysis of the residents' paper notebook.

The notebook is used to memorize some specific know-how. During actual situations of work, when a resident notices useful information, he/she uses the notebook to keep it accessible. For example, a group of new residents is in a given service where a patient suffers from a specific disease. A senior doctor explains them what to do in this situation and each resident notes his/her remarks in his/her own notebook.

Most of time, the notes are not written during the care, but they are carefully reported in the notebook after the event. Information can be duplicated in the notebook, as a same subject can be treated with different approaches or can be encountered in different contexts. Colors are used to highlight some information, but the choice of the colors that are used just depends on the color available when writing notes, it has not a specific meaning. According to the owner, the book may or not be organized in alphabetical order.

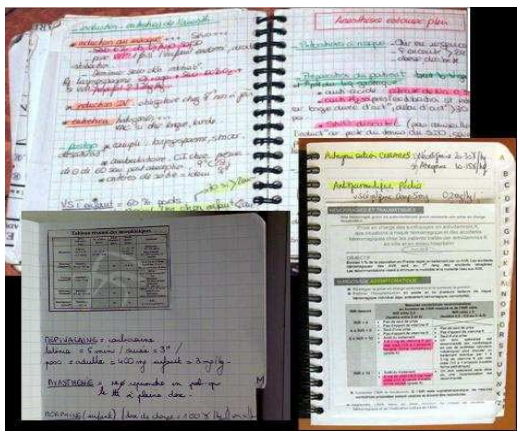

Figure 1- Examples of residents' notebooks.

Various kinds of information are included in the document: written notes but also excerpts from courses, manuals, dictionaries as well as pieces of printed paper. This notebook do not intend to be encyclopedic, it is rather a collection of "recipes" depending on services and situations. These notes will progressively create an accurate knowledge composed of useful information in a precise context of activity. Such a document is personal, dynamic and mobile; it should help to find information quickly.

Towards an augmented note book

Interest of the augmented notebook for pervasive learning

According to the specificities listed below, we have made the hypothesis that a pervasive notebook should be integrated in the activity of the residents:

At the beginning of his/her internship, the caregiver starts with an empty notebook. It is filled progressively, by the reports of important know-how learned during the activity. Obviously, this reporting takes place in the learning process since it helps to memorize the information. However, residents also copy some information manually or photocopy documents and paste them in the notebook. This process is long and bothersome. Moreover, copying is a source of significant errors. The notebook is interesting because it is made of small pieces of learning information, highly contextualized, partially indexed, annotated (color system, keywords, and titles), used during activity and used in a mobile way. The written notebook is rarely consulted but it is very important for users. When used, the consultation is brief and must immediately provide or reinforce knowledge essential for the activity. These specificities are different from usual characteristics of more traditional courses. These kinds of micro items of knowledge, very contextualized, are consulted and integrated during the care activity. It seems that to propose micro-teaching and pervasive learning activities during care, we could benefit from this experience.

Thus, we decided to experiment an augmented notebook.

The qualities of the written notebook should be preserved when computerized. *Mobility*: access to electronic notebook must be immediate and at the bedside, we will therefore emphasize mobile tools (PDA, Smartphone, NetPC, ...). *Conviviality*: the interface must be easy to understand and must lead quickly to relevant information. *Contextualization of information*: the purpose of the notebook is not to build a copy of well-known and exhaustive sources of information (as, for instance, the Vidal[5] which is one of the well known references for drug information in France) but to focus on knowledge that is relevant in a given context (as, for instance, the description of the drugs used for a child over 2 years, for disease D in the pediatric service of Professor P.). Information in the notebook makes sense only if contextualized.

An augmented notebook will enable new features.

Backup and exchange: data could be saved, transferred, with the ability to transfer its information to another media. *Efficient search*: as for example full text research or research by keyword or by category. *Relationships between concepts*: Internal links in the notebook can be proposed to connect different items of knowledge (as for instance all the items relative to acute pain). External links are also very interesting to complete the information provided in the notebook by encyclopedic knowledge, (as for instance, Vidal entries for drug information or UMVF portal for medical courses). *Multi modality*: the electronic document can easily integrate pictures, hyperlinks, sounds, videos, to the notes. It can also be consulted through different devices such as smart phone or computer terminals in the hospital. *Index and Annotation*: meta description of information can be used through tags, annotations or indexes. *Contextualization*: each note can be marked with some context : who, which country, which hospital, which services could be some of the interesting contexts to take into account. *Sharing of knowledge:* the notebook can be shared with other people once written in electronic form. *Cooperative process*: the book can be built by the capitalization of knowledge. Once collected, the information can be used by the other residents, and the information could be enriched by collaborative co-construction of the knowledge. When a new resident arrives in a service of the hospital, he could benefit of a specific know-how, which fits the habits of the service. Augmented notebook should help to share and synchronize the knowledge.

A model for the augmented notebook

We model the book as follows: a memo is the basic unit of information. This memo has a title, as encountered in the written notes. Each memo can have meta-descriptions. Each memo can be linked with other memos. A general Content Management Framework is proposed to connect the memos to external knowledge.

To perform the meta-description of the memos, in a first approach, we have retained the following axes to categorize the knowledge: (i) Geographical location, as most of the specificities comes from the hospital or the service in which the care is performed, (ii) Medicines, (iii) Syndromes, (iv) Diseases, these 3 axes covering the main entries to describe the content of the memo, and (v) Guidelines and protocols. These descriptions help to provide contextualized information. Of course, these axes could change if necessary.

The main features of the augmented notebook come from the analyses and deal with: remote access; import and export of data, collaborative authoring tool, relation to external resources; indexing of the information entered through semantic annotations or through contextual elements from the practice (as the author of the memo or the name of the service in which this resource is meaningful).

Architecture

The architecture developed for testing is based on three components: a server that hosts the memos, an experimental network infrastructure, and mobile learning devices. The server is accessible both from the internal network of the hospital as the Internet, so that residents can learn or improve the memos even when duty off. The experimental network infrastructure consists of a set of wireless terminals located in clinical departments. Only devices provided for the experiment can be accessed. The devices consist of SmartPad (nokia N90) and netbook (eeepc Asus 901).

Implementation

Different kinds of collaborative tools were examined in order to implement this augmented notebook: CMS (Content Management System), Wiki, social networks, blogs. Social networks (e.g. Facebook[6]) are originally designed to improve the social links between individuals, but they can now be implemented in a private sphere (e.g., Ning[7]) and offer many tools to share files or other kind of information, such as forums or "walls" of information. We didn't choose them as to perform a pervasive notebook we needed to structure our data. Blogs, highly structured chronologically were not retained as well.

CMS tools are designed to administrate and manage the online pages. They are effective to publish pages, to facilitate the design of the pages by using templates and to control the different validation steps before the publication of contents. A CMS, however, is not so suited to contextualize the information presented in the memos. We chose CMS to implement the general framework which gives access not only to the residents' notebook but also to external information, pertinent for the caregivers (publication databases, directory, dictionary of drugs, etc..). We used Joomla[8], which is an open source software that provides sufficient features.

Wiki tools effectively facilitate the collaborative construction of information. A wiki can easily build a network of linked

[5] http://www.vidal.fr/

[6] http://www.facebook.com
[7] http://www.ning.com
[8] http://www.joomla.fr

pages. Interesting mechanisms are implemented such as the creation and modification history that helps to control the information. It is possible to organize discussions around the concepts proposed in the pages; it is particularly interesting to secure the validity of the information provided in a collaborative way. We therefore propose to hold the notebook via a Wiki. There are many wiki engines available in open source. The MediaWiki[9] engine is used for the free online encyclopedia Wikipedia, it has proved to be robust. Its features meet fairly well our needs. Each resident's memo can then be viewed as a Wiki page, the title of the memo playing the role of the hyperlink. A discussion area on the pages is easy to implement. The concepts presented in the page may refer to internal or external links. This Wiki has additional features provided by an active community of developers. Among these features, the interface with LDAP for authentication, the possibility of exporting pages to PDF, the advanced text editor are of particular importance for our project. Structuring documents per category is proposed. Each category can be seen as a set of tags associated to that page. The Semantic MediaWiki[10] extension can annotate items or typed relations (links) between items. This Wiki has been chosen for the implementation of our prototype.

Results

Through the analyses of the pedagogical exchanges performed during the care activity, we identified a specific document: the notebook mainly used by residents. The computerization of this notebook opens up interesting prospects for pervasive learning. We have developed the infrastructure necessary to deploy a test in services. Firstly, we distributed mobile tools: Asus eeePC 900 or 901and Smartphone Nokia N90 to some of the residents working on the service in which we conduct our experiments. These tools didn't integrate the augmented notebook. The use of mobile tools was then very low, despite the number of encyclopedic knowledge available online. It confirms our hypothesis about the importance of the services offered. Then, we have developed a prototype of augmented notebook which provides contextual information according to the main axes of categorization identified. Next step of this work is the evaluation of the prototype. In particular, the collaborative aspects for the capitalization of knowledge will be explored.

Discussion

Many research opportunities are opened by this exploratory study. The capitalization of knowledge should help to identify general knowledge, or specific knowledge. Learners should become actors to build learning materials. It could reveal knowledge linked to teams (in such service, this drug is often used with the dosage xx/l) or to individuals. In particular, some habits could become explicit and such knowledge could save precious time when new people arrive and don't know yet the implicit rules. We must explore the duality between the collaborative notebook and the personal notebook, combining the contributions of a wiki tools very efficient to share and co-build information, with fair tools allowing to tag personals data.

Conclusion

The acquisition or the consolidation of knowledge can be based on other activities than the consultation of encyclopedic information; therefore residents store know-how information and examples on notebooks or USB storage. Improving e-learning through pedagogical engineering is obviously important, but there is still a room for new modalities for learning: modest, punctual but precise, which could provide small and contextualized documents. Our analysis of the learning resources that are used and exchanged during the care, highlights the difficulties that we face with in integrating learning in everyday practice. This work just sketches solutions but it provides a model of document able to capitalize applied learning knowledge. It might help us to introduce new digital material in a pervasive learning perspective.

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Advancing the State-of-the-Art for Virtual Autopsies – Initial Forensic Workflow Study

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Abstract

There are numerous advantages described of how imaging technology can support forensic examinations. However, post-mortem examinations of bodies are mainly performed to address demands which differ from those of traditional clinical image processing. This needs to be kept in mind when gathering information from image data sets for forensic purposes. To support radiologists and forensic clinicians using Virtual Autopsy technologies, an initial workflow study regarding post-mortem imaging has been performed, aiming to receive an improved understanding of how Virtual Autopsy workstations, image data sets and processes can be adjusted to support and improve conventional autopsies. This paper presents potential impacts and a current forensic Virtual Autopsy workflow aiming to form a foundation for collaborative procedures that increase the value of Virtual Autopsy. The workflow study will provide an increased and mutual understanding of involved professionals. In addition, insight into future forensic workflows based on demands from both forensic and radiologist perspectives bring visualization and medical informatics researchers together to develop and improve the technology and software needed.

Keywords:

Human engineering, Task performance and analysis, Forensic medicine, Radiology, Tomography, X-ray computed**,** Post-mortem imaging, 3D visualization, Virtual autopsy

Introduction

Thanks to new imaging technology cold human bodies can be virtually examined and the cause of death determined. New Magnetic Resonance Imaging (MRI) and Computed Tomography (CT) technology present new opportunities within post-mortems and forensic medicine. A recent addition to the autopsy workflow is the possibility of conducting post-mortem imaging. In its three-dimensional (3D) version, this is also called Virtual Autopsy (VA), where CT/MRI data from scans of corpses are post-processed with 3D Direct Volume Rendering (DVR) techniques [1-4].

Some of the most apparent potential advantages of VA, compared to conventional autopsies are:

- The VA is time saving and provides novel analysis opportunities. It can also improve the efficiency of the physical autopsy by improved prior knowledge of the case.
- The VA procedure does not alter evidence; the data sets can be stored indefinitely allowing subsequent re-examination by other pathologists.
- The VA can be an option when a conventional autopsy is rejected by family members due to religious beliefs, or threatens the health of coroners, pathologists, and medical examiners from highly infectious diseases.

There are several additional advantages and benefits of VA that, in the long run, will also make a significant wider contribution to healthcare and medicine. An interdisciplinary team of researchers and clinicians, further described below, works in a project to develop VA technology and procedures. To summarize, the mission of the *Advancing the State-of-the-Art for Virtual Autopsies* project is: To develop VA technologies and methodologies that enable widespread use of virtual autopsies in the standard forensic workflow. [5]

Methods and Materials

Previous research efforts have successfully shown the basic and technological benefits of VA [4, 6, 7]. This project aims to fulfill the mission by taking the next steps: to enhance the existing methods by addressing new research challenges and to prove that the full envisioned potential of VA is attainable. The needed advances encompass both technology and workflow issues in VA procedures. To address the required advancement of VA technology and procedure the work is organized into the following areas: Data Capture, Data Management, Virtual Autopsy Workstation, *Virtual Autopsy Workflow Studies*, and Demonstrator Integration (figure 1). The objective of the Data Capture area is to develop scanning procedures tailored for VA, for synthetic MRI, CT and Dual Energy CT. The Data Management research aims to extend and enhance the existing multi-resolution framework in a PACS

environment. The VA workstation area will develop visualization tools to increase quality and efficiency of the VA procedures at both the radiology and the forensics departments. The development of the VA Workstation will depend on the non-technical contributions, such as the VA Workflow Studies and the Demonstrator. [5]

Purpose of the VA workflow studies

VA workflow studies aim to develop collaborative procedures that increase the value of VA and exploit the novel visualization techniques and thus establish documented procedures for VA. In parallel, there is an integration project that puts together the results from previous innovations in a demonstrator system, the Virtual Autopsy Table [8], for dissemination use. The demonstrator and the workflow studies will mutually feed each other's development processes (Figure 1).

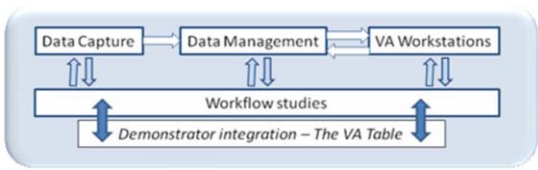


Figure 1-Project work areas' exchange of knowledge.

Methods for the VA workflow study

The technical work is a foundation for the VA deployment, but it is also important to use these tools in an optimal way. There are several aspects to consider; communication, such as instant interplay and asynchronous messaging between different professionals, documentation, the flow of data and documentation items, as well as physical scanning and transport of the deceased.

The workflow studies contain usage and process studies and result in documentation of current workflow and designs of future routines and procedures. The method used is based on a new multi-disciplinary method [9] for user needs analysis and requirements specification in the context of health information systems. This method origins from established theories from the fields of participatory design and computer supported cooperative work (CSCW). Whereas conventional methods imply a separate, sequential needs analysis for each profession, the "multi-disciplinary thematic seminar" (MdTS) method uses a collaborative design process [9]. Application of the method in previous research resulted in developed health information systems as well as new work procedures that were well adapted to the intended user groups. Vital information in the intersection points between different healthcare professions was elicited and a holistic view of the entire process was obtained. MdTS was perceived to efficiently identify in-context user needs, and transformed these directly into requirements specifications for further development [10].

Here, the initial work consists of field studies, observations and interviews, conducted by health informaticians and usability specialists, to understand current work situations and to capture users' tacit knowledge. This is particularly important in situations where different medical professions are, or will be, cooperating. The method further consists of multi-disciplinary work in inter- and intra-professional groups analyzing different topics, or themes, aiming to encompass the necessary knowledge of clinical work situations and procedures in the integrated work. The seminars contain both a holistic and a detailed perspective. In the detailed perspective seminars results from the holistic perspective are further analyzed, examining intersection points and specific details for each profession, items that are necessary for development of medical systems that actually support the integrated clinical work [9].

Materials for the VA workflow studies

There are many actors involved in a Virtual Autopsy procedure: the forensic pathologist, the radiologist, the police, and the court officials. Focus of the workflow studies are the staff of the National Board of Forensic Medicine and the staff at the Radiology Department of the University Hospital in Linköping, Sweden. Researchers working at the CMIV (Centre for Medical Imaging Sciences and Visualization) and the VITA division (Visual Information Technology and Applications) of the Department of Science and Technology at Linköping University and their industrial partners are involved in the study and subject for interviews and observations.

National Board of Forensic Medicine

The National Board of Forensic Medicine is a central government agency. It operates at ten different locations around Sweden and has 370 employees. The principal task of the agency is to produce reports required in legal cases, commissioned by the courts, the police and the prosecutors. There are four different fields of operation: forensic medicine, forensic psychiatry, forensic toxicology and forensic genetics. Experts in forensic medicine perform more than 5000 examinations per year, on both living and deceased persons, at six departments in Sweden, where Linköping is the one studied in this project. The department in Linköping performs around 900 autopsies per year related to unnatural death. Less than 3%, 20-30 of 900, are suspected murder cases. [11]

Östergötland county council

The Östergötland county council operates some forty care centers, four hospitals, of which the University Hospital in Linköping is the largest, and includes highly specialized medical healthcare, in some specialist areas working with all of Sweden as a catchment area.

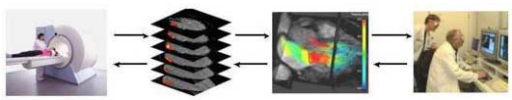
Intensive development work with medical healthcare has been ongoing for several years. Training and research are organized in close collaboration with the Faculty of Health Sciences, the medical faculty at the University of Linköping. [12] Staff from the radiology clinic is involved in this project.

CMIV

Center for Medical Image Science and Visualization (CMIV) is a multidisciplinary research center initiated by Linköping University, Östergötland county council, and Sectra Imtec AB. CMIV conducts focused front-line research within multidisciplinary projects providing solutions to tomorrow's clinical issues. The mission is to develop future methods and tools for image analysis and visualization for applications within healthcare and medical research.

Research within CMIV is based on earlier work within medical image science and visualization. Future directions will strengthen the interdisciplinary approach to enhance the possibilities of image-based diagnosis and treatment. At CMIV research is conducted within several medical problem areas, combining a number of technologies for novel application within clinical routine, medical research and dissemination of information.

Research activities within CMIV include the following four areas (Figure 2), with special emphasis on integration of these areas of expertise. [13]



Data Acquisition/ Image Reconstruction | Image Analysis/ Modeling | Visualization/ Simulation | Medical Application

Figure 2-Research activities within CMIV

The latest generation of CT, synthetic MRI and ultrasound scanners generate multidimensional data sets of rapidly increasing size. Obstacles associated with the handling and analysis of these large-scale data sets are of growing and immediate concern. Medical diagnosis is now facing serious data navigation and management problems. Focused research is required to solve these problems and to fully exploit the possibilities of the new technologies. [13]

VITA

The division for Visual Information Technology and Applications (VITA) contains five different research groups,

- Scientific Visualization,
- Information and Geo Visualization,
- Computer Graphics and Virtual Reality,
- Structural and Civil Engineering,
- Visual Learning and Communication.

The Scientific Visualization group is closely affiliated with the CMIV where the VA examinations take place. The Scientific Visualization research is conducted in the context of medical applications. Main research efforts regard volume rendering of large datasets, multimodal volume visualization and data visualization using augmented reality. The research groups are also affiliated to the Norrköping Visualization and Interaction Studio (NVIS) and share access to the laboratory and state-of-the-art equipment [14], such as the virtual autopsy table [8], Figure 4.

By using the latest technique within medical visualization, on the virtual autopsy table it is possible to study details of volume rendered 3D data sets of real scanned bodies. The user can interact with the 3D images, for instance remove certain layers of the body to look into specific details such as brain, skeleton, heart or the skin. The images are created with for example Dual Energy CT and new methods from the field of MRI and are post-processed by using different tools of image analysis and visualization [8].

Results

VA is currently used in Linköping as a complement to the autopsy procedure in cases of unnatural death [7]. To date approximately 300 cases have preceded a virtual autopsy. They are examined through a CT or MRI scan and the subsequent image analysis. Interviews, field studies and observations from both medical and forensic perspectives report an added value and future potential of virtual autopsies.

Although technological equipment and applications have passed the prototype state and are fully working, the organizational workflow is not yet optimized. This results in that the scanned cases are used mainly for research purposes and not yet smoothly inserted in the routine work of forensic pathologists.

Current Forensic Virtual Autopsy Workflow

In most cases the forensic pathologist investigates the crime scene together with the police and oversees the handling of the body, which is placed in a sealed body bag before being transported to the forensic department and placed in a cold storage. The following morning a full body virtual autopsy is performed using Dual Energy CT. Dual Energy CT is applied in all VA cases whereas MRI and synthetic MRI are applied in specific adult cases and for children, Using Multi Detector CT (MDCT) up to 25000 images can routinely be reconstructed [7]. The radiologist nurse walks through the images and makes short annotations of the findings. If there is additional information available about the body more detailed scans can be performed on specific body parts, e.g. head and thorax. Creating, storing and transfer of images are time consuming; often the pathologist has access to the images in the afternoon after the morning scan. The radiologist and the pathologist would perform a collaborative 3D DVR session in preparation for the physical autopsy and in immediate conjunction with the scanning. To save time however, as the DVD with the 3D images arrives at the forensic department later, in current procedure the radiologist summarizes the findings of the scans orally direct after the scanning is performed.

One advantage of the VA is that the captured MDCT data is stored, in case new circumstances arise. Compared to conventional post-mortems where you only get one chance, iterations of the procedure can answer new questions and re-examination of the VA images can put new light on the facts found during the physical autopsy.

The workflow of the forensic procedure is summarized in figure 3. The conventional physical autopsy is extended by adding the VA activities (shown in red rectangles) which enables an iterative approach. The possibility of a continuous interaction between radiologists and pathologists benefit the post-mortem examinations. Unfortunately current restrictions of the data transfer results in that the workflow often is serial and ends after the phone call between the radiologist and the pathologist. The potential to use the images to a greater extent is stated as high and the workflow will undergo further studies.

The interviewees agree that the technology however could revolutionize forensic medicine. Using the VA procedure, there are cases where completely new findings are detected. For instance, the brains of deceased children can be scanned in order to rule out abuse. Also, with new CT technology, small metal particles which are not visible in any other way can shine clearly and the tiniest fractures show up. Hitherto unrecognized signs of strangulation, fractures and foreign bodies are found and some suspected murder cases have been reassessed after having undergone a virtual autopsy.

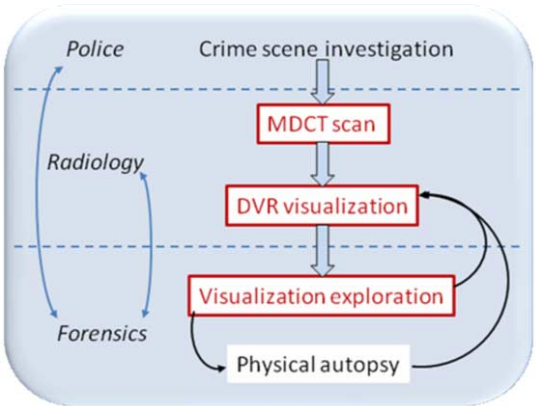


Figure 3-Overview of the forensic autopsy procedure. The VA activities are shown in red, enabling iterations. [7]

In short, the virtual autopsy is a newly developed procedure that will significantly enhance the autopsy, giving it the capacity to achieve more reliable results and by improving the VA workflow for the involved professionals.

Potential research impact

In some cases the virtual autopsy may replace the conventional autopsy procedure. Research on the unique aspects of post-mortem radiology must, however, be undertaken to identify cases and validate procedures. The interviewees foresee that novel visualization, interface and interaction design as well as data management techniques will be generated from this work. The contribution to medical and forensic fields is also imminent from establishing visualization techniques validated against histology and tissue examinations. VA technologies and methodologies will enable widespread use of virtual autopsies in the standard forensic workflow. Furthermore, VA will give a unique opportunity, in many medical research fields, to serve as the real "gold standard".

Potential impact on the society

The outcome of this project will have a significant impact on society at large. The decrease in the number of physical autopsies and some of its consequences can be counteracted, specifically in cases where religion and cultural requirements, in the multicultural society of today, prevent conventional autopsies. Since VA can also play an important role in improving forensics, and enable faster and more accurate crime solving, advancing VA technology and procedures further is of high value. Many aspects of VA can be directly transferred to healthcare in general, improving the quality of medical imaging and diagnosis for society as a whole. VA can also be used in non-forensic autopsies and solve the problem with the decreasing capacity for hospital autopsies.

Potential industrial impact

A major impact for industry is the possibility to commercialize and sell VA-related products. Given the tight collaboration with industrial partners that already have major international products in medical imaging; the commercialization will be easy to bring about. An additional positive impact from the PACS perspective is that VA constitutes a "worst case scenario" when it comes to large data set handling. The VA examinations are, in many ways, like any other diagnostic CT examinations, with the exception that radiation dose is not an issue. This means that a PACS that can handle VA is well equipped for the future challenges of traditional PACS tasks. This work furthermore widens today's applications for the MRI technique which will open a new market for the supply industry of MR scanners and its visualization techniques. Finally, when the applications improve, a second-hand market of CT and MRI equipment from the hospital domain could benefit the dissemination and use of VA worldwide in the standard forensic workflow.

Figure 4- Virtual Autopsy demonstrator: the VA table:

Discussion

The workflow analyses are ongoing; therefore we can not yet summarize all details. Although the potential impacts are clear, the technology is best used in conjunction with regular post-mortems. There are significant differences between living and dead bodies; for example on a deceased the arteries collapse and the veins get thicker, gas arises in different locations. Therefore it is important that the radiologist nurse and physician learn how to correctly interpret the VA images. Whereas other sites that have adopted the VA technology involve sub-specialities, as thorax and neurology, for examination of the VA images, this full-body examination procedure results in a coherent report and not disparate answers. Moreover, recurrent and iterative communication between radiologists and forensics in this workflow is unique and results in improved knowledge of how to interpret VA images. An

evolving profession will be the forensic radiologist, skilled in analysing radiology and 3D images of deceased bodies.

Future work will be to put more effort on developing intuitive user interaction tools and smooth workflows. Human interaction with the visualization is a crucial part of arriving at the goal of creating insight. A forensic pathologist does not want to, nor should he need to, interact with the system using technical constructs. The pathologist, and to a large extent also the radiologist, should be able to stay in their respective familiar professional domain. This means that a mapping must be established between the natural semantics of autopsies and classifiers that can identify the corresponding features in the data. Furthermore, the workflow must be adjusted for both radiologists and forensic pathologists.

Conclusion

The VA technology could revolutionize forensic medicine. Using the VA procedure, there are cases where completely new findings are detected. Although technological equipment and applications are fully working, the organizational workflow is not yet optimized. To bring the VA procedure into the standard forensic workflow, however, the specific demands of forensic examinations need to be adhered to. Virtual Autopsy workstation and image data sets need to be adjusted to support and improve conventional post-mortems. The future forensic VA workflow that is to be cooperatively designed and deployed is required to improve both the radiology and the forensic departments' collaborative and individual work situations.

In conclusion, virtual autopsy is a newly developed procedure that will significantly enhance the autopsy, giving it the capacity to achieve more reliable results and by improving the VA workflow for the involved professionals.

Furthermore, advances of VA resulting from this work are foreseen to play an important role to improve forensics in terms of enabling faster and more accurate crime solving.

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An Analysis of Nursing Education's Immersion into Second Life, a Multi-user Virtual Environment (MUVE)

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Abstract

Second Life (SL) is a multi-user virtual environment (MUVE) using 3-D modeling to replicate real world settings and experiences. However, little is known of the extent to which nursing education is involved in SL activities. This study used four different search strategies to conduct a comprehensive review of print, blog, web and media sources. Twenty-nine unique nursing communities, groups or educational activities were identified. This study identified a number of barriers identified that made the analysis both difficult and time-consuming.
Two main categories emerged: explorers and developers. The explorers used SL for a support group, networking, and uncovering health-related sites. The developers were associated with land ownership and were involved in distance learning and simulation activities. Seven unique simulations for nursing education were identified. Given the number of registered users, the number of universities currently involved in SL, the availability of health-related sites for consumers, and the emerging interest in telehealth in SL substantial growth in the use of SL in nursing education is likely.

Keywords:

Nursing education, Computer simulation

Introduction

A variety of Learning 2.0 technologies have emerged over the last few years as adjuncts to both traditional and distance learning in nursing.[1] One of these technologies is a multi-user, virtual environment (MUVE). Some of the purported advantages of student engagement in MUVEs include active interaction, role playing professional skills, and increased competency in learning a new skill. [2] The degree of immersion and interactivity available in MUVES allows for a greater sense of presence which is believed to contribute to meaningful learning. [3, 4]

Presence is defined as "the subjective experience of being in one place or environment, even when one is physically situated in another".[5] In other words, participants feel as if they are actually in the virtual environment rather than where they are physically. In contrast, immersion refers to the sense of being enveloped by, included in and interacting with the environment. While involvement is "a psychological state experienced as a consequence of focusing one's energies and attention on a coherent set of stimuli or meaningfully related activities and events". [5} According to these authors, both immersion and involvement are required to experience presence.

At this time, one MUVE that is being used for a wide range of educational and healthcare activities is Second Life (SL). Second Life, developed by Linden Labs, has been available over the internet since 2003. Currently, there are over 16 million registered users with over 300 universities teaching courses or conducting research in SL. [6]

Upon entry into this virtual world, each participant creates a free, customizable avatar. Communication is via text messaging or by voice. Avatars navigate SL by walking, flying or teleporting. Real world entities can be replicated in SL through 3-D modeling and can provide simulated learning experiences that are impossible to achieve in the real world or are considered to be of high risk.

While nursing education has long used simulation part of its repertoire of learning activities, little is known of the extent to which nursing education is immersed in Second Life. This study surveys and categorizes the range of nursing education-related sites in Second Life.

Methods

To explore this area, four different searches were conducted. First, the term nursing was entered into the search engine in SL. The SL search engine used the key word "nursing" to search region names and descriptions, group names and descriptions, and individual avatar profiles. In addition to this search strategy, the author conducted additional searches in Google Scholar, Google and PubMed to identify additional nursing education activities through a comprehensive review of print, blog, web and media sources. These latter searches used the terms "Second Life" combined with "Nursing Education". Unique nursing educational activities were identified. Next, all relevant materials, including visits to SL sites, were reviewed to identify associated region or island names, sponsoring agencies or institutions, funding sources and descriptions of educational activities employed or proposed. Catego-

ries were developed that grouped the results based on their primary purpose.

Results

Table 1 displays the search results. Sixty-six percent (66%) of those were identified using the SL search engine. Of the 141 listings identified by SL only 21% were related to professional nursing. Ten (10) additional listings were identified by a Google search. Both Google Scholar and Pub Med did not identify any additional listings beyond what was obtained by SL and Google.

Table 1 – Search Results

Search Engine	Results	Unique Listings
SL	141	19
Google	6690	10
Google Scholar	92	0
PubMed	4	0

Of the 19 listings identified by the SL search, one (5%) indicated a region or island and 14 (74%) were group pages not directly linked to the corresponding region or island in SL. Descriptions contained in individual avatar profiles lead to an additional 4 unique listing (21%). Again, individual profiles were not associated with a SL region.

Initially, 32 sites were identified. Three were found to be members of a consortium and those sites were included with the listing for the consortium. Of the 29 unique institutions or groups identified as using SL for educational activities in nursing, the vast majority (83%) were American. Of the remaining 5 sites, 3 were located in the UK, 1 in Canada, and 1 in Australia.

The 29 unique listings were classified into 2 main categories: explorers and developers. In the larger, developer set (N=18, 62%) the group was associated with a region in SL. However, the 38% of those sites identified, were not linked to given region in SL. In addition, each entity in this latter group was identified in only one of the four searches conducted. Most (64%) were identified from SL group pages and 4 were identified through the Google search.

Those entities not associated with a region in SL, tended to be explorers of SL. They used SL for one of 3 reasons: support (N = 1), networking (3), or nursing educational activities (6). The one support group identified was Nursing Students of SL whose purpose was "to help with NCLEX/HESI questions, critical thinking scenarios, or advice for performing in clinicals". Other educational activities described by these explorers in SL included discovering healthcare resources in SL (Treasure Valley Community College/TVCC), possible use of a paramedic simulation in the curriculum (University of Nottingham/UK), or proposing to develop a virtual poverty simulation in SL for a community health clinical (University of Nevada)

Of greater interest in investigating nursing education's immersion into SL was a further analysis of the listings associated with regions or islands in SL. By purchasing land in SL, these groups had a greater financial commitment to, as well as a greater responsibility for developing and implement educational activities.

However, discovering the names of the respective regions in SL was difficult and often required additional searches in SL. Institution and region names are listed in Table 2 with their corresponding Second Life Uniform Resource Locators (SLurl), when available.

Table 2 – Institution and Region Names (SLurl)

Site	Region
1. Ann Myers Medical Center - Sprott Shaw College – Canada (http://slurl.com/secondlife/Hospital/143/194/22)	Hospital
2. Ball State (http://slurl.com/secondlife/Ball%20State%20University/136/135/22)	Ball State University
3. Boise State (http://slurl.com/secondlife/Ball%20State%20University/136/136/23)	EdTech
4. Duke	DUSON
5. Kansas University Medical Center (KUMC)	KUMC Isle
6. Ohio University (http://slurl.com/secondlife/Ball%20State%20University/136/136/23)	Ohio University
7. University of Arizona (http://slurl.com/secondlife/University%20of%20Arizona/128/128/0)	Arizona Island
8. Vanderbilt University School of Nursing and the University of Kentucky College of Nursing	NurSIM4U
9. Washington State Board for Community and Technical Colleges (Tacoma Community College) (http://slurl.com/secondlife/Evergreen%20Island/76/165/28)	Evergreen Island
10. Wisconsin TECHE (U of Wisconsin Oshkosh; U of Wisconsin- Milwaukee) (http://slurl.com/secondlife/Wisconsin%20Tecne/84/80/2)	Wisconsin Tecne
11. Caledonian U. Saltire Centre/Glasgow Scotland (http://slurl.com/secondlife/Wisconsin%20Tecne/84/80/2)	Glascow Caledonian

Table 2 (continued)

12. HealthLink New York (http://slurl.com/secondlife/HealthLink%20New%20York/188/187/25)	HealthLink New York
13. Learning Commons for Nurses (http://slurl.com/secondlife/Teaching%2010/128/128/0)	Teaching 10
14. Second Health Imperial College of London (U. of Nottingham – UK) (http://slurl.com/secondlife/Teaching%2010/128/128/0)	UK Virtual Hospital
15. SLENZ/New Zealand Tertiary Education Commission (U. of Auckland) (http://slurl.com/secondlife/Kowhai/148/164/32)	Kowhai
16. Texas State Tech. College (http://slurl.com/secondlife/Kowhai/148/164/32)	TSTC-Commons
17. University of Michigan	Wolverine Island
18. U. of Texas Medical Branch at Galveston	UTMB Alpha - Main Campus

It was interesting to note that 50% of these communities in SL were found in only one of the 4 search strategies used. Most common was an individual or group page in SL, or a Google listing. Both Kansas City Medical Center and the Wisconsin Tecne were found in all 4 search strategies.

Given that land ownership in SL requires annual fees, probable funding sources or sponsors for these various SL communities were of interest. Nearly two-thirds (61%) of these communities were part of a wider university endeavor. Seventeen percent were supported or developed using grants. The remaining 4 communities were equally divided between government and consortia sponsorship.

Materials returned from the 4 search strategies that described nursing educational activities in these 18 SL communities were reviewed. Most referenced some type of distance learning activity that created a greater sense of presence. Most notable, was the YouTube video describing Duke University's School of Nursing distance learning for informatics students. [7] Students attended presentation in SL, gave poster presentation, and interacted with other students or communities in SL.

Four SL communities did not provide adequate descriptions of the nursing educational activities occurring within their region. Another one third (N=6) of these communities vaguely described simulated patient encounters or a virtual simulation lab experience. However, visits to these SL sites were either restricted to members only or these simulation areas could not be located on the respective regions.

The remaining 7 SL regions did provide more information that described unique nursing–related educational simulations. Table 3 lists these unique educational activities developed or proposed.

Table 3– Unique Nursing Educational Sims in SL

Site	Unique Uses
Ball State	Health and nutritional histories using volunteers and standardized client avatars.
Kansas University Medical Center	Healthcare Informatics/ Operating room for Nurse Anesthesia students proposed
University of Arizona	Border Crossing Sim
Vanderbilt University School of Nursing	Sims to teach nurse educators how to develop and implement simulations
Washington State Board for Com. and Tech. Colleges	Emergency Room Sim
Second Health Imperial College of London	Detailed Hospital Sim; Paramedic Sim
SLENZ	Post-partum Hemorrhage Sim

Discussion

Investigating nursing education's immersion into SL was both difficult and time consuming. Four different search strategies were needed to fully identify and describe participants and activities in this environment. The professional literature was sparse. Searching within SL resulted in twice as many sites for non-professional nursing listing. It was interesting to note that the SL search engine did not distinguish between "Nursing" (usually related to the profession of nursing) and "nursing" which was related to activities such as such as breast feeding and animal care. Attempting to locate relevant SL communities or activities would be a daunting task for nurse educators new to this environment.

The inability to locate and retrieve pertinent information related to nursing educational activities in SL, limits its adoption and likely underestimates nursing's immersion in this environment. A science-related wiki maintained by SL residents [8] includes a tag for nursing. However, only one site, the Ann Myer Medical Center, was listed that was related to nursing education. As with all wikis, updating and adding pages is a personal endeavor.

Another barrier to identifying nursing education's immersion in SL is the lack of any standardized template as to what to include in descriptions of regions or groups or in individual profiles. A consensus within nursing of users of SL as to a standardized approach to listing information would vastly improve search capabilities. A template similar to the one used

by the SL Health y wiki [9] could be adopted and might contain the following information.

- Group or SIM Name
- Purpose
- Contact Information
- Educational Activities Provided
- Target Audience
- Open to All or Closed (except to Members)
- Special or Unique Features
- Related Blogs, Wikis and Other Outworld Content
- Tags/Keywords
- Additional Comments

Furthermore, even if a SL nursing simulation or community was identified in this study, it was very difficult to uncover where in a given region the activity took place. This was due to either the community being closed to non-members or lack of information that directed visitors to nursing educational activities. In addition, many simulations could not be observed as synchronous participation by a group is required. Machinimas, such as those found on YouTube videos provide greater insight into select simulations.

It is not surprising that most of the SL communities identified in this study relied on institutional, governmental, or grant support, given that land ownership and development in SL is not trivial both in terms of costs and the learning curve. The resources needed to develop, maintain, and improve nursing educational communities is extensive. Therefore, it is likely that these or similar funding models will continue.

Using SL to explore healthcare resources is a valuable learning activity for nursing students. The SLHealthy wiki lists nearly 300 sites related to consumer health locations and groups or general health education resources. Many of these are already providing counseling and patient education. In addition there is growing interest in using SL for telehealth. [10-12] All of these reasons indicate that future nurses will likely need to be able to use navigate and interact with others in MUVEs such as Second Life.

Conclusion

Second Life is an environment that can provide valuable educational experiences in nursing. The degree of immersion and interactivity available provides a greater sense of presence, contributing to better learning outcomes.

Identifying nursing educational activities currently available in SL is very difficult. A number of barriers and possible solutions were identified. The difficulty in identifying educational activities in nursing in addition to the challenges of learning to navigate and develop simulations in a 3-D world and the technological requirements required may contribute to nurse educator's reluctance to consider SL as a viable educational tool.

However, since SL has only been available since 2003; the educational experiences identified by this study most likely represent the early adopters. Better identification of nursing education's immersion into SL can assist in the dissemination of this unique environment in nursing. Given the number of registered users, the number of universities currently involved in SL, the availability of health-related sites for consumers, and the emerging interest in telehealth in SL, substantial growth in the use of SL in nursing education is likely.

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Chapter 9.

Ethics, Governance and Policy

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Trust – Can it be controlled?

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Abstract

Trust is an important component in the security of an information system. The advent of the electronic health record (EHR) and the health information system (HIS) have raised it to greater prominence. These systems and their intended benefits are rendered less effective through a low level of trust between the stakeholders. The potential reciprocal relationship between accountability and trust is investigated. A literature study examines both concepts and their interrelationship. The accountability and audit controls provided by the NIST SP 800-53 security guide and the ISO 27799 security standard are extracted, collated and expanded to strengthen the accountability mechanisms within an HIS security program. A dedicated set of accountability controls (NIM) which is specific to the healthcare environment is produced. It is proposed that through the strengthening of the accountability function of the HIS, its level of trustworthiness may be improved

Keywords:

Medical informatics, Accountability, Security measures.

Introduction

There has been a dramatic change in the management of health information using information technology (IT) during the last decade. The adoption of the electronic health record (EHR) together with the evolution of communication mechanisms such as the Internet have enabled the transfer and sharing of clinical information. These developments have arrived with an attendant increased risk to the safety of sensitive patient information [1].

The EHR provides discernable benefits in the administration of patient care and to medical research [2]. Its use allows easier access to the patient information. The sharing of these records facilitates government health-care decision making and medical research using de-identified patient data [3]. It is seen as superior to the paper version because the information is presented in a coherent manner, can be distributed to many locations and its access rules are explicit. It is not possible to ascertain who has viewed a paper record, but it is possible to record all and any access to an EHR [2].

The wealth of information contained in the EHR, however, poses additional security risks which have far-reaching effects. It contains all the information about an individual that a thief needs to steal their identity. Medical identity theft is a growing trend but healthcare providers are more concerned about protecting the clinical information. It is protected by layers of security but similar regard is not applied to Personally Identifiable Information (PII) [4]. This contradiction was noted in 1998 by Barber and is still an issue according to [4]. Healthcare practices who fail to protect the PII of their patients risk their reputation and harm such as the loss of public trust, legal liability or damages [4, 5].

This apparent security gap affects the confidence of the patient in the usefulness of an automated Health Information System (HIS). This concern about privacy hampers the truthful exchange of information between the patient and the clinician. It is seen as a major hindrance to achieving the full potential of an HIS [6].

The importance of security is highlighted by the global proliferation of privacy and data protection legislation such as the Data Protection Directive of the European Union, the Organisation for Economic Co-operation and Development (OECD) Privacy Guidelines, the Asia-Pacific Economic Co-operation (APEC) Privacy Framework and the Health Insurance Portability and Accountability Act (HIPAA) in the United States of America [5, 6].

Recent research in both Australia and the United Kingdom indicates that healthcare staff enjoy a high confidence level which results in minimal scrutiny of the HIS usage which brings a variety of possible security breaches through the improper use of access rights [7].

The healthcare environment is characterised by its co-operative nature and the trust placed in the judgement and activities of the healthcare professionals. It is an environment where security is not seen as a serious issue due to the professional status of the role players [8]. There are many factors that influence personal ethics and the fact that the healthcare personnel, using an HIS, are, in the main, members of professional bodies implies that a high level of professional trust exists. This type of trusting organisational culture acts as barrier to recognizing security threats and results in information security not being given the prominence it requires [3].

It is essential to build trust in an HIS because quality health care depends on accurate information [6]. The importance of good information within an HIS and its benefits cannot be understated. These include improved patient care and the creation of a culture of trust between the patient and

healthcare provider. As stated by Alshawi, Missi and Eldabi "after all, what is information if you cannot trust it?" [9].

It is proposed, in this research, that a high level of professional trust in healthcare environments may be controlled through a set of accountability measures. It is argued that trust and accountability are seen to exist in a reciprocal relationship and that the greater the accountability of an HIS may result in increased trust by both the users and patients. This leads to an examination of the security controls or measures themselves that are dedicated to accountability and the role they play in establishing accountability and enhancing trust. A resultant accountability control set specific to the healthcare environment is produced.

Method

A literature based approach was used to investigate the concepts of security management and control, accountability and trust. The literature study argues towards a reciprocal relationship between the concepts. The security controls that relate to the concepts of accountability and auditability were re-examined. Those controls that related specifically were extracted and collated. A resultant accountability and audit control set was produced, titled the NIM Accountability control set (NIM). This was achieved using the following method.

The following four source documents were identified as relevant to compile the NIM Accountability control set, viz:

- NIST SP 800-53. A guide to recommended security controls;
- ISO 27002, standard for IT security techniques and guide to information security management;
- ISO 27799, standard for health informatics and information security management using ISO 27002;
- Markle Foundation Connecting for Health – The Common Framework.

The NIST publications are used in this research because they are widely accepted and are freely available. They present generic guidelines that are applicable across a variety of organisational situations and their range of subjects is extensive. The ISO 277002 and ISO 27799 standards are used because they are internationally accepted and are well-known. The Markle Foundation Connecting for Health Common Framework is used because it represents an independent and unrelated viewpoint. It is the result of collaboration between various healthcare and IT professionals.

The NIST Computer Security Division has developed a variety of publications concerned with security programs and controls which encompass fair information practices, privacy principles, management and specifically auditing and accountability mechanisms. The NIST SP 800-53 covers the steps that address security control selection and includes tailoring the security controls. There are seventeen control families which have a two-character identifier unique to each family and are divided in to technical, operational and management classes. Examples include AC-Access Control, Technical Class to SI-System and Information Integrity, Management Class. The family of particular interest to this research is the AU-Audit and Accountability in the technical class [10].

The ISO/IEC in their publications ISO 27002 and ISO 27799, related to information security and health information security respectively, specifically address a security program and an ISMS and include monitoring and audit logging.

The Markle Foundation Connecting for Health Common Framework includes core privacy principles, trusted network design and accountability mechanisms [6, 11, 12].

The NIST SP 800-53 was identified as a natural starting point to define a control set for Accountability, because it specifically contains a family of controls dedicated to Audit and Accountability (AU). Thereafter, the corresponding controls in the ISO 27002 were identified, using a security control mapping tool provided by the NIST SP 800-53. It was noted that all the AU-Audit and Accountability controls, with the exception of AU-13 and AU-14, were covered. This rendered an ISO-27002-based control set dedicated to Accountability as defined by the SP 800-53.

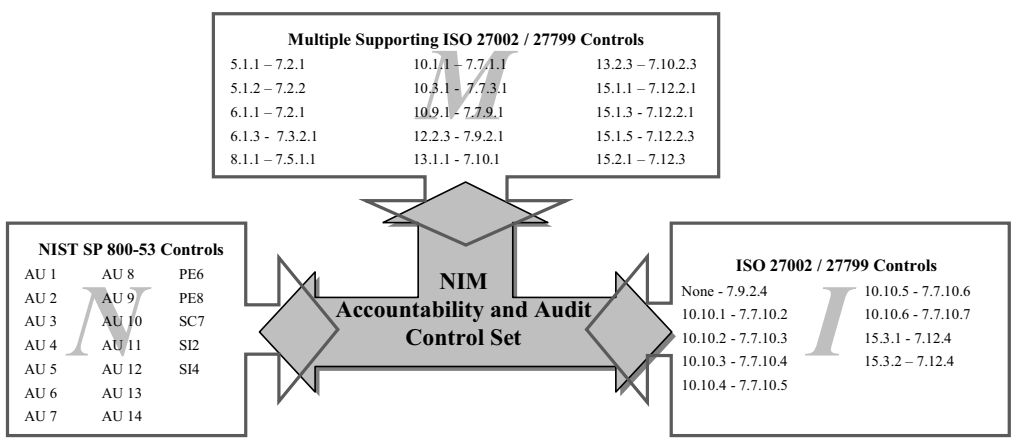

Figure 1 – NIM Accountability control set

The focus shifted to the ISO 27002. The controls dedicated to accountability were identified. These are presented in Figure 1 as Arrow I which contains the ISO 27002 controls that are directly related to accountability. The SP 800-53 security control mapping was used again, this time to map the ISO controls to the NIST controls. This mapping rendered some NIST controls not contained in the AU family. The complete set of identified NIST controls are presented in Figure 1 as Arrow N.

The focus of this research is the healthcare industry, therefore, the ISO 27001 controls needed to be mapped to the ISO 27799 health specific standard. This was achieved using the work of [13] in which a mapping between the ISO 27002 and the ISO 27799 was done. It includes the extent of coverage offered to the security issues by each standard. It was observed that the ISO 27799 includes additional guidance to accommodate the unique needs of health information security.

The activities of accountability exist within a security program and its ISMS and are, as such, directly and indirectly related to other security controls. The mapping between the NIST and ISO 27002 identified ISO-controls that are indirectly related to accountability. These are included in the resultant control set as multiple supportive controls and are presented in Figure 1 as Arrow M. The mapping between the ISO 27002 and ISO 27799 is reflected in the diagram.

The completion of these steps rendered a resultant control set for Accountability. The Connecting for Health Common Framework was consulted, as an independent source, to provide an unrelated analysis of the completeness of the accountability and audit controls.

Results

The NIST AU-family of security controls cover the entire gamut of audit logging and mentoring activities and their related controls are inclusive of a variety of activities including risk management and access enforcement [10].

The ISO 27799 Monitoring security clauses contain additional guidance to satisfy the special, healthcare security requirements for audit and logging that will ensure accountability and provide an incentive to users to conform to a level of acceptable use [13]. It was apparent that due to the unique needs of healthcare accountability it was necessary to include the new ISO 27799 security control - 7.9.2.1. Uniquely identifying the subject of care - into the NIM Accountability control set. There are many references to the need for distinctive identification needs within the EHR and its PII. Healthcare accountability is strongly linked to the unique identification of the users, their actions and the subject (the patient) of their activities.

There are many references in the Audit Record Content to the identification of the user and patient to enforce the concept of accountability through traceability. This raises the importance of uniquely identifying the user and patient interacting with the HIS [14], [12], [10]. This reinforces the decision to include the ISO 27799 security clause 7.9.2.1 in NIM Accountability control set.

The inter-relatedness of the accountability controls is demonstrated in Figure 1. Arrow N presents the identified NIST controls, Arrow I presents the ISO-controls that are directly related to accountability and Arrow M presents the multiple ISO-controls that support accountability. The NIM Accountability control set is represented by the multi-directional arrow.

The NIM Accountability control set is presented in Table 1. It represents the control set at the union of the Arrows marked N, I and M. It tabulates, in full, the controls identified through the mapping between the NIST SP 800-53, the ISO 27002 and ISO 27799 and includes the additional healthcare specific control.

Table 1 – NIM Accountability control set

NIST	ISO 27002	ISO 27799
None	None	7.9.2.4
AU-1 AU policy & procedures	5.1.1, 5.1.2, 6.1.1, 6.1.3, 8.1.1, 10.1.1,10.10.2, 15.1.1, 15.2.1, 15.3.1	7.2.1, 7.2.2, 7.2.1, 7.3.2.1, 7.5.1.1, 7.7.1.1, 7.7.10.3, 7.12.2.1, 7.12.3, 7.12.4,
AU-2 Auditable events	10.10.1, 10.10.4,10.10.5, 15.3.1	7.7.10.2, 7.7.10.5, 7.7.10.6, 7.12.4
AU-3 Contents of audit records	10.3.1, 10.10.1	7.7.3.1, 7.7.10.2
AU-4 Audit storage capacity	10.3.1, 10.10.1	7.7.3.1, 7.7.10.2
AU-5 Response to audit failures	10.3.1, 10.10.1	7.7.3.1, 7.7.10.2
AU-6 Audit review, analysis & reporting	10.10.2, 10.10.5, 13.1.1, 15.1.5	7.7.10.3, 7.7.10.6, 7.10.1, 7.12.2.3
AU-7 Audit reduction & report generation	10.10.2	7.7.10..3
AU-8 Time stamps	10.10.1, 10.10.6,	7.7.10.2, 7.7.10.7
AU-9 Protection of audit information	10.10.3, 13.2.3, 15.1.3, 15.3.2	7.7.10.4, 7.10.2.3, 7.12.2.1, 7.12.4
AU-10 Non-repudiation	10.9.1, 12.2.3	7.7.9.1, 7.9.2.1
AU-11 Audit record retention	10.10.1, 10.10.2, 15.1.3	7.7.10.2, 7.7.10.3, 7.12.2.1
AU-12 Audit generation	10.10.1, 10.10.4, 10.10.5,	7.7.10.2, 7.7.10.5, 7.7.10.6
AU-13 Monitoring for information disclosure	None	None
AU-14 Session audit	None	None
PE-6 Monitoring physical access	10.10.2	7.7.10.3
PE-8 Access records	10.10.2, 15.2.1	7.7.10.3, 7.12.3
PL-6 Security-related activity planning	15.3.1	7.12.4
SC-7 Boundary protection	10.9.1, 10.10.2	7.7.9.1, 7.7.10.3
SI-2 Flaw remediation	10.10.5	7.7.10.6,
SI-4 Information system monitoring	10.10.2, 13.1.1	7.7.10.3, 7.10.1,

Discussion

There are a variety of defined and generally accepted concepts in the area of information security and information security management. It is pertinent to inspect some to frame the proposition that trust can arguably be controlled.

The goal of information security is seen as the "preservation of confidentiality, integrity and availability of information" and includes such terms as the accountability of users, authentication, non-repudiation and reliability [15]. The goal of health information security is stated as maintaining information confidentiality, availability and integrity including authenticity, accountability and auditability [14]. There is a subtle difference between the two definitions and the healthcare security requirements are more inclusive. Additional healthcare considerations include the compliance with data protection laws and privacy legislation, maintaining organisational and individual accountability and maintaining public trust in the healthcare provider and the HIS in use [14]. Notably, accountability, auditability and trust are central to the definition of security in the healthcare context.

The ISO 27799 Section 7.7.10 Monitoring covers audit logging and monitoring and states that "Of all security requirements protecting personal health information, among the most important are those relating to audit and logging. These ensure accountability for subjects of care entrusting their information to EHR systems and also provide a strong incentive to users of such systems to conform to the policies on the acceptable use of these systems…" [14].

There are frequent references in the security literature to the concepts of trust and accountability. These concepts are examined to clarify their relationship. Trust is defined as, according to [16], the firm belief or confidence in the integrity, reliability, honesty etc. of another person or thing. It has the following synonyms: assurance, confidence, certainty and belief.

Trust, as a concept in IT security, is seen as result of good information security. It is not explicitly defined and is seen as an intrinsic concept.

Accountability, conversely, is frequently defined in a variety of standards, practices and guidelines. Its main aim is to ensure that activities are attributable to individuals [12]; similarly as the "property that ensures that the actions of an entity may be uniquely traced to that entity" [14] or as "the security goal that generates the requirement for the actions of an entity to be uniquely traced to that entity." [17].

The question posed by this research is – can trust be controlled by the use of appropriate accountability measures? There is an imperative to maintain organisational and individual accountability and the public trust in the HIS. These, it is argued, can be seen as a function of the implemented security controls that promote the accountability of the users for the data [5].

An HIS environment often relies heavily on the trust of its users who act as "guardians'' to protect its information. Guardianship can be implemented through using IT in monitoring and auditing the system activities [3]. Monitoring and auditing activities are typically associated with the concept of accountability. Therefore, accountability may be improved, through the application of appropriate mechanisms, such as monitoring and auditing. An improvement in accountability may lead to an increase in trust. This is due to stakeholders being sure that all activities are uniquely attributable to individuals, who can be held accountable for their actions. Therefore, it can be concluded that there appears to exist a reciprocal relationship between the level of trust placed in an HIS and the degree of accountability of its users.

Self-regulation is a key element of trust. However, relying on the trust or ethics of the users, who enjoy a professional status, is in-adequate and some control measures are necessary. Strong, user-identification procedures strengthens the ability of the HIS to prove accountability through its audit processes. It is possible to uniquely trace all activities within the HIS through examining the audit records.

The NIM Accountability control set is proposed to cover all the aspects of accountability within a healthcare environment and is specifically expanded to strengthen the identification of the user and patient. It is necessary to examine how the NIM Accountability control set may strengthen accountability and, therefore, trust.

The ISO 27799 text underlines both the importance of and inter-relationship of accountability and trust. The implication is that the stronger the accountability measures, the greater the resulting trust because all system actions are uniquely traceable to an individual. The rationale is that these mechanisms ensure accountability for the patient who has entrusted his personal information to the HIS and that it is used in an acceptable manner [14].

An audit log and the traceability afforded by the EHR are an important benefit provided by the use of an HIS. Privacy and accountability can be ensured through the audit and logging mechanisms which record all the access, activities and use of the EHR [2]. Strong privacy protection is seen to enhance the quality of the data and the subsequent health care that can be provided, by increasing the trust and the amount of truthful information shared by the patients, according to [18]. The inclusion of transparent and effective logging and audit control practices will promote trust among both the patients and participating institutions [12].

Accountability is established when the activities of the users of the HIS can be uniquely identified through a meaningful audit trail which is created for the actions of the users who can be held responsible for their actions. It is argued that robust audit controls may produce a greater level of accountability through enhanced traceability which, in turn, may promote the level of trust in the HIS.

The NIM Accountability control set contains a set of robust audit controls which are augmented to satisfy the health-specific accountability needs of health information security. The NIM Accountability controls are designed to provide an increased degree of accountability, for an HIS, when implemented. The reciprocal relationship between trust and accountability implies that the level of trustworthiness of the HIS, as perceived by its stakeholders, can be improved by the use of the NIM Accountability control set.

The use of the NIM Accountability control set may promote a tangible culture of trust within the healthcare environment.

This may help overcome the barrier of treating information security as a serious threat issue [3].

There is link between strong audit mechanisms that promote accountability which may lead to a reciprocal increase in trust by the users and patients of an HIS. This is the rationale behind the argument that trust may be controlled by implementing strong accountability control measures which influence the amount of trust placed in an HIS by its stakeholders. An HIS which employs a set of strong audit controls, as provided by the NIM Accountability control set, may improve its accountability and therefore, its level of trust.

Conclusion

The increasing reliance of healthcare management on IT and use of the EHR has brought benefits which carry an increased but unrealised security risk. This security gap has affected the confidence of the stakeholders in the operation of an HIS. It has raised the issue of trust in the provision of healthcare IT services. The research argues that a reciprocal relationship exists between trust and accountability. The viability of implementing accountability controls or measures, in healthcare security, to strengthen trust is examined.

A literature based approach is used and the NIST SP 800-53, ISO 27002, ISO 27999 and Markle Foundation Connecting for Health Common Framework were examined. A set of augmented accountability controls, the NIM Accountability control set, were identified from these documents.

An area of future research is the creation of dedicated security performance measures which will measure the effectiveness of the NIM Accountability control set.

The NIM Accountability control set is inclusive of the special needs of an HIS. It is proposed that when the controls are implemented they create greater user accountability which may result in increased patient trust in the use of an HIS, therefore, trust may, arguably, be controlled.

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Informatics and Evidence-Based Medicine: Prescription for Success

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Abstract

This article reports on the experience of one organization between 2004 and 2009 to develop an effective people-process-technology system to better manage the quality of health care. The creation of this system started with creating a strategic plan for quality and then establishing a structure to implement the plan. The next phase consisted of establishing a number of simultaneous steps that ranged from identifying and leveraging the appropriate informatics tools to the oversight process, and from the implementation team to strategies for working with clinical groups. The outcome as of 2009 is a well established evidence-based quality process and team in place. There are over 450 evidence-based medicine quality sets. More than 52% of all patients are admitted on quality evidence-based medicine pathways and protocols. This article reflects a successful prescription for combining informatics and evidence-based medicine to improve the quality of health care.

Keywords:

Evidence based medicine, Informatics, Quality of health care, Medical order entry systems, Leadership

Introduction

There are many imperatives for organizations focusing on quality improvement. Health care delivery is not as good as it could be and progress toward a system that reliably delivers high-quality outcomes still has significant challenges [1]. Health care workers (clinical providers and ancillary staff) would like to improve, but achieving high-reliability, quality care cannot be achieved by simply working harder [2]. A new system of care must be created, but it is difficult to move from current practices without organizational leadership to sanction the needed changes and to ensure the importance of this direction [3].

Developing a new system of care is a significant change management/transformation process. This article reflects the experiences of one organization over five years (2004-2009) to improve the quality of health care through an organizational change process [4-6].

Vanderbilt University Medical Center (VUMC) is a comprehensive healthcare facility located in Nashville, Tennessee. VUMC consists of four hospitals: Vanderbilt University Hospital, Monroe Carell Jr. Children's Hospital at Vanderbilt, Psychiatric Hospital at Vanderbilt, and the Vanderbilt Stallworth Rehabilitation Hospital. It is home to the region's only Level I Trauma Center as well as the region's only Level IV Neonatal Intensive Care Unit. There are over 100 ambulatory specialty practices within the Vanderbilt Medical Group and the Vanderbilt-Ingram Cancer Center is Tennessee's only Comprehensive Cancer Center.

During this time period, Vanderbilt's Chief Medical Officer (CMO) had responsibility for the quality of patient care, for oversight and partnership in quality improvement efforts, and in developing systems to sustain high-quality care processes through time. To develop and implement an improved system, the CMO engaged the medical staff, resident physicians, nurses, nurse practitioners, dieticians, social workers, pharmacists, financial counselors, etc. to collaborate in on the goal of creating the most effective quality patient care delivery system possible [7,8].

Methods

In order to create a comprehensive quality effort, the CMO developed a strategic plan with input from multiple VUMC stakeholders. Based on this plan, quality committee structure included a new Quality Council and an Evidence-based Medicine (EBM) Committee, to better support quality-related goals and objectives.

One component of the quality plan was to identify all externally reported measures and develop internal methods for improving all of those metrics. To accomplish this, the following were included as key elements of the plan:

- assigning accountabilities
- developing internal metrics
- creating incentives for the organization
- working on motivation for those involved
- reinforcing our infrastructure to support these efforts

In addition to establishing operational accountability for quality-related items, infrastructure was needed to support achieving institutional goals. This infrastructure included support for determining best evidence applied to particular populations, determining the standardized practice that would be needed to deliver this care in a reliable fashion, and

electronic systems to support the delivery of desired care and also to monitor real-time status of patients with respect to desired care. To this end, an evidence-based medicine committee was established to identify opportunities for improvement, remove barriers to progress, and provide a forum to jump start moving from evidence to practice.

Pre-existing infrastructure was utilized as a platform on which to disseminate and implement evidence-based care pathways. Vanderbilt hospitals had used patient care pathways and order sets for a Clinical Provider Order Entry (CPOE) system for a number of years, but the order sets were not necessarily standardized, nor fully based on evidence. The informatics systems (such as CPOE) provided a platform to more uniformly implement and disseminate evidence-based care pathways to directly impact day-to-day care decisions. Thus, the Informatics organization was a significant component in creating a sustainable system of care that reliably delivers quality care.

With a quality strategic plan developed and a Quality Council in place, it was important to begin an effective organizational implementation process. A key component of the quality strategic plan was ensuring Vanderbilt's order sets and pathways were evidence-based. The initial goal was to begin to transform the organization away from expert-based care, where a lack of standardization can lead to unnecessary variability, to one of standardized, evidence-based care where every patient receives the care that he or she should receive for a given clinical situation, while still allowing appropriate variability to account for differences between patients. To kick-off the initiative, the organization established several simultaneous components to set the stage for success:

Ensured that the appropriate informatics tools and informational resources were available:

- Content creation tools and resources (e.g. order set creation).
- Content "vetting" tools that make comparing and contrasting current evidence with current practice simple and efficient.
- Expert assistance from an Evidence-based librarian to aid in evidence searches where answers are not found in off the shelf resources.

Created an oversight team which was responsible for:

- Approval Process
- Clinical sounding board to help prioritize the work
- For Vanderbilt, this group was the EBM Committee which consisted of the Chief Medical Officer, The Chief Nursing Officer, the Chiefs of staff for the various hospitals, Case Management leadership, and Informatics Leadership.

Established a support model for clinical teams:

- An integrated support team to facilitate this effort was essential. Clinical teams consisted of physicians, nurses, pharmacists, librarians, and informatics professionals we termed "Evidence-based Medicine (EBM) Specialists" to facilitate the work.

Created guidelines for facilitating change with clinical groups:

- Processes were established for contacting the teams, what information to share, sign-off sheets, communication strategies, etc.
- Created operational agreements to promote smooth functioning of work across business units (e.g. timely pharmacy review of orders to facilitate rapid development)

Identified areas of concentration:

- There were over 120 possible concentration areas. These were classified into current stages of "completeness." The eventual stages that evolved were: (1) Promised; (2) Preliminary Work; (3) Well along; (4) Ready for Oversight Group approval; (5) Ready for Case Management and Informatics Implementation; and (6) Completed. As we started "test-driving" this system a significant number of items from the "promised" category were eliminated to enable concentration on those topics that had the highest probability of success.

Alignment of informatics to actively support the initiative:

- CPOE – Content creation, and content clean up. New functionality to improve access to order sets (e.g. the creation of an "admission wizard" as a final common pathway to display order sets related to the admission service as a part of the admission process)
- Enterprise Data Warehouse – Data integration with other systems to track usage and outcomes related to pathway use
- Pharmacy Informatics – to develop clinical decision support to aid in the order creation process (e.g. creating a simplified renal dosing algorithm based on clinical indication for levofloxacin, rather than having the content duplicated across numerous order sets)
- Advanced Analytics – to aid in data analysis (e.g. opportunities for further work, analysis of impact outcomes)
- Content tools (e.g. "canned" evidence-resources such as Zynx Evidence)

The Process

The key in any successful program is not just to start but to think about the barriers, the desired end goal, and begin to design a process that people can understand and that can be used repeatedly. At the beginning of this initial phase, the needed products were purchased, the appropriate tools were created, and appropriate staff were engaged. This became a team effort. In order to identify efficient methods of developing evidence-based pathways and order sets, multiple development models were tried, with the idea that one of the models would prove superior to the others. Models that were tried included ones where multiple physician "leads" were involved, a model with a single physician lead researching evidence and creating the practice, and a model that utilized a team to facilitate the evidence discussion and content creation with the clinical team. The facilitative model proved most successful in terms of efficiency of time for the clinical

experts, as well as the ability to rapidly achieve consensus around a standard "Vanderbilt" practice. This model served as the basis for all ongoing work to support the EBM order set effort, and is still in place.

Developing and implementing content, however, is only part of the story. A major challenge is whether or not clinical teams view the content as their own, or whether they view it as owned by informatics or operations. If the former, clinicians are much more likely to use the order sets. Critical to achieving this view was the approach taken by the EBM Specialists while facilitating the clinical teams. The approach was one where the EBM Specialist asked the question "What to you defines good care for this patient population" and the resultant practices specified by the clinical team were then implemented. We found that by taking this approach, we mitigated fear by the clinical team that the EBM process would dictate care, and we also reassured the team that the organization would support what they considered to be best care. In other words, informatics, operations, and the clinical staff formed a partnership for success, with all parties focused on an end goal of reliable, high-quality care. In following this process, all evidence-based considerations were included, but were voiced first by the clinical team, thus establishing direct ownership of content by the team rather than informatics. The approach also consisted of a structure to support this ownership strategy [9].

The Clinical Teams

Each clinical work group consisted of physicians, nurses, a pharmacist, a librarian, and an EBM specialist. The EBM specialist facilitated clinical team meetings and built evidence packets that linked evidence directly to orders in current order sets (e.g. our current practice). The evidence packets focused helped clinicians focus discussion on desired practice. In addition to the evidence packets, a key feature of the teams was to assign a single physician lead. The lead was chosen strategically, and was specifically not a person who was viewed by peers to be a "techy" person. It was critical to find a leader who was clinically respected and whom others could identify with. Once selected, the physician lead served as the broker of agreements with other physicians to standardize practice where practice might vary but where standardization could prove beneficial. This was done outside of the team meetings in a one-on-one fashion and proved very successful. Previous to this, physicians often felt a need to justify practice differences, which lead to difficulty in coming to consensus. The "off-line" nature of the new model, greatly improved establishing a consensus, as well as fostered further "ownership" by the clinical team.

To more effectively facilitate arriving at a standardized "Vanderbilt" practice, evidence is presented to the clinical teams in a focused way. This allows the work group team to come to consensus on how they will treat a particular population of patients. The focus was not on "follow this guideline," but rather on "based on this evidence what would you like to do in taking care of these patients?" To accomplish this part of the process there were three key components:

1. Identifying the members of the clinical work group team, defining everyone's roles and structuring the team for more effective outcomes
2. Having evidence resources available that streamlined the looking at the evidence related to an orderable and order sets
3. Feeding back information on order set usage and performance to the clinical teams, so they can track to the kind of care they intended to deliver.

We were strategic about how the clinical teams were structured. For example, the physician lead is someone who needs to be respected by the other physicians in that group, someone whom other physicians would follow. The desire was to have other physicians trust and identify with the leader such that they would say, "Yes, that's a good way – I could do that as well." This physician then brokers any areas where there is disagreement among physicians or other members of the clinical team. Division chiefs or the department chairs were to identify the work needed, to help to prioritize, and identify the leaders. This was to ensure that the effort had upper level ownership. Residents and/or fellows were also included on the team. When needed, an Evidence-based Librarian completes more extensive searches.

Evidence Resources

For streamlined evidence resources, the EBM Specialists create "Evidence Packets" that list available evidence from a variety of sources, and organize the evidence around a template order set. Directly listing evidence for specific orderable items allows the clinical teams to focus their discussion, rather than having to deal with an entire corpus of evidence all at once. This process helps in developing consensus.

The CPOE System

Vanderbilt University Medical Center has a computerized provider order entry (CPOE) system. CPOE is an excellent mechanism to embed evidence-based guidelines and display to clinicians at the time of they are implementing orders. This is accomplished mainly through order sets that are lists of individual items that someone might want to use at a particular phase of patient care. For example, on admission to the hospital for congestive heart failure (CHF) exacerbation, there are a set of things that need to be initiated. A CHF admission order set is targeted to that particular phase of care to make the "right thing" easy to do. Later when the patient is moved to another phase of care another related order set is available and finally at discharge yet another order set is available. Making these order sets evidence-based was one of the avenues for affecting our inpatient care and we wanted consensus from the clinical teams about practice.

Reports to show actual performance with respect to desired performance

Feedback is provided for those items that clinical teams identified as key elements of the evidence-based care pathways. For example, one group explicitly added an evidence-based pain management section to their post-op order sets. This usage information could be provided to the clinical team that showed how often various pain management items

within the order set were being used. This allowed the clinical team to address potential issues with appropriate management of post-op pain.

Results

To date the process has been very successful. There are over 450 evidence-based order sets in the system with new ones being created all the time. Over 52% of all patients are admitted on EBM order sets. The basic process from four years ago continues and is built on a foundation of agreeing to a standard "Vanderbilt" practice that is based on evidence. Once agreement is reached, the order sets are created, utilization is monitored, and the data are provided to clinical teams to optimize use and performance within the desired practice. Data are reported to clinical teams to a) ensure that the order sets are being used; b) ensure that components of the order set are used in the manner that was planned; and c) to track to desired patient outcomes.

Monitoring is a critical component that enables the Evidence-based Medicine Specialists to serve in a facilitative partnership role with clinical teams helping them deliver correct and desired care to patients and drive that care toward desired outcomes. Utilization data is critical to promoting appropriate use and further promoting ownership of the content by the clinical teams. For example, a new order set may be created but after a few months it may not have been used. The reasons for this could be several, including the fact that people may not be able to find it in the system. Each of our order sets has synonyms associated, and it is possible that commonly entered terms that relate to a particular order set may not bring up the order set in the list of search results. For example, "Succinylcholine" is ordered for certain types of intubation protocols, but when typed in by a physician, order sets that pertain to these protocols were not showing in the search results. Adding Succinylcholine as a synonym resolves this issue, making the order set easier to find.

Order set usage data are important to ensure that the content is being used, but order set usage does not tell the story of *how* the content is being used. Order Set *Performance* is monitored to show the utilization of individual orders within an evidence-based order set. This can be viewed for a single patient (i.e. which elements did a single patient receive) and also in aggregate to see what percentage of the time certain elements are used across patients. For example, when the stroke admission order set was examined, orders for aspiration precaution were not utilized as often as the clinical team preferred. The patient population being evaluated had 100% of the patients on the clinical pathway but only 38% of those patients had orders for aspiration precautions. These data when presented to the clinical team caused them to investigate what elements of care workflow needed to be changed in order to ensure high performance with desired care. Discussion included whether or not this should be a standard of care for the unit and therefore did not need an order or whether they wanted an order "in the chart" for aspiration precautions to drive appropriate care. This case illustrates that with only simple order set utilization information, we could have been satisfied that 100% of the patients that came in with stroke were on the stroke pathway. However, after investigating the details of the performance with the desired care for these patients it was discovered that we were not at the 100% level and had additional work to accomplish this goal.

Our system allows us to know if an order set is being used, and also if we are performing as desired with respect to key evidence-based elements of the order set. However, once all is performed as planned, what does that mean for patient outcomes? This is a more difficult item to track. Looking at common outcome measures such as risk-adjusted observed to expected mortality, observed to expected readmission rate, and observed to expected length of stay is one major approach. Another approach that is being pursued is to have clinical teams and other groups define measures of clinical quality and build in capture of these data wherever possible, including using physician note templates, and automated capture from devices and other clinical systems such as bar-code medication administration systems. The plan is to aggregate these data and develop a more comprehensive picture of quality outcomes that extend across the inpatient-outpatient paradigm, and then associate performance and practice data with outcomes. This is the final piece in closing the loop for quality and is proving a challenge to accomplish. However, this is critical in ensuring that the desired care leads to desired outcomes. Each component of data feedback cycles back into the desired practice to inform whether or not changes are warranted. This basic approach for creation of evidence-based content in the form of order sets has been utilized for more complex evidence-based advisors that include complex logic within the order entry system as well as initiatives to reduce ventilator associated pneumonia, and other "hospital acquired conditions," such as pressure ulcers, falls, and reduction of adverse drug events. The Evidence-based Medicine Team is truly a partnership between IT and clinical teams to identify, establish, and implement standard practices and ensure reliable, high quality care that tracks to desired patient outcomes.

Discussion

It is easy to say that you would like to start an evidence-based medicine program so that the majority of patients are admitted to the hospital or treated in an ambulatory area using evidence-based practices. From a leadership perspective there are barriers that arise that make this difficult. The following are a few of the barriers.

Getting Started

Our first attempt with starting this effort was to hire a retired physician who had worked with evidence in the past to head this program. This was not successful. At this point an internal person from informatics with the leadership skills and the process knowledge to basically take what she called "going through the rainforest with a machete" to figure out where the roads actually could be or should be. She started a process that helped align people in the direction desired.

Agreeing on the resources

When starting this we did not know how many staff were needed, what type of electronic resources were required, etc. It

took several attempts at creating evidence-based medicine packets to know the needed resources. For example, library and pharmacy professionals needed to be included in the core team. The team needed to be staffed by nurses who were in the "bridge" role between the evidence based medicine information and the practitioners in the clinical areas.

The right leadership

The evidence-based medicine process needed the right leadership to be in charge of it. After an initial start it was determined that there was an informatics based physician who understood this process, had a personality to engage clinical and non-clinical staff, and had the style to create teams. That person was selected to lead this effort on an on-going basis and has demonstrated excellence in this area for a number of years.

Converting the doubters

When you live in an academic institution everyone is certain that they are the "world expert" and therefore evidence-based medicine is what they are creating or what they are doing. It was extremely important to show that the experts can make changes in their practices that would ensure and drive higher quality. To this end, the approach in achieving clinician ownership of order sets and pathways, coupled with ongoing support through data reports and iterative improvement established a new way of working that built momentum over time. People who started off on the sidelines saying "Evidence-based Medicine is cookbook medicine" began to say "Why didn't you work with me first?"

Conclusion

To have a successful link with informatics and evidence-based medicine requires leadership at the senior levels of the organization and at the process/operational level. It requires process metrics, measures of *performance*, and clinical teams that understand and respect feedback to enable the highest quality of patient care. Further, links to clinical outcomes are critical to ultimately assess the effectiveness of the implemented order sets and pathways. The implementation methodologies used, created a framework in which trust developed between clinical teams and informatics, and enabled true partnerships to flourish in which the pursuit of clinical excellence and excellence in patient outcomes is the goal.

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The Trajectory of Scientific Discovery: Concept Co-Occurrence and Converging Semantic Distance

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Abstract

The paradigm of literature-based knowledge discovery originated by Swanson involves finding meaningful associations between terms or concepts that have not occurred together in any previously published document. While several automated approaches have been applied to this problem, these generally evaluate the literature at a point in time, and do not evaluate the role of change over time in distributional statistics as an indicator of meaningful implicit associations. To address this issue, we develop and evaluate Symmetric Random Indexing (SRI), a novel variant of the Random Indexing (RI) approach that is able to measure implicit association over time. SRI is found to compare favorably to existing RI variants in the prediction of future direct co-occurrence. Summary statistics over several experiments suggest a trend of converging semantic distance prior to the co-occurrence of key terms for two seminal historical literature-based discoveries.

Keywords:

Literature-based discovery, Distributional semantics, Random indexing, Latent semantic analysis

Introduction

The field of literature-based knowledge discovery can be traced at its inception to the fortuitous discovery by Don Swanson of an implicit and therapeutically useful connection between fish-oil and Raynaud's Disease [1]. The idea underlying Swanson's approach to this problem is that two concepts may be meaningfully associated despite not yet having occurred together in the literature. The discovery of such implicit connections constitutes a literature-based knowledge discovery, and a number of computational approaches have been applied in an attempt to automate discoveries of this nature (for a review see [2-4]).

These approaches generally attempt to identify unknown connections by first identifying a "linking term" which co-occurs with the cue term. However, the explicit identification of linking terms imposes certain limitations on the discovery process. Firstly, the number of possible linking terms is generally large, and a combinatorial explosion in the size of the discovery search space occurs with the number of linking terms permitted on the path from cue to target. Consequently, automation of Swanson's discovery paradigm in this manner incurs I/O and computational costs that limit the possibilities for dynamic and responsive literature-based discovery tools. In this context, the development of methods to directly identify implicit connections, without the need for explicit identification of a linking term presents a desirable alternative. Such goals have led researchers in the field to explore methods of distributional semantics that directly identify implicit connections (without the need to explicitly identify a linking term), as an alternative [5, 6]. In our recent research, we have shown that Reflective Random Indexing (RRI) [7], a customized variant of the Random Indexing (RI) [8] approach to distributional semantics, is effective in identifying meaningful implicit connections.

However, a further limitation of existing approaches, including our own, is that they attempt to determine meaningful implicit connections by considering the distribution of terms or concepts in a corpus at a single point in time. From another perspective, the detection of meaningful implicit connections in a time-delimited set of documents can be viewed as the prediction of future explicit connections [9, 7]. One might hypothesize that changes in the strength of implicit associations over time would be important in predicting explicit connections in the future, as the associative strength between two concepts from disparate fields would be expected to grow as new connections are discovered between other concepts in these fields. In this paper we explore the extent to which changes in implicit associative strength over time are predictive of explicit connections in the future, in the context of two historical literature-based discoveries. In order to do so, we require a scalable model that is able to derive implicit connections from text, and is also easily incrementally updateable to accommodate adding new documents chronologically to the model without significant re-computation.

Both RI and RRI offer significant advantages in scalability over established methods such as Latent Semantic Indexing (LSI) [5] (for a computational details see [7]). In addition, both RI and RRI allow for incremental updates, as new documents are added to the corpus [8, 7]. As we have shown in our previous work [7], RI as originally implemented is ineffective in deriving meaningful associations between terms that do not occur together in any document. The reason for this is that RI produces a reasonably accurate reduced-dimensional approximation of the term-by-document matrix describing the

distributional statistics in the corpus concerned. Distance between terms is measured using the cosine (or normalized scalar product) between the vector representations of these terms in the reduced-dimensional space. Two terms that do not share any document between them will be represented as two vectors with no non-zero dimensions in common, and consequently their relatedness as measured by the cosine metric will be zero. RI does a good enough job of preserving the relative distances in the original matrix that there is a high probability of this being true in the reduced-dimensional matrix also [10]. In our previous work, we have addressed this limitation using RRI [7], however on account of its iterative nature the process for incremental updates using this method requires several steps.

Methods

To simplify the process of incremental updates for the purpose of exploring changes over time, we have developed a simple yet novel variant of RI which is also effective in deriving meaningful associations between terms that do not co-occur. The idea underlying this variant emerged from the observation that in the Singular Value Decomposition, which is used for dimension reduction in LSI, a reduced-dimensional approximation of the initial term-document matrix is obtained by finding the eigenvectors of the matrix AtA. This matrix is constructed by multiplying the term-document matrix by its transpose. Consequently a more consistent mapping between LSI and RI is obtained by adapting RI to reduce the dimensions of this symmetric matrix, in which each term is represented in terms of the extent to which its distribution across documents is similar to that of every other term. We will refer to this variant as Symmetric Random Indexing (SRI).

The procedure for dimension reduction of a term-document matrix using RI is as follows:

(1) Assign a *k*-dimensional (*k* in the order of 1000) zero vector to every **document**. We will term these elemental vectors.

(2) Set at random on the order of 10 of these zero values to +1, and the same number to -1.

(3) Assign a *k*-dimensional zero vector to every term. We will call these semantic vectors.

(4) Each time a term occurs in a document, add the elemental vector for this document to the semantic vector for this term (a weighting metric can optionally be applied here).

An advantage of RI is that the full term-document matrix is not ever represented in its entirety, which offers significant space advantages. As the elemental vectors are sparse, there is a high probability of their being orthogonal, or close-to-orthogonal to one another. Consequently, rather than assigning an orthogonal dimension to each document, as is the case in the full term-document matrix, a near-orthogonal elemental vector is assigned to each document, and semantic vectors for terms are projected directly into the reduced-dimensional space. The procedure for dimension reduction of the symmetric matrix AtA using SRI is as follows:

(1) Assign a high-dimensional (in the order of 1000) zero vector to every **term**. We will call these elemental vectors.

(2) Set at random on the order of 10 of these zero values to +1, and the same number to -1.

(3) Also assign a *k*-dimensional zero vector to every term. We will call these semantic vectors .

(4) Every time a term occurs in a document, add to its semantic vector the elemental vector for every other term occurring in the document, multiplied by the frequency with which this term occurs in the document (a weighting metric can be optionally applied here).

This procedure can be understood best by reviewing the process of matrix multiplication (Figure 1).

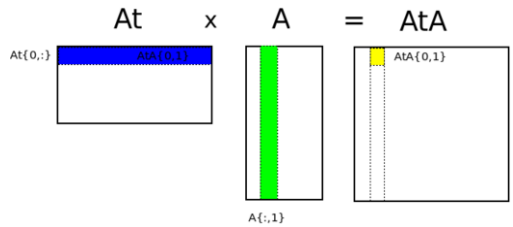

Figure 1- Matrix multiplication to generate AtA

A given cell, for example the cell {0,1} in the AtA matrix is obtained by taking the scalar product between the row At{0,:} and the column A{:,1} (Figure 1). To affect dimension reduction using random projection, we would like to assign a reduced-dimensional elemental vector to the column AtA{:,1}, thereby achieving dimension reduction by replacing each orthogonal dimension of the matrix AtA with a near-orthogonal approximation, in a similar manner to the process of RI. However, as the scalar product is a linear process, it is not necessary to calculate it simultaneously (Figure 2).

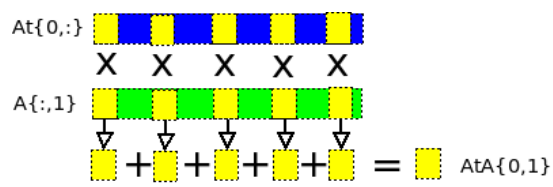

Figure 2-Components of the scalar product

Rather, we can calculate each linear component of the scalar product independently and multiply this by the elemental vector for AtA{:,1}. The sum of these linear components each multiplied by the elemental vector will equal the product of the elemental vector and the cell AtA{0,1}. In this way, we are able to create a reduced-dimensional approximation of AtA on a document-by-document basis, without constructing the full matrix. Consequently it is possible to derive implicit associations from large data-sets using this method. The space complexity of this model is $O(tk + ts)$ where t is the number of terms to be indexed, k is the dimensionality of the reduced-

dimensional space, and *s* is the number of non-zero values in each elemental vector. As with other variants of RI, time complexity is linear to the number of documents in the corpus.

In the experiments presented in this paper, we utilize SRI to derive implicit associations from abstracts in the MEDLINE corpus, and monitor the strengths of these associations as new documents are added incrementally to the model. In addition to the four steps of SRI described above, we use the log-entropy weighting metric to minimize the effect of disparities in local term frequency and emphasize the effect of terms that are focally represented [11]. In addition, we perform an on-the-fly equivalent of normalization of the document vectors to minimize the effect of differences in document length. Both of these customizations are common practice in Latent Semantic Analysis (LSA) [12], which has been successful in the derivation of meaningful implicit associations from smaller corpora in a number of applications [12]. In all cases, we generate vectors for those unique terms occurring 10 times or more in the corpus concerned, that do not contain any non-alphabet characters. In addition, we exclude terms on the stopword list distributed with the Arrowsmith system [13], which has been customized for the purpose of literature-based discovery.

Experiment 1: SRI and Implicit Associations

For the first experiment, we use SRI to derive a model of a time-delimited segment of the MEDLINE database. As in our previous research [7], this segment consists of the titles and abstracts of all citations added to MEDLINE between 1980 and 1985. For comparison with existing models, two 2000-dimensional SRI spaces are constructed, one with and one without the use of log-entropy weighting. For each of a set of 2000 randomly selected cue terms, the same set as employed previously, the 50-nearest indirect neighbors (NINS) are retrieved. NIN's are the terms most associated with a cue term that do not co-occur with it in any document in the corpus. Finally the proportion of these NINS that co-occur directly with the cue term in citations added to the 2008 release of MEDLINE after 1985 are evaluated. The assumption underlying this evaluation and similar methodologies [9], [14] is that an implicit connection at one point in time will be stated explicitly once it becomes discovered public knowledge.

Experiment 2: Trajectory of Historical Discovery

Having evaluated the ability of our model to derive meaningful indirect connections, we proceed to explore the trajectory of scientific discovery in the context of two of Swanson's seminal discoveries. For this experiment, we derive a 1000-dimensional space from all of the abstracts in the 2009 baseline release of MEDLINE (n=9,573,614), generating vectors for every unique term meeting the constraints described previously (n=333,214). We build this model incrementally, processing those abstracts added to MEDLINE every year, and evaluating the strength of association (as measured with the cosine metric) between the term "raynaud" and the term "eicosapentaenoic" which represents eicosapentaenoic acid, the active ingredient of fish oil. In addition, we keep track of the points in time when these two terms occur together in an abstract. As a control, we also assess the strength of association between the term "raynaud" and the term "kuru" which was selected by the authors on the account of their inability to conceive of a reason for these two terms to be meaningfully associated. On account of the stochastic nature of SRI and the small sample size, this experiment is repeated 50 times establish an average and to assess the statistical significance of the observed results. We perform the same experiment using the terms "migraine" and "magnesium", another implicit association identified by Swanson in his early experiments.

Results and discussion

Experiment 1

Figure 3 shows the results of the first experiment, presenting the proportion of the 50 NIN's extracted prior to 1985 that co-occur directly with their cue term after 1985.

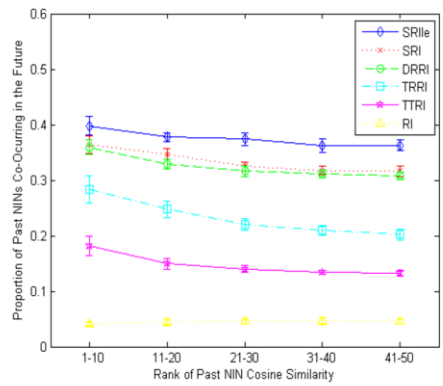

Figure 3-Comparison of RI variants. RI = Random Indexing as originally implemented [8], TTRI = term-term (or sliding window) RI [15], TRRI = term-based RRI [7], DRRI = document-based RRI [7], SRIIe = SRI with log-entropy weighting.

Each column in Figure 3 shows this metric for a range of rank, with the first column showing the proportion of the 10 nearest indirect neighbors that predict future co-occurrence. This column can be interpreted as precision at k=10, if future co-occurrence with the cue term is taken as a gold standard. SRI is compared to results obtained with other RI variants on this data set in a previous publication [7], which includes a detailed comparison of the methodological differences between these models. For the purposes of this paper we note that the SRI model is more effective in predicting future co-occurrence than any of the models evaluated in our previous work. As can be determined by the error bars on the graph (+-1 standard deviation) along with the sample size (n=2,000), most of the differences between SRI and other models are statistically significant, as are the changes in rank with decreasing cosine similarity. However, we note that SRI also favors NIN's with a higher global term frequency than other models, as illustrated in Figure 4. Terms with high global frequency are more likely to occur directly with cue terms by chance, and are generally less informative. Nonetheless, the results of this experiment show that log-entropy weighted SRI is able to predict future direct co-occurrence more effectively than any of the RI variants we have previously evaluated.

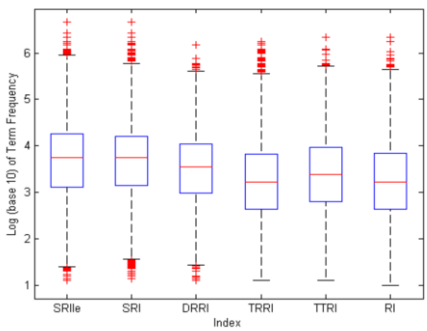

Figure 4-Boxplot of the global frequencies of NIN's.

This experiment proves SRI is able to predict future co-occurrence, which can be viewed as a measure of its ability to draw meaningful associations between terms that do not co-occur directly together in any document. When considering the ten NIN's, the precision of SRI with log-entropy weighting approaches 0.4. By comparison, in our previous research precision at k=10 on this data set ranged between 0.25 and 0.36 for RI variants, with one exception: a second iteration of the term-based RRI approach did produce a precision at k=10 of 0.4. However, repeated iterations make it more difficult to implement the incremental updates that are essential for the experiments presented here. All of these results exceed those obtained in a similarly-structured comparative study of discovery methods requiring explicit identification linking terms [9]. While these results are not strictly comparable due to the additional constraints and smaller size of the test set in the evaluation using linking terms, that the precision at k=10 of SRI in our experiment exceeds any published estimate for other methods in similar evaluations suggest it will make a useful addition to the set of tools currently employed for literature-based discovery. However, SRI tends to retrieve on average terms with higher global term frequency than other RI variants, suggesting that some of the predictions may be less informative than those produced by, for example, term-based RRI.

Experiment 2

Figure 5 illustrates the aggregated results of fifty runs of the second experiment. The figure show an increase in the association between "raynaud" and "eicosapentaenoic" that precedes the first time these terms co-occur together in a MEDLINE abstract, which is shown by a circular marker. We note that while the first observed co-occurrence occurs approximately five years after Swanson's discovery, the increase in associative strength begins before this. This increase in associative strength is also greater than that observed between "raynaud" and the control term, "kuru", and this pattern is consistent across runs. A similar pattern is observed in relation to the implicit association between "migraine" and "magnesium" (Figure 6).

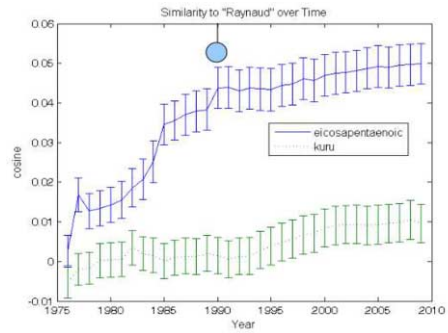

Figure 5-SRI associations between terms "raynaud" and terms "eicosapentaenoic" and terms "raynaud" and "kuru" between 1981 and 2009. Mean values over fifty runs depicted.

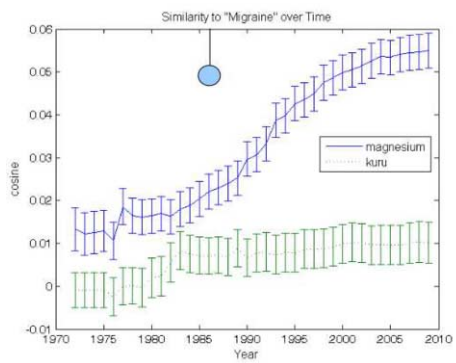

Figure 6-SRI associations between terms "migraine" and "magnesium" and terms "migraine" and "kuru" from 1981 to 2009. Mean values over fifty runs depicted.

In both cases, the increase in the strength of the implicit association precedes direct co-occurrence. This experiment provides some suggestive evidence that an approach incorporating changes over time may offer an advantage over approaches that view distributional statistics as a static snapshot in time. There is evidence from this study of a sharp rise in the strength of implicit association between the terms "raynaud" and "eicosapentaenoic", as well as between the terms "migraine" and "magnesium" that precedes both their first direct co-occurrence in an abstract and Swanson's seminal literature-based discoveries. However, as in all experiments simulating historical literature-based discoveries, there is the concern that findings related to a particular discovery may not generalize.

Limitations and future work

In our current research, we are investigating the extent to which trends in time, as measured using SRI, can be of use in the prediction of future co-occurrence from a large sample set. Results up to this point have been inconclusive: re-ranking of SRI-based NIN's according to the positive change in their cosine to the cue term over time does not appear to improve predictive ability. Furthermore, while terms with the greatest increase in association to a given cue term (Table 1) are often meaningfully related, this measure of relatedness does not

appear to be as predictive of future co-occurrence as SRI alone. Further research is required to develop methods that utilize the additional information provided by trends over time.

Table 1 – terms with the greatest increase in (direct) association strength (1980 and 1985)

thrombolysis	Schizophrenia
0.127: intracoronary	0.065: dimond
0.109: stk	0.055: casenotes
0.100: reocclusion	0.054: multiconditional
0.083: recanalisations	0.053: constructivist
0.077: reoccluded	0.049: schizoform
0.075: recanalised	0.048: balogh
0.074: recanalization	0.047: nonsimultaneity
0.067: thrombolysin	0.047: palau
0.065: reperfusion	0.045: murky
0.063: myocardial	0.044: schizoaffectives

While this work does demonstrate the effectiveness of SRI in deriving meaningful implicit associations, and provides some suggestive evidence that additional useful information is obtained by following trends in these associations over time, the methods used to measure changes over time are rudimentary. In our future work we will explore linear regression models and other more sophisticated approaches to measuring change over time to determine the extent to which these improve the ability to predict future co-occurrence. In addition, we will evaluate other factors we have not attended to here, such as the point in time at which future co-occurrence occurs.

Conclusion

In this paper, we present and evaluate SRI, a method which enables highly efficient updating of term vectors as additional documents are added to a database. The ability to track changes in the strengths of implicit associations over time is one of the advantages of the method. We find suggestive evidence that the additional information provided by this method may be of use in the prediction of future co-occurrence, and consequently it is of interest for literature-based knowledge discovery. The finding that this method is productive in deriving implicit associations has implications for information retrieval also, as it is both scalable and more conveniently amenable to incremental updates than similarly productive models.

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Access Control in Healthcare: the methodology from legislation to practice

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Abstract

Translating legislation and regulations into access control systems in healthcare is, in practice, not a straightforward task. Excessive regulation can create barriers to appropriate patient treatment. The main objective of this paper is to present a new methodology that can define, from legislation to practice, an access control policy as well as a RBAC model, in order to comprise generic legislation and regulation issues together with the access control needs from the ends users of a healthcare information system. The methodology includes the use of document analysis as well as grounded theory and mixed methods research. This methodology can be easily applied within a healthcare practice or any other domain with similar requirements. It helps to bridge the gap between legislation and end users' needs, while integrating information security into the healthcare processes in a more meaningful way.

Keywords:
Computer security, Access control, Computerized patient medical records, Mixed methods, Grounded theory.

Introduction

Healthcare Information Systems (HIS) allow the collection, extraction, management and search of information and involve several people, processes and services within its environment, stressing therefore the need for information security [1, 2]. Both patient and healthcare organization concerned can be seriously damaged if no proper security is provided [3]. Access control constitutes the baseline for information security [4] and is one of the first interactions between humans and technology. In order to access information within a system there are usually 3 steps: identification – where a user says who he is (e.g. using a unique login or username); authentication where the user proves he is who he says he is (e.g. using a password or PIN number); and authorisation where access rights are given to the user. Authorisation can usually only occur after the first 2 steps are successful, and it checks if users meet all the requirements to exercise those rights and access the resources they requested. Access control is part of the authorisation process that checks if users may access resources they asked for. Current access control policies and models are usually not properly defined. Either they do not exist or do not integrate users' needs (i.e. healthcare professionals and patients), so when it comes to their usage, healthcare professionals can have many difficulties [5]. Also, recommendations and legislation are available in healthcare to protect sensitive medical information and to guarantee that this type of information is only accessed and used in specific and justified contexts [6-9]. These regulations tend to be generic and orient attitudes within the medical practice. However, to translate these orientations into practice is not straightforward. Many times this is not even possible. Research shows that excessive regulation can actually create a barrier that physicians have to surmount when treating patients [10]. The main objective of this paper is to present the development of a new methodology that can define, from legislation to practice, an access control policy as well as a RBAC (role-based access control) [11] model in order to comprise generic legislation and regulation issues together with the access control needs from the end users of a HIS. This methodology will try to bridge the gap between these two parties and help to reduce the barriers that are usually present in the integration and use of a HIS.

Background

One obstacle mentioned by healthcare professionals for the use and integration of EMR within healthcare is the lack of controls to provide for patient privacy [12]. Access control, which is one means of providing confidentiality, needs to be improved so that patient's privacy can be effectively protected. There are also other barriers that impede the effective integration of EMR within the healthcare practice. These barriers can be grouped in: time/cost, relational and educational [13, 14]. The relational barrier includes the perceptions that physicians and patients have about the use of the EMR and how their relationship may be affected by it. An example could be when the physician uses the computer during a consultation and the patient does not trust the information the physician is inputting and searching on the system because he usually does not know how that information can be used and what kind of protection is provided. The educational barrier comprises the lack of proficiency and difficulties that healthcare professionals have in interacting with the EMR in order to perform their daily tasks [15]. Healthcare professionals do not usually participate in the design and development of working tools (in this case the EMR) so they usually have to redes-

ign their practice workflow and processes, which is very challenging and consumes more time and costs [14]. Results from a systematic literature review on access control for both generic and the healthcare domain showed that although access control is a security service that has been widely studied and applied in healthcare systems such as EMR (Electronic Medical Record), the fact is that the most interested parties, the users (both healthcare professionals and patients), are not usually consulted when the access control policies are integrated into these systems, and when the system is integrated within their workflow environments. Healthcare professionals usually needed to change their workflow patterns and adapt their tasks and processes in order to use the systems [5]. This study [16] showed that EMR designers and implementers should monitor healthcare professionals' attitudes, opinions and experiences through the use of comprehensive evaluation methods such as focus groups and structured questionnaires in order to obtain substantial information to input into the design and implementation process. In this way the implemented systems are more likely to succeed. The use of both qualitative and quantitative methods (i.e. mixed methods) can elicit a wider range of information from the end users, thereby helping the designers and implementers to gain a deeper knowledge about the human needs from the EMR system. Further, the analysis of legislation and regulation documents that focus on defining the rules for access control can also be integrated within the same goal. The study and analysis of both generic and specific access control issues for the healthcare environment and the integration of these results within the healthcare access control policy should improve, not only the acceptance of EMR, but also the design of the access control component in order to reduce some of the educational and workflow problems that were found to be very common among the EMR systems in use. This type of research or methodology has not been published before and so the results cannot be compared to previous work.

Materials and Methods

Method Development

As there were not much research available on this subject the process started by analyzing published material on access control, both in generic and healthcare domains [5], as well as on the type of methodology to gather information that is not yet available. So in this case, literature reviews were performed in order to select the most appropriate methods for this purpose [16]. It was decided that there was the need to include both generic issues (legislation and regulations) as well as specific issues (end user needs – both healthcare professionals and patients).

1. For generic issues: a document analysis regarding legislation and regulations was performed to retrieve access control related issues;
2. For specific issues: grounded theory together with mixed methods was selected in order to collect data.
    a. After qualitative data collection, the analysis was performed according to Figure 1.
    b. Results from the qualitative analysis were used to develop the quantitative methods that were subsequently applied.
    c. The analysis of the quantitative data was done according to Phase 4 of Figure 1.
3. Generic assumptions were taken into account since there was not much information available aposteriori;
4. All analyzed data was then transformed into Access Control Rules;
5. Access control rules were standardized into IF THEN rules to comprise a generic Access Control Policy;
6. The generic Access Control Policy was transformed into a RBAC Policy;
7. A new extension of the RBAC model was developed in order to comprise the new RBAC Policy.

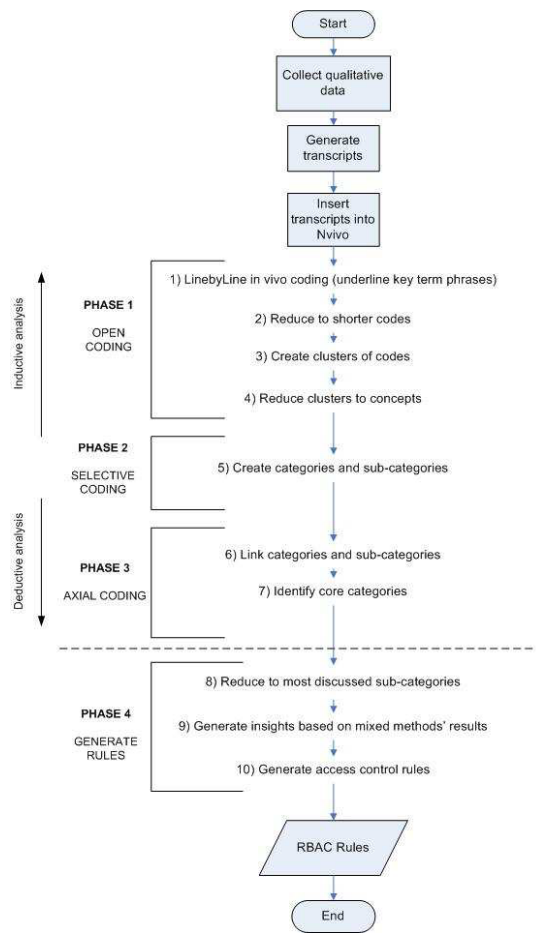

Figure 1 – Grounded Theory method used to analyze qualitatively focus groups' data.

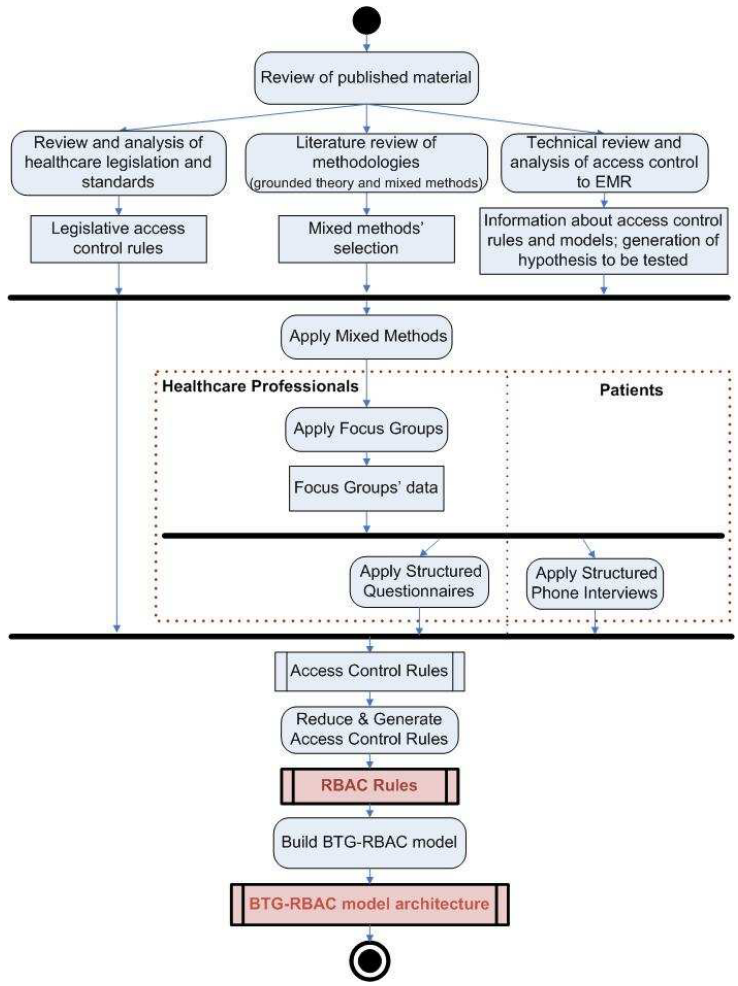

Figure 2 – Methodology description.

The method described in Figure 1 that is included within the bigger methodology presented in Figure 2 ("Reduce & Generate Access Control Rules") for the analysis of focus groups' data is the central part of this research. It describes how qualitative data was analysed and how the whole grounded theory process was done.

In more detail, the data generated from the qualitative research was collected and then transcribed and inserted within qualitative coding software (NVivo [17]). Phase 1 of this process included the line by line coding and grouping of codes of the whole transcripts; Phase 2 included a more focused or selective coding that allowed for the generation of categories and sub-categories from the codes in Phase 1; Phase 3 comprised the organization and ordering of the previous categories; and Phase 4 reduced the generated categories to the most discussed ones that were then included within the Access Control Rules' list.

Method Description

The methodology that was developed and can be used in a generic way by other researchers is described in Figure 2, with an activity diagram.

1. For generic issues: HIPAA [6], European Healthcare Recommendations [8,9] and the code of ethics for health information professionals were analysed; for specific issues, a technical review on access control was performed;
2. From the revised material assumptions were made for both healthcare professionals and patients regarding access control, these were used to confront with the results obtained;
3. A literature review of methodologies was performed. For grounded theory and mixed methods: focus groups (the main qualitative method) were applied first:
    a. Data was analysed according to Figure 1;

   b. Results from the most discussed categories were included into the subsequent quantitative methods;
   c. Structured questionnaires were applied to healthcare professionals;
   d. Structured phone interviews were applied to patients.
4. Access control rules were generated for both healthcare professionals and patients;
5. Each access control rule was separated into fundamental blocks of conditions and operations to be transformed into a RBAC rule, using the format as in [18];
6. A new access control model (the BTG-RBAC model) was developed in order to model the RBAC Policy generated from this method [19].

Results

In order to validate the presented methodology, a case study was performed. It used the BTG (Break the Glass) concept [19, 20] and instantiated every step of the method in Figure 2 as described below.

The first step of revise published material was previously performed and applied generically for every case study, and so it was used for this specific one.

1. **Document Analysis**: Portuguese Legislation - Law 12/2005;
2. **Generated Assumption**: There is the need for an override policy (e.g. Break The Glass);
3. **Mixed methods appliance and results** (Table 1):

Table 1- Description of the mixed methods applied.

Method	N	Data results
Focus groups	26 (4FG)	Access in emergency situations: requires different access(6 references);
Struct. questionnaire	27	A majority of respondents 74% (n=20) agreed with the existence of providing access in emergency situations depending on the situation and healthcare professionals
Struct. Phone interviews	200	YES: 191; NO: 3; no answer: 5; does not know: 1

4. **List of generated access control rules after applying the method in Figure 2**:

   A. Specific roles must be able to BTG and access (visualize only) information in emergency (or other unanticipated) situations
   B. It must be possible to define a fine-grained BTG (i.e. it may depend on roles as well as time and location restrictions)
   C. Logging and obligations must be provided at all times
   D. Access to genetic information must be managed and accessed only by medical doctors from the genetic specialty
   E. The number of healthcare professionals that are authorized to access information regarding DNA and biological products must be restricted in order to guarantee security as well as prevent losses, modification or destruction

5. **Access Control Policy based on RBAC-ACF [18]**:

Access control policies are often expressed through policy specification languages each of which may have different syntaxes. However, fundamental building blocks of any access control policy are: **subject, object, operation**, **condition**, **effect**, **obligation** and **purpose** [17].

A subject is a computer system entity that can initiate requests (e.g., user, agent, application process) to perform an operation or series of operations on objects. An object is a system entity on which an operation can be performed (e.g., a file, a table, a view). A condition describes the additional restrictions that must be evaluated in order to GRANT or DENY access to a particular subject for a particular data object. Effect is the outcome of evaluating a policy rule (e.g., GRANT or DENY). For these rules, the effect is always GRANT or allow because they are all described in the positive. Obligations are additional actions to be performed when the access control rule is triggered. The purpose has usually two objectives: business or data purpose.

The access control rules are defined as:

> Allow **[user/role/subject]** to perform **[operation]**
> on **[object]** provided **[condition]**
> Carry out **[obligation]**

The access control rule D was separated in two rules (D & E) in order to comprise both actions *access* and *manage*.

A. Allow **[specific users/roles]** to perform **[BTG (visualize only)]** on **[medical data]** provided **[emergency or unanticipated situations occur].** Carry out **[BTG obligations: logging, alert, email to responsible parties and proof of justification]**
B. Allow **[specific users/roles]** to perform **[definition of BTG operations with or without constraints]** on **[other users/roles]** provided **[they are authorized]**
C. Allow **[users]** to perform **[logging and obligations]** on **[medical data]** provided **[a BTG action is performed]**
D. Allow **[medical doctor(role)]** to perform **[access]** on **[genetic information]** provided **[medical doctor is from a genetic specialty]**
E. Allow **[medical doctor(role)]** to perform **[manage]** on **[genetic information]** provided **[medical doctor is from a genetic specialty]**
F. Allow **[users/roles/subjects]** to perform **[restrict access to a minimum required]** on **[DNA + biological products information]** provided **[they are authorized]**

6. The generated access control policy for BTG is comprised of 6 access control rules. Rules A to C can be modelled by the **BTG-RBAC model** [19], while rules D to F can be modelled by a generic RBAC model, and therefore, the BTG-RBAC model as well.

Discussion

This paper presents a new methodology that did not exist in the literature in order to ground security in the healthcare domain. It is a simple methodology to apply and integrate both generic and specific needs of the healthcare environment approaching this way legislation to the healthcare daily practice. This methodology can be applied not only in healthcare but also in similar domains with similar requirements in terms of security. It is flexible enough to be adapted according to the requirements of the system, both in terms of types of qualitative and quantitative methods chosen as well as the number of participants in each one of them.

Limitations of this work include the need for time and costs involved within the qualitative and quantitative methods setup, appliance and data analysis. Studies that do not involve end users of an information system may not benefit from this methodology.

In order to improve and refine the methodology presented in this study, it must be applied and tested with several other similar case studies and, if possible, in other domains besides healthcare.

Conclusion

The methodology presented in this paper can be used to generate, from legislation to practice, access control rules to be integrated within an access control policy for the healthcare practice. This methodology helps to bridge the gap between legislation and users' needs while integrating information security in a more meaningful way into the healthcare processes.

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Can Signalling Theory and the Semaphoric Nature of Information Systems Explain Clinicians' Ambivalence to Informatics?

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Abstract

Investment in information systems has traditionally been justified in terms of productivity or value-added gain. From this point of view the slow rate of adoption of IT in the healthcare sector appears paradoxical because the rapid increase in medical costs has created an urgent need for productivity improvements. Spence's market signal theory may explain why some information system investment decisions are made and may, in part, explains the reluctance of clinicians to embrace informatics. Case studies are presented where we argue that information system investment was made primarily to send a market signal. We call information systems that are used primarily to send a market signal, semaphoric information systems. Characteristics of semaphoric information systems are presented. It is postulated that the therapeutic relationship between doctor and patient is central to current models of healthcare, and that the semaphoric 'message' of the current generation of IT systems may be detrimental to this relationship. This suggests that clinicians will continue to be reluctant to embrace information systems until information systems are developed that can send signals that enhance the doctor-patient relationship.

Keywords:

Semaphoric, Doctor-patient relationship, Market signal, Economics, Clinical informatics, Consultation.

Introduction

It is generally recognised that clinicians and the healthcare sector have been slow to afford themselves of the opportunities offered by information technology. Yarbrough and Smith noted that "the proliferation of information technology has been a revolutionary force that has increased efficiency and effectiveness in many industries. However, health care organizations, particularly physician practices, are noticeably lagging in the adoption of such technologies" [1].

The semaphoric nature of information systems may, in part, explain this. A signal can be considered semaphoric if:

1. The signal reveals some quality of the organisation as a whole, or of the goods or services it produces. The signal recipient must regard the quality signalled to be of importance.

2. The costs involved in generating the signal are significant and do not in themselves increase productivity, and the risks of signalling are proportionally higher for dishonest signallers than they are for honest signallers.

Traditional evaluation methods of IT use quantitative and objective measures derived from accounting. These approaches are based on the principle that the purpose of information systems is to improve operational efficiency or productivity of the organisation [2-4]. The success of It investment is typically measured in terms of return on investment and improvements in efficiency, although the need to take a broader approach that includes organisational criteria based on the structured consideration of financial and non-financial concepts is also recognised [2, 5-8]. While there is considerable debate on how best to measure the benefit of information technology, it is clear that information technology has resulted in a substantial increase in productivity in many areas.

For clinicians this may be beside the point. Clinicians offer their professional skills for the benefit of patients, and the interests of the insurance industry or the taxpayer are secondary. From the clinical point of view it is the effectiveness, not the efficiency, of health interventions that is of primary interest.

We suggest that the economic theory of market signalling is applicable to information systems in general, and present case studies from non-medical fields to support this assertion. The application of this theory to clinical informatics systems suggests that the clinicians' conservative attitude to the current generation of health information systems is rational economic position, given the current structure of medical practice in the industrial world. Clinical information systems that are designed to overcome this before may gain a more enthusiastic endorsement from clinicians.

Market signalling theory

Akerlof [9] observed that information in the marketplace is distributed asymmetrically, with gaps in information between a seller and a buyer. Typically, while buyers have information

about the market as a whole, sellers have better information about the particular good on offer. As buyers only have information on the market as a whole and not the specific good, buyers will only offer average prices for the good. This will benefit sellers of inferior goods but will not be attractive to sellers of superior goods. Akerlof concluded that adverse selection would occur – sellers of superior goods would leave the marketplace.

Spence [10] developed this further by noting that sellers need not leave the marketplace if they could signal the superior nature of their goods to the buyer and thereby command a higher price. This signal would be cost-effective even if the cost of issuing the signal was significant and this investment did not itself increase productivity. Spence's worked showed that costly and unproductive signalling could occur in equilibrium, even if markets operate with gross inefficiencies introduced by costly unproductive signalling.

Attempts have been made to classify costly signals according to the way the costs are incurred [11]. For example, costs could be incurred as an up-front expense, or deferred and taken in the loss of future income. Costs could also be fixed or dependent on other factors, such as sales. While these distinctions may be important for some of the wide variety of market signal types, for the purposes of this paper costly signals will be classified as semaphoric if the investment required to generate the signal is both visible and unproductive, irrespective of how this cost is met. This expenditure can be used by the recipient as a sign of sincerity and gives the signal more credibility.

Characteristics of Semaphoric Signals

The above discussion has listed a large number of costly signals, and these signals differ from sending the market a signal through, for example, a press release. We term these semaphoric signals. They reveal some quality of the organisation as a whole, or of the goods or services it produces. The signal recipient must regard the quality signalled to be of importance. The costs involved in generating the signal are also significant and do not in themselves increase productivity, and the risks of signalling are proportionally higher for dishonest signallers than they are for honest signallers.

Information Systems as Semaphoric Signals

In the following cases we consider examples of investment in Information Systems where the justification for such investment cannot be conventionally supported but is made on the grounds of the value of its market signal. We call such systems 'semaphoric information systems'.

Real-time parcel tracking.

United Parcel Service (UPS) and Federal Express (Fedex) have both established themselves as major international players in the logistics market. Both offer a high quality service, and both enjoy high levels of customer satisfaction [12]. They have also both deployed semaphoric IS in the form of real-time parcel tracking.

While there are many similarities between these two organisations, there is a significant difference in corporate culture. UPS began as a bicycle messenger service and prides itself on reliability and dependability. "[The] press describe us as a plodding and disciplined company" said then UPS Chairman Jim Kelly [13], but dull and reliable were attributes that UPS were proud of. In contrast, Fedex was funded by venture capital, began with a purchase of a fleet of aircraft and established itself in the niche overnight delivery market.

Fedex pioneered web-based package tracking in 1995 [14]. It was a development that UPS did not immediately appreciate. "I thought … that the cost of supporting real-time package tracking would never be justified", admitted Jim Kelly [13]. Kelly was not alone in this view. "We don't want you to remember tracking an overdue package: if the package is overdue, the sooner you find it and forget about the whole thing, the happier we will be" suggests web design commentator Bernstein [15]. Nevertheless UPS quickly followed Fedex and introduced the service. We argue that the justification for doing so lay in their intention to send a signal to their customers of their reliability.

Ultimately, this signal was appreciated by UPS' customers despite their reputation for reliability. By 1996 UPS were receiving 1 million queries a month. By 1998 this hit 1 million queries a day, and by 1999 it had reached 2.5 million per day. By 2002 the figure had risen to 6.6 million tracking requests per day [16,17].

Signalling with Enterprise Information Systems 2: Clinical Trial Registries

The success of the pharmaceutical industry in developing medicines that have cured disease and alleviated suffering might have made them the heroes of the age, but is this the case? Fiona Godlee [18], in an editorial for the BMJ, wrote:

"If there's one group in urgent need of repositioning it is, as even members acknowledge, the pharmaceutical industry. … When your customers see you as 'manipulative, dark, menacing,' you could be said to be losing the battle for hearts and minds."

The pharmaceutical industry itself is highly regulated, and the medicines development process involves a rigorous process of clinical study design, conduct and reporting. As part of the regulated process all clinical studies are reported to the relevant authorities. Requirements and coverage of regulated systems is patchy and not always publicly available. The European Union clinical trial registry, EudraCT, in which studies are recorded as a part of the regulatory process is not openly accessible [19].

Information is disseminated via publication in peer review journals, where the results are open to careful scrutiny. While peer reviewed journal articles have been the standard method for disseminating scientific knowledge for decades this system has serious shortcomings. Some information may not be published and so not reach the wide range of interested parties such as prescribers and other medical practitioners. Peer review journals also have a built in time lag and give no assur-

ance of a complete disclosure of information, there is also a bias in published studies in favour of positive or promising results [20]. Trials are frequently reported several times, leading spurious weight to the findings [21] and it may be difficult to determine how many trials have in fact been done [22]. By 1999 both the British Medical Journal and The Lancet felt the case for a register of randomised trials was unanswerable [23].

The lack of trust in pharmaceutical companies, and the need for transparency to signal honesty, is appreciated by the industry, and in 1998 the Chairman of GlaxoWellcome Richard Sykes announced that a basic clinical trials registry would be set up. This would be an internet based application, openly accessible, in which variable amounts of information about clinical studies being undertaken would be recorded and published, and would cover all of GlaxoWellcome's completed Phase 2 to Phase 3 studies which are the studies required for registering a medicine. Protocols for completed studies were to be registered at regulatory approval. Sykes stated:

"GlaxoWellcome has taken the lead in disclosure of information, and I hope that the rest of the pharmaceutical industry will join this initiative. As knowledge based industry we understand well the value of information, and we want to create a climate of openness where the evidence for prescribing our products is clear" [24].

In 2004, Eli Lilly & company launched its clinical trials registry, which it claimed was 'the most comprehensive effort to date, by either a public or private entity, to publicly disclose clinical trial information' [25]. Novo Nordisk made a similar release of their register stating 'We're conducting our business in a transparent way, and offering information on our clinical trials activities should be seen in this perspective'[26]. By 2008 most major pharmaceutical companies had clinical trial registries publicly accessible via the internet.

Once Glaxo had signalled its honesty, other pharmaceutical companies were obliged to do the same because not to signal would imply something to hide.

While clinical trial registries appear to display the features of an semaphoric system, there is a further factor to consider. In 2004 Glaxo faced prosecution for failing to make public clinical-trial data that raised concerns about the safety and efficacy of one of their products used to treat children with depression [27], and this renewed calls for compulsory registration of clinical trials in a public registry. The International Committee of Medical Journal Editors instituted a policy that required that clinical studies be registered in order to be considered for publication [28]. In 2009 Section 113 of the FDA amendment act came into law [29], requiring registration of clinical studies for current and future trials.

The trend is clearly for clinical trial registration to become a regulatory and stakeholder requirement but ahead of this many large companies have developed their own publicly available registries, and advertise that they are exceeding the requirements and the timelines. This illustrates that some aspects of semaphoricism are not only non-optional as far as competitors are concerned, but may even become a regulatory requirement within a sector.

Discussion

The case studies described above lead to the following observations on the characteristics of semaphoric systems.

The signal reveals some quality of the organisation as a whole, or of the goods or services it produces. Real-time parcel tracking signalled reliability, while the Controlled Trials Registry signalled honesty and transparency. In the case of PowerPoint the quality was professionalism and preparation. These are all qualities that the signal recipient regards as being important.

The costs involved in generating the signal are significant and do not in themselves increase productivity. The cost of installing a real-time parcel tracking system provides information for customers but does not ensure trucks leave fully-laden or on time. However, a logistics company that has a highly efficient operation with good quality assurance systems will find the cost of implementing a real-time parcel tracking service less onerous than a logistics company that does not have these systems in place. The same is true for Clinical Trail Registries. Making clinical trial data accessible limits the company's ability to market its products, but an honest pharmaceutical company that has a solid evidence-based foundation for the efficacy of its products will find this less limiting than a company that does not have this evidence.

Implications for Clinical Information Systems

Adoption rates for clinical information systems are driven by a variety of factors, and the clinical maxim *Primum non nocere*, 'First do no harm', applies here. The negative effects of clinical information system manifest themselves in increasing demands on clinician's time and decreasing patient satisfaction.

The effect of clinical information systems on clinicians' time is controversial, and may vary between implementations and between individual users. Saving time is frequently cited as the motivating factor in adopting information technology (Hier et al. 2005; Ash and Bates 2005; Irani et al. 2009). Implementing information systems is a hazardous undertaking in healthcare and other sectors, and a large number of implementations fail. Systems which place burdens on the clinicians' limited time are less likely to succeed [30].

Several studies on the effect of the use of clinical information systems have, in general, found that the effects on patient satisfaction are neutral or slightly positive [31], and that computers can be integrated into the clinical consultation without a detrimental effect on patient satisfaction [32]. This is consistent with a review of earlier studies done between 1980 and 1997 [33]. While clinicians do express reservations about the effect of the computer on professionals' interactions with patients [34], the literature suggests that clinical information systems do not have a negative impact on patient satisfaction.

While this may be true of clinical information systems in general, it is not be true of all clinical information systems. While clinical decision support systems have been shown to improve patient safety and clinical decision-making, there is evidence that patients do not value the benefits of computerised decision

support systems and have less esteem for clinicians who use these systems[35, 36].

One explanation for this is that patients expect clinicians to be concerned, compassionate and knowledgeable, and expect clinicians to signal these qualities. It can be argued that computerised decision support systems send the opposite signal. They suggest that the clinician is not knowledgeable because they need to look up information, that the clinician is more concerned about recording 'hard' data and following protocols than about the patient's idiosyncratic needs, and the impersonal nature of the CDSS's knowledge base is contrasted unfavourably with human judgement, which balances compassion with necessity.

An awareness of the signals sent by clinical informatics systems may result in improvements in the design and structure of these systems. For example, a system that emphasises a primary care clinician's gatekeeper role, and demonstrates their knowledge of the availability and quality of locally available services sends a positive signal. A similar system which concentrates on patient workflow and requires the clinician to behave as a clerk in bureaucracy sends a different signal.

Conclusion

The rate of diffusion of information technology has been slower in the healthcare sector than it has in other sectors, this cannot be ascribed to an anti-technology bias. It has been noted that physicians are adopt new technology enthusiastically, have embraced PACS, video cameras and BlackBerries, and will be more than happy to adopt information technology solutions that will improve their own lives and the lives of their patients [37].

Information technology is not neutral. The adoption of new technology does send a signal about some quality of the organisation as a whole, or of the goods or services it produces. In the case of the clinical information systems, the 'organisation' is embodied in the person of the clinician, and clinical information systems send a very personal signal about their quality.

Developers who would like clinicians to adopt their information technology solutions need to be aware of the signals that technology sends, and to concentrate on developing systems that send appropriate signals.

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Why do People Want a Paper Copy of Their Electronic Patient Record?

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Abstract

Changes have recently been passed in the Norwegian legislation, allowing for more exchange of patient information between health personnel. These legal changes came as a result of a long and still ongoing debate concerning the potential conflict between confidentiality issues and patient safety as health care is getting more fragmented. At the same time, an increasing number of patients now make use of their legal right to access their patient record. In this paper, we shed light on some of the reasons why patients request a copy of their record. We report the preliminary results from an interview study in which seventeen patients who have asked for a copy of their patient record following a hospital stay have been interviewed. In our interview study, securing transmission of information between health care workers is one of the main reasons for requesting a copy of the record. We will discuss how this finding might contribute to the ongoing debate.

Keywords:

EPR, Medical record, Patient access to records, Patient information, Communication, Confidentiality, Patient safety, Empowerment, Interview study

Introduction

An increasing number of patients now make use of their legal right to access their patient record in Norway, as in other countries [1-3]. This legal right can be seen as part of a larger trend in health care during these past several years to strengthen patient autonomy. Making health personnel's assessments and decisions more transparent is expected to contribute to patient empowerment and reduce the power imbalance between patient and providers. It is claimed that in order for patients to be true partners in the health care encounter, they must have access to their own personal clinical health information [4-6]. In Norway, the legal term has changed from medical record to patient record, to emphasize these changes. But in Norway, as in other countries, like for instance Canada, there has been some unwillingness on the part of health personnel to give up "ownership" and embrace the new role as custodian of the patient record [5]. Norway is likewise facing a shift from paternalistic attitudes in health care to a more consumer based approach. In this process health personnel have tended to be more skeptical of the benefits patients might receive from reading their own records. Like in other countries, Norwegian health personnel have been worried that reading their own record may worry, confuse or embarrass patients [7].

Changes have also recently been passed in the Norwegian laws regulating health registers and the work of health personnel, allowing for more information exchange inside the hospitals, between hospitals, and between hospitals and primary care/community services. These legal changes came as a consequence of a long ongoing debate due to strict legal confidentiality regulations in Norway and an increasing fragmentation of the health care system that has made efficient transmission of information between health personnel more and more important [8;9]. The debate concerns the potential conflict between confidentiality issues and patient safety, a conflict that does not seem to be completely solved by the recent Norwegian law changes. A similar debate has been going on in other countries, e.g. in England in connection with the creation of a national database of health records [10]. We conducted an interview study to explore why patients request a copy of their record and their experiences in connection with receiving such a copy. In this paper we are reporting some preliminary results from this interview study that contributes to the debate mentioned above.

Materials and Methods

In this explorative study we conducted in-depth interviews with former patients who have asked for and received a copy of their patient record following their stay at two Norwegian hospitals. EPRs (electronic patient records) have been in use for some years in these hospitals, but patients who want to read their record receive a paper copy by mail from the central

record archives. There is no electronic record access for patients.

Inclusion criteria

Men and women over 18 years old, who have requested and received a copy of their patient record at the hospital, speak/read fluent Norwegian, and have no known cognitive impairment were included in the study.

Participants

A convenience sample of the 17 first patients that volunteered for an interview - sixteen women and one man - between the ages of 28 and 67 were interviewed. They had different diagnoses (e.g. cancer and childbirth) and different lengths of hospital stay.

Procedures

The interviews took place either in the researcher's office or in the informant's home or work place depending on the patient's preferences 3-4 weeks after the informants had received the copy of their record in the mail. The interviews were tape recorded and then transcribed verbatim.

Analysis

The interviews were analyzed by qualitative content analysis [11]. The first author conducted the textual analysis by reading and re-reading sections of the interviews and identifying differences, similarities and patterns in the text. All interviews were divided into meaning units that were coded, condensed and abstracted. To address trustworthiness the co-authors who were experienced in the field and the method, checked and discussed analysis and interpretations to reach consensus. In the analysis of the manifest content of the interviews a main theme was constructed and grouped into sub-themes.

Results

A main theme coming out of the analysis is that informants wanted to have a copy of their record due to *"a wish to have control"*. This main theme consisted of several sub-themes that will be presented inn full elsewhere. In this paper we are focusing on one specific subtheme that seems to be relevant to the debate on patient safety vs. confidentiality issues. We have called this sub-theme "*transmission of information*".

Transmission of information

Patients who volunteered to be interviewed explained that they wanted a copy of their record to secure the transmission of information between health personnel, inside the hospital, between different hospitals, between hospital and GP or specialist outside the hospital. The informants discussed at length during the interviews that the documentation of care was poorly communicated and largely unused by health personnel. Informants felt that a large number of different health personnel they met during a hospital stay and/or at the outpatient clinic did not have a full overview of their situation. The informants took it upon themselves to be fully updated on their record content to make sure that the health personnel did not forget or misunderstand anything. To have a copy of the record gave some of the informants a feeling of control in this situation. They could choose to show a copy to who ever in the health care team that they thought needed it or tell them to read for example the admission note for a certain piece of information that they knew was documented there.

Informants were also concerned that important information would not be transmitted between different hospitals where treatment took place, so they took on the role as "messenger" or "postman". One informant described it like this: "*I did have questions that I wanted an answer to when asking for a copy of my record, but first and foremost my purpose was to pass on the record information to this other hospital where the birth was going to take place, to get help to decide whether a caesarean or a normal birth would be best.*" Later in the interview this informant said: "*... I find it strange that there is no common patient register… If I move to another part of the country, then it's only me that can pass on relevant information in case of complications with the birth… And what if I'm not sufficiently aware of things – is this safe enough?*"

Likewise there were examples in the interviews of how informants felt they had to take responsibility for the transmission of information from the hospital to their GP or specialist outside the hospital and the judgment of what information that would be relevant and necessary for these doctors to receive.

Informants pointed out that one does not normally get a copy or even a receipt of the correspondence between health personnel, like referrals and discharge summaries, as one would do in many other situations in the role as a customer or a client. This lack of confirmation made some of the informants unsure if the letter or referral that health personnel said they would send was actually sent and how their case was explained in that document.

One informant described that she received the referral from her GP and got the responsibility to find a specialist herself to make an appointment. She felt quite troubled about this task, as she did not know any specialists, and just had to look it up in the telephone directory without knowing who would be the best to see. She also commented that they all had limited calling hours that she had to find out. Although she was interested in what the referral said, she would rather not see this information, when it implied making all these phone calls.

Discussion

From the findings in this study we get a picture of patients requesting a copy of their record as representatives for the modern patient, conscious about their civil rights and free will, but also aware of their duty to take responsibility [12]. The patients' experiences can be seen as statements of the fact that the problem in health care today is not lack of information, but bad communication [13]. Bad communication might potentially threaten patient safety and the use of ICT in health care could lead to better communication and more efficient flow of information. It is certainly in the patients' interest that health personnel have the necessary information when they need it. Through the experiences of our informants, we get the impression that the hospital routines for transmission of information

might not be good enough. The patients are left with an unreasonably big responsibility, not only to transmit important information within the health care system, but also to decide who needs what information. In this way, the patient might be seen to be exploited as a customer to enforce cuts in public expenditure [12]. The investment in extra time and resources to improve continuity of care through better routines for information exchange is not a prioritized task within the system of financing that dominates Norwegian hospitals today. This illustrates how the role as the modern patient contains new opportunities for patients' empowerment, but at the same time expectations of self-responsibility that do not always seem reasonable [12] The informants in our study are surprised that transmission of information doesn't happen in a more smooth and automatic manner. Moreover, patients are often unsure if information is transmitted or not. They therefore take action to get the information transmitted, just to be on the safe side. This speaks for a more efficient transmission of information between health personnel and preferably electronic transmission. However, is a more liberal sharing of EPR content between hospitals and between hospitals and GPs the best way to go then?

Risk of information overflow

Patients feeling that they have to secure transmission of information between health personnel even inside the hospital, indicates that the EPR solutions that exists on the hospital level in Norway is not well enough organized to make it easy for health personnel to find relevant and necessary information. The EPRs are still to a great extent organized the same way as the paper records were. Consequently all the various information from a hospital stay will be spread out in many different folders and these are normally not easy to put together in one view.

To expand the electronic access to this record to other hospitals and the primary care as well might therefore turn into a new example of bad communication and information overflow. There is reason to believe that exchanging knowledge about the patient, as it is done in referrals and discharge summaries, is more efficient than sharing all the record content (giving electronic access to the whole record). This view is supported by other studies [14-16] and is also emphasized in a report from the Norwegian Centre for Electronic Patient Record [17]. The writing and reading of summaries calls for reflection on the patient's situation by the health care workers, in a way that sharing of information does not equally contribute to [17]. There is a certain risk that less effort will be put in the discharge summaries if other hospitals and the GP have full access to the hospital's EPR. This could in fact increase the time health personnel spend looking for relevant information, which is not in the patients' best interest [17].

Related work is going on in Norway to develop a "core record" (in Norwegian, "kjernejournal") similar to what already is in use in Scotland under the name of Emergency Care Record. In our view, this would be of much more help in most clinical situations than hospitals opening the whole record and sharing all information with each other. At the same time this would hopefully reduce the patients' burden to secure the transmission of essential information between health personnel.

The right information at the right time

Some patients in our study had experienced that it took so long (several weeks and even months) to get a copy of the record that when they received it, they no longer really needed it. This was certainly not an empowering experience and did not leave the patient with a sense of control. In Norway there is some pilot work going on to develop electronic access for patients to provider held electronic records. So far there has been focus on electronic access to the discharge summary after a hospital stay and the possibility to communicate with health personnel by secure e-mail (e.g. www.minjournal.no). The experiences of the informants in the current study, that it sometimes took unreasonably long time to receive a paper copy of the record, should be an argument to put more resources into the further development of electronic access for patients to provider-held records, such as EPRs in hospitals. Given the increasing number of patients requesting paper copies of their EPRs, the development of electronic access for patients to the EPR, from the patients' point of view, is long overdue. Access to the EPR is a fundamental patient right and this development should therefore not be delayed. As stated by Wiljer et al. (2008) health care organizations should create a culture of custodianship, rather than ownership, of patient data. This shift could be alleviated by creating models of shared control between health care professionals, patients and the public [6].

From a patient autonomy and empowerment view, a requirement for sharing the patient record between healthcare institutions (hospital-hospital and hospital-GP) should be that patients get electronic access to their own record as well. Similar to what was found by Whiddett et al. (2006) in a New Zealand study, most of the patients interviewed in our study did not know to what degree their information was shared between health personnel in the hospital [18]. In our view, they should not be ignorant about the information that is exchanged between health personnel and a log should be easily accessible to the patient listing who reads their record, where, and when. Patients should have the right to know when and for what purpose their data is used [19] as well as the ability to control the flow of their clinical data and also to delegate access to the data. In addition, the patients seem to be in the best position to discover documentation errors in a situation where so many different health personnel are involved in their care. This is also pointed out by others [1-3;20;21]. When patients in our study discovered information in the record that was not correct or information that they would not like everyone to see, the lack of an effective system both to shield and correct record information bothered them terribly. Lastly, judged by these patient experiences it would not only be extremely timesaving for the archives if electronic access for patients was the norm and that a paper copy of the record was only sent out on request, but it would be an important step towards real patient empowerment and autonomy.

Limitations

First of all, these are preliminary results based on analysis of the manifest content of the interviews. A limitation of our work is that the sample is self-selecting. Patients who have a story to tell about bad experiences with health personnel or the hospital as an organization might be more likely to volunteer for an interview than patients who don't have these kinds of experiences. One should therefore be careful to generalize these findings as typical for patients' experiences on this area. Other studies have found that women are much more likely than men to be interested to read their record [2]. Even if the low number of men recruited to the study may reflect the number of men requesting to read their record in Norway the unequal participation of genders is a limitation of the study.

Conclusion

From the experiences shared by patients in this interview study, we conclude that there is a need for improvement in the organization of content as well as flexible views in the patient record system. Improvements can also be made in the system for electronic transmission of referrals and discharge summaries, so that patients can be sure of what is communicated and do not have to bring a copy to be on the safe side. Ongoing work to develop a "core record" should consider findings presented here.

Better discharge summaries and a "core record" might in many cases cover the patient's need for written information too. A requirement for providing broader electronic access to records as the legal changes now allow would in our view be that patients have access to the same information as health personnel to avoid diffusion of documentation errors without anyone noticing it. This is in accordance with the conclusions of Powell et al. [10]. Better organization of the record content is needed to be able to limit health personnel's access to what is relevant and necessary information about a patient to avoid information overflow and to shield information that is not in the patient's best interest that everybody see. Thus we support the view of Wiljer et al. (2008) that providing electronic access to EPRs is a vital next step in promoting active involvement of patients in their care and improving the health system on a profound scale [6].

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Exploring Control in Health Information Systems Implementation

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Abstract

Health information systems promise opportunities for improved healthcare. However, these opportunities may become challenges and obstacles to practice. This research reflects on the outcomes of implementing healthcare information systems in three English hospitals. In each case qualitative methods were used to observe and interview doctors, nurses and pharmacists as they carried out their daily healthcare routines. The changes that the implementation of health information systems brought for both the clinical encounter, as well as health care professionals' work flow, were explored. We argue that such technologies have become a central orchestrator of the clinical setting, to the extent that they often impose control on healthcare practices. Using a socio-technical approach we seek to understand how information systems technology and healthcare professionals can work together rather than apart, or around one another.

Keywords:

Information systems, Medical informatics, Medical records systems, Computerized, Hospital information systems, Electronic prescribing, Implementation, Healthcare practice, Workarounds.

Introduction

Health information systems are often implemented with anticipation for their delivering improved health care practices as part of a complex promise of reduced cost and enhanced quality, safety, and efficiency of healthcare [1,2]. However, beside these desired benefits, researchers acknowledge unexpected outcomes and changes in healthcare routines that may emerge as a result of the use of such technologies. Unintended adverse consequences are cited in studies of computerized provider order entry (CPOE) implementation [3-5]. Other literature has cited similar outcomes as 'workarounds' [6], while studies in the IS field consider issues of technology and control [7]. This research has confirmed such findings, and suggests that in addition to workarounds, health information systems impose degrees of control on clinical encounters and the professional's work practices including shifts in time and space. This control that emerges from health information systems has potentially important consequences for the way healthcare is performed and for healthcare outcomes.

This paper explores in theoretical terms these unexpected (or sometimes less expected) control-driven changes in healthcare practice. It draws on four studies we have been engaged in where the everyday work routines were to a degree controlled by a technology-in-practice [8]. The use of this technology, and the intentional and unintentional controls emergent from the technological systems in use, at times cause healthcare professionals' work practices to become obstructed, modified, or delayed. As a result and as often observed in other studies, health professionals adopt workarounds, which let them (to some extent) subvert the system's controlling features.

In the past, clinical encounters usually included a doctor or nurse and a patient. For centuries professionals have been reliant on some medical technologies too, e.g. to carry out physical examinations of the patient using a stethoscope, blood pressure monitor, or magnifying glass, alongside some technology for record keeping to make informed temporally coherent decisions (patient paper record or medical notes). The flow of the consultation was doctor-led and would be naturally dependent on the severity of the patient's condition, the completeness of his or her paper record, the time the doctor had to examine the patient, and the decisions made on how to move forward with a care plan. Today's clinical encounter continues to carry on most of these traditions, but increasingly, it is dependent on health information systems as new 'clinical leaders'. We argue that clinical encounters have changed (or are changing) significantly, from being clinician-led (by physician, nurse, or pharmacist), to technology/computer/information system-led encounters. These changes are characterised by new aspects of control. We define control here as 'the power to influence people's behaviour or the course of events' [9] through exercise of restraint, directing, auditing, or eliminating possible outcomes.

Our research stems from an interest in work practices [10]. Hence, we first present four changes in work practices: work obstruction, modification, disjunction and shifts in time and space. We present this along with examples from our field work in the results section. In the discussion, we explain two reasons for these changes; one is intentional and the other unintentional controls mediated by technologies-in-practice. We relate these findings to models of technology drawing upon ideas and constructs from sociotechnical theory. Finally, the potential implications as well as suggested areas for future research are presented in conclusions.

Methods

We follow here the tradition of information systems research that focuses on contextual, social approaches, and adopts an interpretive research methodology [11- 14]. Three healthcare institutions are considered here, drawing from our previous and

ongoing research including two London teaching hospitals and a district general hospital in England. The research we draw upon was carried out across four medical specialties; general surgery, cardiovascular surgery, elderly care, and cancer care. Qualitative methods were used to collect data [15], particularly semi-structured interviews, alongside observations. Interviews were tape recorded and subsequently transcribed, and hand-written notes were taken. Data collection was carried out during different periods in different settings, between 2005 and 2009. Further, research findings were indexed, interpreted and analysed against concepts from the sociotechnical approach [16].

We have studied the implementation and use of different health information systems in varied settings.

1. Electronic Prescribing Studies (completed):
    a. A pilot of a closed-loop electronic prescribing, automated dispensing, barcode patient identification and electronic medication administration record (EMAR) system introduced on one ward (general surgery) in a London teaching hospital [17]. We refer to this case as (1a).
    b. An integrated electronic prescribing, administration and records system implemented over time in English district general hospital. We refer to this case as (1b)
2. Electronic Patient Records Studies (on going):
    a. A study of a London teaching hospital's clinical information systems, which included a patient administration systems (PAS), electronic clinical letters, picture archiving and communication systems (PACs), a pathology results reporting system (OrderComms), and an electronic prescribing and discharge systems (eTTA). We refer to this case as (2a).
    b. A Study of a Clinical Data Repository, based in a large London teaching hospital which integrated many sub-systems. These included PACs, PAS (Patient Administration System including appointment scheduling and real time bed state), Clinical Letters, Proactive electronic document capture (i.e. discharge summaries), Order Communications (pathology requests and results), Nursing assessment (ePAN), Therapy activity recording, and Knowledge management tools. We refer to this case as (2b).

Results

A repeated observation made across these healthcare settings is that the clinical work flow is manipulated or orchestrated by the health information system. This characteristic of the technology-in-practice is described by us as 'control', though this word may have some over negative connotations. The control that is seen in action seems to result in four different types of outcomes (sometimes in combination). These we describe as; work obstruction, work modification, work disjunction, and work-related shifts in time and space. Each one of these themes are explored below, with examples.

Work Obstruction

We define work obstruction as a control that is a direct consequence of the technology-in-practice, and which results in the healthcare professional's work flow stopping, or being halted and she or he are not able to carry on their work as usual.

Health information systems often control when the clinical encounter begins and when it ends. Consultations would often begin and (or) end with the physician making the patient's electronic record available on the computer terminal, rather than by ensuring the availability of patient's paper record or the physical presence of the patient. An encounter could be seen to begin, for example, before the patient enters, as in an outpatient clinic where a doctor reads the electronic record for 5 minutes while the patient is waiting outside. At other times, healthcare information systems can pause or obstruct the physician from carrying out his or her chosen task as when a record is slow to download. This may be particularly the case when the technical performance of a system was poor, which meant the system would take a long time to load, would occasionally freeze, or cause the computer to restart. The physician may have the paper record at hand, but such an obstruction would still delay his or her consultation. This resulted in major frustrations, delays in the clinical start and end time, and, less often, cancelations (2a and 2b).

Pharmacists also reported their work being obstructed by slow computer terminals. Additionally, they also had difficulty finding a single available computer terminal to use for discharging their patients. Unlike the paper system which was fast and practical and always available to carry out the discharge task. This resulted in discharge from in-patient care being delayed, which ultimately made managing hospital flow of patients and bed management more complicated (2a).

Work Modification

The term work modification is used to describe a small temporary change in usual practice in order to get work done. Similarly, workarounds have been defined as "work patterns an individual or a group of individuals create to accomplish a crucial work goal within a system of dysfunctional work processes that prohibits the accomplishment of that goal or makes it difficult" [18] and do not include deviations, mistakes or shortcuts [6].

When pharmacists compiled discharge summaries, they often could not find the exact detail on the drop down menu which they used describe some drug specification. They resorted to using the closest description that the system would accept, and then finding a free text box (often the dietary information field, which was not limited in capacity) to clarify this in more detail (2a). Another example is of a hospital where there were eleven different clinical systems used by one department, and each of those systems required different sign-on details as a security measure. It was also programmed to 'time-out' every three minutes. Physicians commonly wrote the eleven different user names and passwords on a notepad on their desktop, in their personal diaries or agendas. In one instance, a surgeon had them listed on the back of one of his business cards. While this made the physicians' work flow possible, it allowed for a new

'security breach' in the confidentiality of patient information stored on all systems.

Another workaround was commonly practiced when dealing with random pop-up boxes that usually occurred when physicians were navigating PACs. Pressing 'cancel' several times was the quickest way to by-pass the 'glitch' and carry on their work. It became common practice to flag it up to junior colleagues during orientation and training (2a).

A third example is from nurses who printed patients' identification bar codes and stuck them on their bedside lockers or tables in order to be able to dispense medication when the patient was away from the bed. This was done as the drugs trolley only opened upon reading the bar code. This workaround subverted a safety feature intentionally included in 'computer logic'. Also, doctors used a subsidiary paper chart to prescribe certain drugs (i.e. warfarin, sliding scale insulin, variable dose heparin and intravenous fluids). This was a necessary work around. These drugs could not be safely prescribed through the system because their protocols did not fit easily into the structures embedded in the software –just regular doses of drugs at set times (1a).

Work Disjunctions

By work disjunctions we refer to situations when the information system has a direct or indirect effect on a healthcare professional's control over work flow, or by simply slowing down their ability to complete a task. For example, at one hospital notes regarding administering a drug in the future could not be made on the computer record, consequently the pharmacist would have to note it physically in other records. This meant that potentially important information might not be recorded or remain unnoticed (1b).

Work disjunctions are also caused indirectly by the increased structure that a health information system may impose. In the case of drug administration nurses had to follow the system's logic when dispensing drugs, and could not easily override it (unless in emergency). Initial evaluation showed that this feature might have lead to fewer dispensing errors but some procedures took more time, requiring additional work flows in some instances. Prescribing or administration that was not undertaken as part of regular drug rounds, e.g. when a nurse gives a "stat" (occasional or elective) dose, called for another work flow to log and administer. This involved the nurse walking to the computer and back twice to obtain the drug and then to record administration (1a).

Surgeons reported difficulties encountered when viewing heart ultrasound images, which forced them to change their physical space, and leave their consultancy suites, and in one incident, a live-surgery, in order to find a computer terminal that can load the images quickly enough (2a). Similarly, nurses using an EMAR system found that at times they had to queue to use the computer on the ward (1a).

Work Shifts in Time and Space

By shifts in time and space we refer to controls imposed by information systems that cause healthcare professionals to physically change their work location in order to carry out their work. We also refer to the flexibility that these systems bring, allowing professionals to manage their work from different locations and at different times than the usual ones.

When researching electronic prescribing systems, it was observed that doctors often prescribed away from the wards (e.g. from the doctors' mess). By accessing computer records, doctors could more easily deal with out of hours calls, sometimes avoiding going to the ward. This, as suggested by a doctor interviewed, should lead to more accurate prescriptions as compared to phone prescribing (a practice which sometimes took place at night). However, the availability of relevant data might mean that even less prescribing activities are done by doctors who actually see the patient. Thus, the potential implications of this shift are ambiguous (1a).

One related consequence was found in two healthcare institutions. There, before electronic prescribing was implemented, pharmacists would visit each patient daily and check their drug chart if available; now they could check through the computer and assess each patients' computer chart for changes and only visit those whose records indicated a pharmacy-related problem. This resulted in some (but not all) pharmacists choosing to do the majority of checking in the pharmacy and limiting their visits to the wards. When checking prescriptions, pharmacists had access to relevant data, for example test results more easily than in paper-based system and thus might be more likely referred to them. This potentially reduces errors and improves care. However, certain cues might be missed if patients are not seen in person, and less interaction was possible with other health care professionals. Computerisation of prescribing also meant that pharmacists could check prescriptions at any time with no need to have a set time or set amount of time and pharmacists were no longer tied to the ward timetable. This allowed a degree of flexibility and enabled them to prioritise work. Pharmacists reported that this has led to efficiency gains (1b).

The integrated nature of hospital information system has meant that doctors could potentially re-organise their clinics and conduct some aspects of care in different locations. For example, patients' notes could be accessed and tests ordered remotely. One senior doctor reported regularly accessing patients' notes and ordering tests remotely from home (1b).

Discussion

The view that ICTs do not have predefined 'impacts' is increasingly accepted in information systems, health informatics and medical informatics literature. Indeed, it is now widely acknowledged that ICTs have many unintended positive and negative consequences [3] and that these consequences depend on the organisational context, culture and the fit between the task, the clinical environment and the technology [19,20]. This suggests that we cannot study technology per se or unreflectively take findings from one setting and generalise them to another. Rather, we need to consider ICT as embedded in work (and social) practices and part of heterogeneous relations both potentially enabling and obstructing activities, i.e. as *technology-in-practice* [21].

> *... technologies are embedded in relations of other tools, practices, groups, professionals, and patients and it is*

> *through their location in these heterogeneous networks that treatment, or any other action, is possible in health care.* [21]

Furthermore, it is through the situated practices of everyday users and in particular circumstances that consequences of technologies are manifested and felt [22]. But different studies have shown that the models of care delivery underpinning information systems are often based on what ought to happen (e.g. according to formal rules and practices which are not followed), rather than on what actually happens, and on perception of care as a linear process with a clinician at the centre rather than as a collaborative, non-linear process undertaken by a multi-disciplinary group [23].

The difference in theoretical and practical perception of medical work practices leads to 'aberrations', including workarounds created to by-pass the system, parallel communication channels or duplication of work due to lack of coordination [20, 24, 11, 25]. Workarounds may be introduced because of work flow blocks associated with technology or organisational processes not effectively integrated with technology. Workarounds tend to distract staff and take them away from patient care and can result in errors [6, 26].

Our paper complements and builds on this literature by focusing on controls emerging from the systems in use. Other studies have identified different types of controls [27]. Our categorization of controls is derived out of the four changes in work practices described above. We classify these controls as:

(a) ***Intentional controls***: These may be in the form of *work flow control*, when for example technologies are seen as 'clinical leaders', controlling the flow of clinical encounters and other activities, such as prescribing of medications (orders). Increasing dependence on these new 'clinical leaders' means that when they break down activities might be halted. We identify *adherence* controls, when systems are designed to enforce different ways of working, e.g. adherence to local or national guidelines. These often overlap with *work flow controls*.

(b) ***Unintentional controls***: Such as in *accidental controls* imposed by pop-up boxes appearing apparently randomly due to arbitrary systems errors, inadequate hardware or faulty software. These controls may be caused by 'unintentional mismatch of practice' when computer systems do not reflect work practices they are supposed to support. This may be a result of poor analysis and design, changing work practices and organisational context, or practices that are difficult to model in the technical system (e.g., warfarin prescribing and administration). We term these *disjoint controls*.

Controls inherent in technologies-in-practice result in different outcomes and workarounds, such as work obstruction, work modification, and work disjunctions. Information systems also have profound implications for shifting time and space of clinical encounters and clinical work and these in turn may have varied implications for the quality of healthcare delivered [18]. This implies that workarounds are to be expected and that they are inherent in work systems, which (like computerised information systems) tend to be highly structured. However, information systems not only constrain but also enable work and may lead to emergent changes in healthcare practices and ambiguous consequences.

Conclusion

Our findings lead us to conclude that when implementing and evaluating information systems it is important to consider implications of control and structuring of work due to 'computer logic', and of work shifts in time and space. Deceptively simple decisions, e.g. of where to place computers, have consequences for the practice of healthcare, e.g. for communication with patients and between health professionals. Computers can become 'centres' where different professionals meet or catalysts for further compartmentalisation of work and distancing of different healthcare professionals from each other and from patients.

We give examples of when computerised systems facilitated prioritisation of work and shifting times and places, as well as when systems obstructed or structured work and imposed their own work flows. When controls embedded in computer systems break the flow of work it is likely that people will find workarounds to subvert the logic. Thus, when implementing information systems the following need to be carefully considered: (a) what controls (and values, norms and guidelines) we want to embed in information systems and what (potentially reengineered) work processes we want them to support ; (b) in what circumstances should workarounds be 'designed into the computer and work systems' (e.g. how exceptional, emergency situations should be dealt with,); (c) how to limit 'undesirable' workarounds (e.g. by reflecting existing practices in computerised systems and when appropriate limiting the number of intentional work flow stops, as well as by re-organising work and physical spaces to make adherence to work flows easier; and (d) what emergent changes these technologies-in-practice might bring about.

There is a substantial literature on organisational impacts of information systems and implications for healthcare practice. But as new systems are implemented in varied settings new research opportunities open up. In particular, research "unpacking" information systems, such as that outlined in this paper, that reveals embedded controls, values, norms and policies and their implications for healthcare promises to deliver important insights relevant to both practitioners and researchers alike

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Ghost Charts and Shadow Records: Implication for System Design

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Abstract

Ghost charts, sometimes referred to as shadow charts, are duplicate medical records. Governance documents in several countries suggest that ghost charts present a risk to patient safety, to the extent that they contain information which may not appear in an official hospital record. Although most would agree ghost charts should not exist, their existence is widespread. This paper reports on an in depth multi-method qualitative study of ghost charts undertaken in two ambulatory care settings in a Canadian hospital. The study was undertaken in order to inform the design and implementation of a clinical information system which it is hoped will eliminate the need for duplicate charts. Our research demonstrated that ghost charts filled a variety of needs only some of which are typically accounted for in electronic record design. We suggest that if the functions ghost charts fill are not addressed, their existence will persist. This work is significant in that few studies of ghost charts have been undertaken, and in the in-depth understanding it contributes to design requirements for electronic record systems.

Keywords:

Medical records, Duplicate, Electronic health records, Ambulatory care, Patient safety.

Introduction

A study of duplicate medical records (referred to here as ghost charts) was undertaken in order to develop in depth understanding of work practice issues related to the existence of duplicate paper based medical records (PMRs) in ambulatory clinical settings, in order to gain insights about the use of paper based charts that can inform the design of electronic records. Study objectives were a) to develop an understanding of the work practices regarding paper medical records in 3 ambulatory settings; b) to document how different clinical user groups interact with the PMRs including ghost charts, (e.g., what information do practitioners require? what information is shared with other practitioners, and under what circumstances? why is some information maintained in ghost charts?); c) to develop an in depth understanding of ghost charts, including what information they contain, what needs they fill on clinical units that are not met with the official clinical record, and underlying reasons for their existence; and d) to share insights gained from the study described here with stakeholders who will engage in decision making about electronic medical records. Material reported here is based on findings from observations and interviews in 2 clinical settings (a neurosurgery unit and a gastrointestinal (GI) clinic), and focuses on the functions that ghost charts fill. Additional findings pertaining to other aspects of the study (e.g., a detailed analysis of the contents of ghost charts compared to hospital records, in depth information about how charts are used during clinical encounters, and different stakeholders' views of health records) are beyond the scope of this paper and will be reported elsewhere.

Our hypothesis was that ghost charts meet a variety of needs for varied groups of workers who interact with charts, and the need they have for these additional charts is poorly understood—and this has implications for system design. When work is computerized, if system designers do not have a thorough understanding of how work is carried out (or, in other words, if the existence of ghost charts and the needs they meet are not acknowledged), then the resulting system will in all likelihood not meet staff needs. Hence, it is important to understand what role(s) ghost charts fill so that computer based systems can be designed in a manner that meets the needs of varied stakeholders who interact with charts. Our goal was to develop a better understanding of the roles ghost charts filled.

Background and Scope of Problem

The term ghost charts is sometimes used to describe a uniquely identifiable patient record that does not reside in an officially sanctioned hospital record location. Other terms used to describe the phenomenon of maintaining a patient care record independent of the main medical record include shadow charts, soft charts, duplicate medical records, working charts and clinical or clinic charts or records. Ghost charts are "duplicate record[s] kept for the convenience of a department or healthcare provider."[1] They exist in addition to health records (here referred to as hospital records), which are defined by the Canadian Health Information Management Association [2] as:

> a compilation of pertinent facts of an individual's health history, including all past and present medical conditions, ill-

[1] AHIMA FAQ [1] http://library.ahima.org/xpedio/groups/public/documents/ahima/bok1_017169.hcsp?dDocName=bok1_017169

nesses and treatments, with emphasis on the specific events affecting the patient during the current episode of care. The information documented in the health record is created by all healthcare professionals providing the care.

Although there is a paucity of written material about ghost charts—no doubt reflecting concerns about exposure to legal risk associated with acknowledgement of their existence-- informal conversations with a range of care providers as well as a review of reports written as part of the hospital accreditation processes[2] suggests that ghost charts are a common phenomenon, and their existence is not limited to ambulatory care settings [3, 5-9]. Several sources suggest that ghost charts emerged because paper based records are unwieldy in that they cannot be in two places at once, which leads to the need for ghost charts.[3] One article suggests the problem is most prevalent in multidisciplinary care [10]. Other explanations for the existence of ghost charts identified though grey literature searches include:

- the need for quick access to charts for patients with unscheduled visits is too challenging to manage through a central hospital records department, which providers responded to by keeping ghost charts [6, 7, 9, 11, 12;
- that patients visiting multiple clinics, often on the same day creates a situation where the "chart could be anywhere" so staff create ghost charts [6, 7, 9, 11, 12];
- that some staff have ongoing unscheduled contact with patients (e.g. calls regarding patient education, medication or symptom management that the clinic handles without requiring a formal appointment) and want/need the records handy as a quick reference [9, 12];
- that test results, specialist reports and other documents arrive as hard copy and are not integrated into the chart immediately, so ghost charts are created to keep this information together and ready at hand and are used in conjunction with the medical record, until such time as the medical record is updated [5, 8, 13];
- that staff make up their own charts because they cannot readily access the information they need in the formal chart [11 -13];
- that ghost charts can contain information useful to clinical management but that are not part of the formal medical record, or are not kept for a long period of time (e.g. because of "thinning policies" for medical record storage);
- that ghost charts have a reminder function – the chart is put aside as a reminder that staff are waiting for critical test results etc., rather than filing them away and relying on memory or the return of the result to trigger subsequent steps in treatment or scheduling [12];
- that ghost charts support continuity of care across transitions (details about how this is accomplished are lacking, but presumably relate to the ghost chart as a receptacle for more detailed information than would normally appear in the hospital chart, which is required to manage care across transitions);
- that research study records are often kept in a ghost chart accessible to researchers (which can occur in the context of formal research involvement or clustering of charts to support ongoing quality improvement or retrospective chart review research in clinical areas, which is particularly important in terms of intern and resident projects) [11];
- that some clinical areas "hang on" to charts or pieces of information from the chart for an extended time period (e.g., 6 months) for their convenience before submitting them to medical records [6].

Ghost Charts as a Problematic Phenomenon

Ghost charts present many challenges. Within the context of this research project, while our primary reason for studying ghost charts has related to the eventual computerization of hospital records and a desire to develop an understanding of the roles ghost charts are filling in the provision of care, it is important to note that computerization is often cited as a means through which ghost charts can be eliminated. A frequently offered rationale for the use of electronic medical record (EMR) systems is that they can integrate across physical sites or services where ghost charts have been in use [7, 9, 12, 13]. It should also be noted that ghost charts are generally viewed in a negative light, for a number of reasons related to problems associated with the practice of using ghost charts, and exposure to medico-legal risk related to the use of ghost charts. Each of these is discussed briefly below.

Problems Arising from the Practice of Using Ghost Charts

The practice of maintaining and using ghost charts has been identified as problematic in both the Canadian Council on Health Services Accreditation (CCHSA) and the Joint Commission on the Accreditation of Healthcare Organizations (JCAHO) standards [3, 14]. Ghost charts are considered substandard practice in that they are presumed to compromise patient safety. Current norms and standards for good practice in patient safety are predicated on the need for complete, accurate, reliable and accessible patient data and information, and ghost charts are seen as a threat to record completeness, accuracy and accessibility. Hence ghost charts are seen as under-

[2] For example,

- A 2007 accreditation report for Capital Health (Nova Scotia) cites the existence of shadow records in 11 clinical areas, including acute geriatric medicine, surgery and neurosurgery and cancer care, and noted that the physician groups had begun stand alone medical record systems in some areas [3].
- A Saskatoon accreditation summary notes the recommendation for "examination of multiple chart approaches with the intent to make all healthcare information available during the healthcare encounter."[4].
- An accreditation report for PEI written in 2007 indicated that the Emergency Department stored ECGs separately from patient charts [5].

[3] AHIMA FAQ [1] http://library.ahima.org/xpedio/groups/public/documents/ahima/bok1_017169.hcsp?dDocName=bok1_017169

mining informational continuity of care,[4] as well as practitioners' abilities to be responsive and effective.

Problems identified with ghost chart use include that some ghost charts contain more information than the official medical record, which may lead to gaps in information among care providers [6, 11], and that a lack of up to date information may lead to inappropriate treatment and detrimental consequences to the patient [3, 14]. In addition to potential problems related to informational continuity of care, concerns have been raised about exposure to medico-legal risk related to the use of ghost charts. For example, issues have been raised about confidentiality/privacy and compliance with Freedom of Information and Protection of Privacy (FOIPOP) [16] and the U.S. Health Insurance Portability and Accountability Act of 1996 (HIPAA) legislation [11]. In addition, an organization's obligation to release records under freedom of information acts may be thwarted by the existence of unofficial records [16]. Finally, ghost charts may not comply with policies governing controlled access to patient information under FOIPOP regulations. Discussions about ghost charts suggest that they can be seen as both an adjunct to medical care, and as a legal document, and efforts to computerize hospital records should be undertaken with both of these views of a chart, as well as the notion of supporting staff in carrying out their work.

Although our primary purpose in exploring the existence and use of ghost charts has been within the context of future computerization of ambulatory care clinics, we have considered regulatory, governance and legal aspects of charting, and materials pertaining to the governance of medical charts (including ghost charts). While issues pertaining to the governance and legal status of ghost charts warrants further attention than space here allows, a preliminary examination of governance instruments pertaining to charting practices suggests that the push for a single medical record is rooted in accreditation standards rather than governance tools coming from professional associations or legislation (with the exception of the Canadian Health Information Management Association definition cited above), and that guidelines pertaining to the specific contents of medical records are often vague. Legal issues seem to arise when there is a discrepancy between what is documented in ghost charts and hospital records (the "officially sanctioned" record, herein referred to as hospital records), or when a hospital record is ordered under a freedom of information and protection of privacy request, and only the contents of the hospital record are furnished, and the patient is aware that a ghost chart exists, but it is not furnished in response to the FOI request.

The reliance upon ghost charts by medical staff for patient care raises important legal and ethical issues about what constitutes adequate information for good patient care. One view is that ghost charts should not be used because comprehensive information is not available for the doctors to make their decisions and do their work if they rely primarily on the ghost charts (GCs) rather than the hospital record, which is the officially recognized chart. In contrast, it can also be argued that the ghost charts exist for a reason (usually several reasons), and provides doctors with more in depth information about their patients than what is contained in hospital records, and, that they facilitate a number of other activities which take place in the ambulatory care clinics (such as scheduling of procedures, telephone-based nursing consultations), and elimination of ghost charts may compromise the clinics' ability to carry out their work (e.g., the removal of GCs from clinics would interrupt the provision of telephone support and education to patients and their family members).

Although the existence of ghost charts is well known, concerns about exposure to risk (e.g., based on an argument that a practitioner may not have consulted all available information when treating a patient, or has failed to release information held in ghost charts in response to a Freedom of Information and Privacy Act request) and questions about whether or not patient care is compromised as a result of ghost charts (seen by some as a threat to informational continuity of care, which in turn is seen as an important aspect of patient safety) result in a situation in which publication of material about ghost charts—whether scholarly, operational or in the form of reports—has been limited.

Methods

The study described here is a multiple method single-case study using embedded units of analysis. In this context, the single case is a single hospital, and embedded units of analysis are ambulatory care clinics (one hospital bounds the case, and three different ambulatory clinics—referred to in research design terminology as units, serve as focus for in depth study). Methods of data collection have included participant observation, formal and informal interviews and chart review. In addition, interviews have been carried out with staff from facilities other than the facility which serves as the focus of our study, in order to determine what practices are in place in other facilities in which ghost charts exist. We have also consulted medical literature and grey literature (e.g., hospital accreditation reports, material that is not peer reviewed but was located through on-line searches) about ghost charts, and conducted a search aimed at identifying governance instruments which address ghost charts.

Methods of Data Collection

Suchman's [17] observation that planned work activities differ from situated actions, and her observation that often people are unable to voluntarily describe what they take for granted (e.g., tacit elements of their work) lay the groundwork for the use of observational methods of data collection, in which researchers observe work activities, and seek clarification of activities from staff whom they observe. Observational methods of data collection are used to develop an overview of work practices in clinical settings, and interviews—both formal and infor-

[4] Informational continuity reflects the idea that details about past events should be available to inform current care [15]. See Reid et.al. [15] for a more extensive discussion of continuity of care. Varied meanings of the term continuity of care are useful to keep in mind within the broader context of discussions about both the functions that ghost charts serve, and both the explicitly and implicitly stated goals of computerization of electronic health records.

mal—have been used to clarify issues as well as gain additional insights about the nature of work.

Observations have focused on i) the setting (describing activities in a given space); ii) people's use of ghost charts and hospital records in order to understand practices from the perspectives of different persons/professions (physicians, nurses, secretaries etc.); iii) objects, (with a focus on the artifacts that mediate the work); iv) tasks (identifying tasks that constitute the work); v) information (focusing on information flow between groups of workers, in different locations, over time).

Sampling

The two units reported on here were chosen for in depth study because they represent varied service provision models within a single provider agency. In addition, units chosen for study fall under a single director, who was able to ensure access to each of these clinical settings. All staff members—from clerical and support staff to nursing, allied health and medical staff—working on the units included in the study have been eligible to participate. Only staff members who choose not to participate (n=1) have been excluded from participation. Research participants have been staff (doctors, nurses, and administrative staff) who work in two of three ambulatory care settings. Future study will add a third clinic.

Findings reflect data collection which occurred between August, 2007 and February, 2008. Observational data which forms the basis of what is reported here were collected on days when clinics occurred, and on days when no clinics were scheduled. Interview data and observations which formed the portion of material reported here were collected on 31 different days, in sessions ranging in length from one and a half hours (for an interview) to 8 hours (for observations).

Results and Discussion

Through this research it has become evident that clinic charts serve an important role as a working document (e.g., information in ghost charts is required to schedule procedures, support telephone based patient education, coordinate appointments between multiple units, etc.), and the removal of ghost charts in the absence of new mechanisms for addressing the needs that ghost charts fill would be likely to significantly interrupt work flow and patient care on those units using ghost charts.

While some duplication of information (e.g., lab results) exists between the hospital record and the ghost chart, the hospital record is archival in nature and serves as a repository of information, while the ghost chart serves as an active or working document, and must be ready at hand in order to support activities such as patient education, complex appointment scheduling, etc. Information required for the ongoing treatment and management of in-patients resides in the hospital record. Information in clinic charts which is not duplicated in the hospital record pertains only or primarily to the service maintaining the clinic chart (e.g., nursing notes pertaining to patient education). It is required for smooth operation of ambulatory care clinics, and would normally be culled from the hospital record.

Medico-legal norms and FOIPA regulations create a demand for a single record. The contents of the hospital record are ill defined and the legal status of a single hospital record is unclear. The current governance climate which identifies a single record as the standard of care is not reflective of the working realities of out patient or ambulatory care clinics operating within an acute care facility, in which paper based records are the predominant form of record. If the ambulatory care clinics were not located on-site or were not part of a single governing institution, there would be no expectation of a single record.

Although they fill critical roles for a variety of staff involved in the chain of care, ghost charts are not without their problems and challenges. If the use of ghost charts is to be reduced, any computer based system introduced will need to support the tasks that ghost charts currently support**.** Challenges related to the maintenance and use of ghost charts are numerous (e.g., the volume of paperwork created by interim lab results). To some extent, these problems could be mitigated with the advent of an electronic system, however, whether they are or are not mitigated will depend in part on the design and implementation of that system.

Building electronic records that reduce ghost chart use will require undertaking in depth data collection and analysis aimed at determining who requires access to what information in hospital records, so that the often neglected aspects of record use (e.g., scheduling, phone consultations) are supported. Additional research aimed at ascertaining how best to present clinical information to varied specialties in electronic format may also reduce reliance on specialty-specific charts.

Calls for a single record are also based on a normally tacit assumption that the availability of all information pertaining to a patient leads to better provision of care by a specialist than the provision of a relevant subset of information that relates to the providers' specialty. One of the things we observed is that each clinical group prepared its own 'face sheet' that summarized specialty-specific information about a patient, and that such specialty-specific views of the patient were essential to clinical consultations. This practice—along with our observation of differences in content of charts related to specialty areas-- suggests that ghost charts play an important role in organizing specialty-specific views of patients for providers. Further research is warranted in order to determine if providers are more effective in diagnostic work when they must deal with more information about a patient, some of which may not be relevant to their diagnostic frame.

Subsequent Directions for Research

As our work on this topic progressed, we undertook observational data collection aimed at determining how doctors use charts during clinical encounters. In addition, we explored issues related to the flow of patient information into and out of the health records department. Although not initially planned, chart review has been added to the study protocol and is being undertaken in order to determine to what extent chart contents vary from clinical area to clinical area and within clinical areas, and to determine to what extent there is overlap in the

contents of ghost charts and hospital records. Results from this chart review will be reported at a later date.

Anecdotal information has suggested that ghost charts may also be used to protect privacy in some circumstances. For example, care providers addressing issues such as psychiatric or mental health illness, sexual or other assault trauma, or addiction issues may rely on ghost charts to protect patient privacy. Additional research and policy discussion will be required to determine under what circumstances such information should be visible to all care providers, and when additional privacy is warranted.

Conclusion

Any attempts to computerize patient records beyond a single clinical area or geographic location will need to take into account the functions that ghost charts fill in supporting unplanned care (e.g., phone consultations), the work of nonmedical staff (e.g., in scheduling procedures), and should strive to preserve specialty-specific views of the patients, and at the same time adequately protect patient privacy. Failing to account for these aspects of charts—arguably the reason ghost charts exist—will fail to eliminate the need for ghost charts.

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Why don't innovation models help with informatics implementations?

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Abstract

This paper describes various models that have been postulated to understand and explain the acceptance and diffusion of technological innovation. The wide range of factors relating to the innovation itself, and, most importantly, the human and organisational factors which will impinge on these processes, is detailed. Attempts to apply the model to healthcare settings are explored. In particular a systematic review in 2005 which attempted to integrate the models and apply them in the UK's National Health Service will be critiqued. The strengths and weaknesses of the models are explored, particularly in relation to the minimal testing they have been subjected to. It is argued that the complexity of the theoretical models makes them difficult to apply and questions their efficacy in supporting informatics implementations. The need for a clearer understanding of the factors which make staff positively disposed towards informatics innovation, and those which are likely to make them resist them is made apparent.

Keywords:

Computers; Attitude of Health Personnel; Diffusion of Innovation; Organizational Innovation; Models, Theoretical

Introduction

The process by which new technological innovations are adopted and disseminated has been extensively studied for many years. Data have been collected from many settings internationally and within different academic paradigms [1]. However, many of the models of innovation development and diffusion are developed from a limited empirical evidence base and have only been tested by post hoc application to previously published reports and fail to demonstrate predictive capabilities. More recently these models have been applied to the introduction of Informatics applications in healthcare; however the components of the models which relate to human and organisational factors are often considered secondary to technological issues when it comes to real world use.

This paper will argue that complex theoretical models are not currently helping to predict the factors that will lead to the success or failure of informatics developments. The models have similar components, but each with slightly different emphasis, and have increased in complexity over the years.

Models

Many of the models that attempt to explain the factors affecting whether an innovation will be shared and adopted by other individuals and organisations have been based on Rogers Diffusion of Innovation Theory [2]. Rogers argued that each adopter's willingness and ability to adopt an innovation would depend on their awareness, interest, evaluation, trial, and adoption. This led to the proposal of a five stage model for the diffusion of innovation [3]:

- Knowledge - learning about the existence and function of the innovation;
- Persuasion - becoming convinced of the value of the innovation;
- Decision - committing to the adoption of the innovation
- Implementation - putting it to use and
- Confirmation - the ultimate acceptance (or rejection) of the innovation.

An alternative approach to Roger's work is the Technology Acceptance Model (TAM) that focuses on the factors and decision processes an individual will go through in any decision to accept and use a technology or other innovation. The model suggests that when users are presented with a new innovation, two key factors influence their decision about how and when they will use it. Perceived Usefulness is defined as "the degree to which a person believes that using a particular system would enhance his or her job performance" and the Perceived Ease-of-Use: "the degree to which a person believes that using a particular system would be free from effort" [4]. The TAM can be seen as an extension of Ajzen and Fishbein's theory of reasoned action [5, 6], which suggests people's volitional (voluntary) behaviour is predicted by their attitude toward that behaviour and how they think other people would view them if they performed the behaviour. A person's attitude, combined with subjective norms, forms behavioural intention.

Several researchers have replicated Davis's original study to provide empirical evidence on the relationships that exist between usefulness, ease of use and system use; [6-11]. Davis, [12] using newly developed scales, demonstrated that perceived

usefulness was 50% more influential than ease of use in determining usage.

Malhotra and Galletta [13] argued for much greater emphasis on social influences, rather than the nature of the technology, and developed and tested constructs based around these factors which may be particularly significant in complex organisations in which many different players are likely to be in a position to influence the success or failure of the innovation, even if they are not involved in adoption decisions.

Further work has tried to integrate individual and organisational factors. Venkatesh et al [14] compared existing models in an attempt to identify and test a model that integrates elements across them. Based on their work in a variety of settings they produced a set of hypotheses to explore and explain the variables which impinge on acceptance and use.

- The influence of performance expectancy on behavioral intention will be moderated by gender and age. The effect will be stronger for men and particularly for younger men.
- The influence of effort expectancy on behavioral intention will be moderated by gender, age, and experience. The effect will be stronger for women, particularly younger women, and particularly at early stages of experiencing the innovation.
- The influence of social influence on behavioral intention will be moderated by gender, age, voluntariness, and experience. The effect will be stronger for women, particularly older women, particularly in mandatory settings.
- Facilitating conditions will not have a significant influence on behavioral intention.
- The influence of facilitating conditions on usage will be moderated by age and experience. The effect will be stronger for older workers, particularly with increasing experience.
- Computer self-efficacy will not have a significant influence on behavioral intention.
- Computer anxiety will not have a significant influence on behavioral intention.
- Attitude toward using technology will not have a significant influence on behavioral intention
- Behavioral intention will have a significant positive influence on usage

Application to Health Informatics

In 2005 a major systematic literature review was undertaken, in an attempt to draw together the research on the diffusion of innovations and apply them to health service organisations. A particular emphasis was placed on the relevance of the work to the United Kingdom's National Health Service which funded the work [1].

The review reaffirmed many of the well known themes such as the importance of the attributes of the innovation itself, of social networks and organisational cultures, but also pointed out the lack of empirical evidence demonstrating that work from product-based innovation in companies can be applied to process innovation in service organisations, such as healthcare providers. The review attempted to integrate work from a variety of paradigms into a single conceptual model. The model seeks to encompass the whole range of factors and was tested against purposively sampled case studies.

The Greenhalgh et al model[1] covers several key areas:

- **Innovations** which covers relative advantage, compatibility, complexity, trialability, observability, reinvention, fuzzy boundaries, task issues, the nature of the knowledge required to use it and support required.
- **Adoption by individuals** which explores general and context specific psychological antecedents to, and the nature of the adoption decision.
- **Assimilation by organisations** where there is a dynamic relationship between initiation, development and implementation.
- **Diffusion and dissemination** which covers network structure, homophily, opinion leaders and harnessing their influence, champions, boundary spanners and formal dissemination programmes.
- **The inner context** addressing organisational antecedents and readiness for innovation, discussing structural determinants of innovativeness, absorptive capacity for new knowledge, the receptive context for change and the resources available.
- **The outer context** which covers inter-organisational networks and collaboration
- **Implementation and routinisation** which includes structure, leadership and management, human resources, funding and communication issues.

The Greenhalgh model accepts the importance of interactions between different components, but argues that it is not possible to make "formulaic, universally applicable recommendations for practice and policy" based on the model. This makes it impossible to use to predict behaviours and outcomes. It also becomes difficult to test or use in implementation projects, and lacks any ability to how much effect will be brought about by different factors.

Greenhalgh et al. [1] sought to test the model with four case studies; integrated care pathways, General Practitioner fundholding, telemedicine and the electronic patient record. Telemedicine is subtitled "the maverick initiative" and was selected partly because it had previously been studied from a diffusion of innovations perspective (e.g. [15, 16]). It was highlighted as being an initiative that tends to be introduced by individual enthusiasts rather than as part of an organisational process. The importance of human actors and the processes between them is described as being more important than the hardware and software of the technologies concerned [1]. The

evidence for the effectiveness and cost-effectiveness of telecare is inconclusive and barriers to adoption are extensive, however small teams of enthusiasts, have devoted time and personal resources to development, often in the face of institutional indifference and made the projects successful. May et al [17] used telehealthcare as a case study in their examination of the processes surrounding health technology assessment. They suggest that although the technology is attractive to policy makers as a "technological fix" for some structural problems that affect access to health care, it is unstable in clinical practice, not widely used and there are doubts about its efficacy, acceptability to patients and cost effectiveness. They suggest that evaluating these sorts of technological developments involves debates about evaluation methodology and professional dynamics that conceal more fundamental difficulties in conceptualising a technology in play, and which are difficult to resolve in practice. May et al [17] produced a set of terminology about how these innovations are adopted including; Ideation, Mobilisation, Clinical specification and Specific application which are not dissimilar to the stages originally set out by Rogers in his diffusion model but do focus this on application to clinical settings.

The other case study by Greenhalgh et al. [1] with direct relevance to Informatics is their review of the electronic health record which they dub "the big roll-out". This major national initiative is seen in the context of the UK's National Health Service which is fragmented across multiple sites and sectors posing obstacles to clinical care, administration, research and public health initiatives. The strong "external mandate" from central government is seen as being in conflict with the response from staff, because of "high complexity, questionable relative advantage and low ease of use" Greenhalgh et al.[1, p208-210]. These problems are identified as being significant because of the critical dependence on simultaneous adoption by multiple users, and low absorptive capacity of many parts of the system. These findings are further reflected by the independent evaluation of the summary care record early adopter programme, which identified positive mediators, including organisational readiness and aspects of the implementation, and negative mediators including the concerns of the potential adopters of the innovation [18].

Weaknesses of the models

The Greenhalgh et al, [1] model could be seen as being rather un-dynamic and undifferentiated, avoiding ranking the importance of the various factors and really providing a checklist rather than a full exploration of the complex factors involved in the diffusion of new technologies. Although highlighting a wide range of factors they did not place these in any order of priority. The research team also postulated that power relations were critical to successful implementation, but suggested they were very difficult to explore systematically. They also bemoaned the lack of research on the complexities in spreading and sustaining innovation in service organisations as opposed to initial innovation.

The general complexities of identifying the factors that contribute to the diffusion of innovations are complicated within specific organisational contexts and interpersonal relations. West [19] showed how, in the UK, the networking behaviours of senior nurses and medical staff, and their cliques, were different. The differences influenced the way in which they gained and shared information with colleagues, and suggested that these were a result of the occupational socialisation within the different professions, which had led to the development of subcultures [20]. Similar work in the USA examining the implementation of an electronic medical record system found that the new working practices which were inherent in the electronic system required "clarification of clinical roles and responsibilities which was traumatic for some individuals" and that "no single leadership style was optimal – a participatory consensus-building style may lead to more effective adoption decisions, whereas decisive leadership could help resolve barriers and resistance during implementations: the process fostered a counter climate of conflict" [21]. These professional variations and the wide variety of roles played by individuals mitigate against finding models which can encompass all the myriad influences of adoption and dissemination of technologies within the healthcare domain.

Resistance to innovation

There is a need for clarity in looking at the "fit" between the technology and the task it is intended to support. System design (from IT people) may not match well with objectives and values of clinical staff [22]. The degree to which a "one size fits all" solution can cause local resistance in organisations and individuals who have been used to "locally grown" systems which have high degrees of customization and localization was also highlighted by Hendy et al [23]. They found this factor was a significant driver in the development of resistance to new systems by clinicians.

Nursing staff reactions and strategies when employed to use software driven algorithms for decision making in a variety of settings, are influenced by the inflexibility imposed by the system which hampered their work. The nurses often overrode the guidance given by the system because it was not seen as being individualized to the specific patient problem [24]. At NHS Direct, nurses using similar software felt it was sometimes unable to consider contextual or other relevant information. They described the software as "interfering with their consultation with the patient, leading either to dependence on, or avoidance of, the software" and it was seen as a limitation imposed by management on the nurses' practice [25]. These types of reactions are to some extent predictable, but are not included in the models and need to be taken into account by system developers and those with responsibility for new implementations.

The 'Design-reality gap' has been given as a label to identify some of the factors which may influence the outcome of eHealth systems taking into account the situation specific factors which are relevant [22]. The Information, Technology, Processes, Objectives and values, Staffing and skills, Management systems

and structures, and Other Resources (ITPOSMO) model is based on a continuum between reality as it exists, and what the design is trying to achieve and helps as a way of identifying the need to reduce the gaps on all dimensions [22]. This model attempts to take into account attitudinal and organisational factors as well as technology based ones, although the models use as a predictor of implementation effectiveness remains to be tested.

Implementation models which accept the importance of involving users require consultation with individuals who will be affected by the change, both on an individual basis and through representative organisations. These require recognition of professional autonomy and an understanding of the different values and assumptions which may be held by different groups such as managers and clinicians. Kaplan [2] illustrated this with examples of the introduction of a computerised records system within one health care institution. She argued that the focus of the project team on a system which provided an automated patient history, rather than providing tools which the physicians thought would facilitate their work caused "information overload and standardization, clerical task load increase, work organisation rigidity and expert autonomy negation" [2, p 44]. The same system was found by nurses to be "highly normative as it tried to impose a new reality, producing uniformity and predictability in thought and behaviour patterns in nurses". These could be summarised as "a failure to appreciate the nature of decision problems and a mismatch in motivations between developers & users" [26].

In 1997 Myers and Young reworked Broadbent et al's [27] application of Habermas' model of societal development to examine the work of the information services unit within a mental healthcare provider in New Zealand, which encountered opposition from clinical staff. Clinicians objected to the "hidden agenda" of time based costing which underpinned managerial attempts to introduce a new recording and communication system. The resistance appeared to be in reaction to a perception that computers were being used to "control professional people" [28].

The systems need to provide user interfaces and response times which are acceptable within a clinical environment where the pace of change in patients' conditions and the interactions with health professionals may be rapid. The effects of the interaction between health professionals and patients in face to face settings have been studied however the social effects of interaction at a distance, mediated by technology in the growing fields of telemedicine and telecare applications are still unclear. The "human factors" need to be taken into account at all stages of the design, implementation and use phases of informatics implementations and need to be included in the models which aim to explain them.

Conclusion

The factors influencing acceptance or adoption of a technology and its subsequent diffusion will be influenced by the application itself, but also by a variety of other factors which will form individuals' attitudes towards the application. It is the individuals within organisations who are the ultimate users and consumers of the technology, [29] and the true benefits and impacts of IT are contingent on the extent to which individual users appropriate and use IT in their ongoing work activities that, in turn, contribute to organisational productivity [30].

Adoption and diffusion models offer us some insights into the myriad of factors which may impinge on the success or failure of informatics innovation; however they also have their limitations. Often they focus on policy drivers and barriers to innovation and do not fully take into account the complex organisational and personal factors which impinge of development and adoption.

Further empirical work to test and refine the existing models is needed, but the more effective approach may be to simplify the models, focusing on the most important or significant factors in the hope of producing something which can be used to predict and support informatics implementations.

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Chapter 10.

Quality, Safety and Value

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The Information Quality Triangle: A methodology to assess Clinical Information quality

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Abstract

Building qualitative clinical decision support or monitoring based on information stored in clinical information (or EHR) systems cannot be done without assessing and controlling information quality. Numerous works have introduced methods and measures to qualify and enhance data, information models and terminologies quality. This paper introduces an approach based on an Information Quality Triangle that aims at providing a generic framework to help in characterizing quality measures and methods in the context of the integration of EHR data in a clinical datawarehouse. We have successfully experimented the proposed approach at the HEGP hospital in France, as part of the DebugIT EU FP7 project.

Keywords:

Data quality, Medical informatics computing, Hospital information systems, Total quality management, Information storage and retrieval, Database management systems

Introduction

Clinical Information Systems (CIS) are built to record operational data about the patient, to record her/his pathway through the health institute and everything that relates to her/his care. CIS includes Electronic Healthcare Records (EHR) data and other sources, such as laboratory systems data. Besides, Clinical Data Warehouses (CDW) are built to aggregate a great amount of data reliable for healthcare decision-making: decision support, monitoring, alert or data mining [1]. Today, building CDWs [2] is the right opportunity for health institutions to enhance the quality of their information systems.

CIS and CDW are different entities since the requirements of clinicians do not necessarily meet the ones of research physicians or organizations. In many health institutes, one issue is to feed automatically CDWs with heterogeneous data from CIS. Since CIS are not built to specifically structure and store clean aggregated data, quality is often not accurate enough in CDWs, which sometimes lead to wrong decisions [3].

We believe it is necessary to assess data quality within the CIS prior to its storage and use within a CDW. Therefore we propose a methodology to assess data quality of a CIS, then we introduce a framework and tools to control and enhance the information quality based on three dimensions: *concepts*, *terms* and *objects*.

This work takes part in the European DebugIT[1] project [4,5] which goal is to build a technical and semantic information technology platform able to share heterogeneous clinical data sets from different hospitals for the monitoring and the control of infectious diseases and antimicrobial resistances in Europe. The Georges Pompidou European Hospital in Paris (HEGP) is one of DebugIT's partners; a dedicated CDW named Transmed has been developed locally for this project. This CDW is fed with medical data including antibiotherapy and antibiogram data, recorded over the last decade within the HEGP EHR system.

In the following, we present an Information Quality Model and a methodology that we experimented to improve information quality in the context of importing HEGP operational EHR data into Transmed. Results are then presented and discussed.

Background

Data volumes have been growing massively along with inconsistencies and erroneous data. Data quality started to be studied in the late 60's by statisticians [6]. Then, at the beginning of the 90's, computer scientists considered the issue of defining, measuring and improving data quality. ISO defines quality as "the totality of features and characteristics of an entity that bears on its ability to satisfy stated and implied needs" (ISO 8402-1986, Quality Vocabulary). Wang [7] proposes to define a piece of data as of good quality if it matches the intended use in its context. However, that concept being broad enough to be an axiom, it is not narrow enough to be able to characterize precisely data quality. Redman [7] has proposed to specify that axiom into four dimensions: *accuracy*, *perfection*, *freshness*

[1] Detecting and Eliminating Bacteria UsinG Information Technology

and *uniformity*. Other quality factors were introduced in order to assess data quality criteria depending on semantic [8, 9], process [9] or goal [10, 9]. Wang [7] also introduces a Total Data Quality Management (TDQM) methodology based on Deming wheel[2] that defines a quality improvement process. Likewise, the data warehouse communities have introduced various methods to measure, enhance and monitor the quality of data in CDWs [11, 12].

Besides the evaluation of the quality of data, many frameworks were introduced for evaluating information models quality [13, 14]. However, it remains difficult to assess quality of information models only with metrics [15]. Moody *and al.* proposed eight quality factors as metrics candidates. They also introduced subjective measurements of the information model quality by grading from 0 to 5 each of the 7 factors known as: *correctness, implementability, completeness, understandability, integration, flexibility and simplicity.*

In healthcare, data quality works have also been studied. A recognized need is growing for a secondary use of qualitative electronic health records for research (epidemiologic, public health). Nevertheless, it remains challenging to rely on good quality data [16]. Causes of insufficient data quality in medical records have been classified between systematic or random errors types [17] at different stages of the recording process. Kerr [18] introduced a framework to measure data quality based on the CIHI[3] recommendations. It led to setup a framework composed of 69 quality criteria grouped into 24 quality characteristics that groups into 6 quality dimensions: *accuracy*, *timeliness*, *comparability*, *usability*, *relevance* and *privacy & security*. These works propose methods and measures to assess data quality, yet we believe they have been essentially focused on data accuracy.

Beside this, the healthcare domain has built over years reference knowledge sources that could help in data quality assessment, namely, the standardized information models and domain terminologies or ontologies [19]. Reference terminologies have gained general acceptance over the research community [20], as they are key resources to interoperability and decision support. In addition to reference terminologies, "interface terminologies" are defined as "systematic collections of clinically oriented phrases aggregated to support clinician's entry of patient information in computer programs". Methods to compare the quality of interface and reference terminologies were introduced in [21].

Materials and Methods

Information Quality model

The clinical information contained within the CIS can be defined through 3 main dimensions: 1) data, or instances of real world objects, are physically stored information into CIS data stores, 2) information models are representations of concepts or relationships (among other properties) used to organize and structure information and 3) terminologies store referential data in various forms: terminology (list of terms), thesaurus (index and synonyms), classification (with generic relationships) or vocabulary (with definitions). We propose to classify the quality measures proposed in the literature, given those three dimensions defined as *objects*, *concepts*, and *terms*.

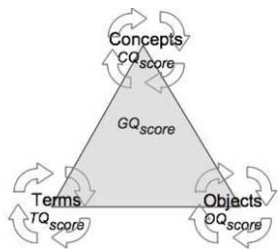

Figure 1- The Information Quality Triangle

The three information quality dimensions are the vertexes of our Information Quality Triangle (IQT) depicted in figure 1. For each vertex, there are methods and scores to measure information quality. Each score is then aggregated into a global score that would be defined as an information source score prior to data integration.

Material

The main data source in our experiment is the EHR system of HEGP. It stores 10 years of EHR data in various domains. We have focused our work on data domains that concerns infectious diseases, and particularly the laboratory results related to antibiotic resistance tests and antibiotic prescriptions.

The EHR dataset is composed of a volume of 1 200 000 patients, 1 600 000 admissions, 3 200 000 antibiograms, and 24 000 drugs/substances.

Most of the *object* quality criteria are measured using Talend© Open Studio[4] open source software as well as developed stored procedures in SQL[5].

Our domain is modelized with the help of the 6 following HL7 information models of the January 2009 version of the HL7 ballot:

- A_Encounter universal (COCT_RM010000UV01),
- Result Event (POLB_RM004000UV01),
- Composite Order (POOR_RM200999UV),
- Common Observation (POOB_RM410000UV),
- Adverse Reaction (REPC_RM000022UV),
- BillableClinicalService Encounter (COCT_RM290004UV06).

This covers the conceptual scope of the DebugIT project. The information model includes 61 classes and 262 properties.

[2] Plan-Do-Act-Check iterative problem solving process
[3] Canadian Institute for Health Information: a pioneer on health care information quality domain

[4] http://www.talend.com/products-data-quality/talend-open-profiler.php
[5] Structured Query Language

To standardize the EHR vocabulary, we have first focused on two consensual resources in use within DebugIT: 1) ATC: The WHO drugs and substances international classification and 2) NEWT: organisms taxonomy database.

Perl routines have been developed at the University Hospitals of Geneva (HUG) to map free text terms to terminologies' entities. The drug names mapping is performed in several steps, until a successful candidate is found, consisting mainly in removing letters (the French version of the drug names often adds a final "e") or part of the term. For instance, the term *ac.fus* is not found by exact matching. When searching only for the second part (*fus*), the system returns several possible answers, but only one is an antibiotic: *fusidic acid*. The bacteria names mapping follows a similar approach. Moreover, when no candidate is found for a species, we attribute the parent taxon, the gender, to this term.

Quality method

We applied the TDQM 4 steps approach to score quality of each vertex [7]. They can be grouped into two functions, assessment (*audit* and *qualification*) on the one hand and enhancement (*standardization* and *surveillance*) on the other hand.

The *audit* consists in scoring the source for each vertex using defined criteria. Table 1 reports the criteria used at each vertex to build the overall score of the IQT. Each object quality score is composed of various criteria scores measured using computerized algorithms. Concept quality score is based on the subjective rating of information model quality proposed in [16]. Terminology score measurement is a statistical distance between the reference and the interface terminologies.

Table 1 – Criteria and Methods for auditing the data at each vertex

Vertex	Criteria	Method
Concept	Domain	Subjective Rating of Data Model Quality
Objects	Completeness	Total number of records filled compared to total number of records
Objects	Accuracy	Data format
Objects	Uniqueness	An algorithm that searches for uniqueness
Objects	Consistency	An algorithm to check consistency, for example check if Start Date of Prescription < End Date
Terms	Consistency	Distance to reference terminologies

The criteria are measured according to a reference for each of those dimensions. From the *object* dimension level, the reference is a set of rules (for example the date of death is after the date of birth). From the *concept* dimension, we state as a reference the HL7 version 3 information models specialized from the reference information model (RIM)[6], which proposes a conceptual representation for electronic health records. As for the *terms*, we use as reference the NEWT and WHO-ATC standards in order to normalize the terms of our domain of study.

The *qualifying* process aims at scoring the source information based on the IQT and the measures of the *audit* phase. Criteria scores are precise and accurate, though the qualifying of a source of information can be quite subjective. We use grades to score each IQT vertex of our information source, varying from A to D. For each quality domain, we made the average percentage of every criterion and split them every 25% to the corresponding grade. The meaning of the global scores can be qualified as following:

- A: The information quality is excellent. The information source carries enough semantics and organization to be queried without needs to be adapted.
- B: The information quality is good though it requires some work to improve one of the vertexes of the IQT.
- C: The information source quality is narrow. It could be usable only after some consequent work to improve information quality.
- D: The information quality of the source is low. The time and/or effort to improve it would be too high to consider this information source as a potential source for a CDW project.

Then, we enhance the quality within the *standardization* phase and we make sure the quality is controlled over time in the *surveillance* phase that helps to ensure the information is controlled over time within the destination CDW.

Results

For each step of the methodology, we present the results of our experimentation for the three vertexes of IQT.

Audit

For the *objects*, Table 2 shows result samples for three criteria on a limited number of objects.

Table 2 – Object Criteria Scores

Object	Criterion	Score	Comments
Discharge Date	Completeness	69,9%	Helps calculating the length of stay
DrugUCD	Consistency	75,6%	The UCD is a French classification code
Patient ID	Uniqueness	100%	The patient ID has unique values

As for the *terms*, Table 3 shows a sample result obtained against NEWT taxonomy for the Bacteria names, and against a local referential for sample location and type built by a medi-

[6] The RIM is a pictorial representation of the HL7 clinical data domains. See (http://www.hl7.org/implement/standards/rim.cfm)

cal expert. The measured distance is a percentage of correct terms within the EHR system compared to the standardized terminology.

Table 3 – Terminology Distance Scores

Terminology (Standard Referential)	Distance to Standard Referential
Bacteria Names (NEWT)	85,53%
Sample Location (local)	93,11%
Sample Type (local)	36,77%

For the *concepts*, we obtained the scores shown on Figure 2 with the help of a domain expert and a data modeler. Each axis represents the empirical evaluation of the source information model rating from 1 (poor) to 5 (excellent). Many examples illustrate the weaknesses of the EHR information model compared to HL7 version information models. In the field of lab results, the HL7 version 3 model "Result Event" (POLB_RM004000UV01) proposes a specific class to manage clusters of tests to be made on a given derived specimen (aliquote), which allows better management of the microbiological lab test results compared to the implementation done in the HEGP CIS. In the field of medication order, from a vocabulary perspective, a table named C_SPECIALITE records in fact drug prescriptions. A strength of the EHR information model is that it integrates a repository of shared data elements that are linked to national and local referential terminologies. This helps for integrating the EHR into the CIS.

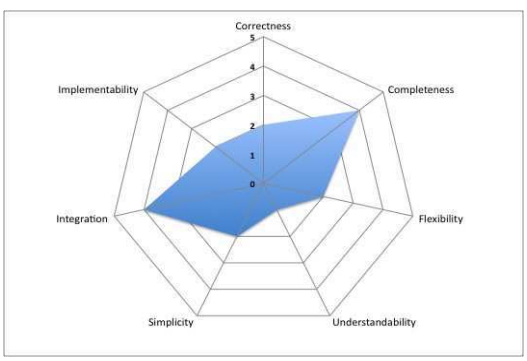

Figure 2- The EHR IM Quality subjective rating

Qualifying

The overall Information Quality Triangle of our information source for the restricted domain chosen is shown in Table 4.

This qualification phase can be considered as the validation method to our IQT. Each score is calculated given the scores found at each vertex. For example, the average of scores of the *concept* vertex being 2.42, the score is C. The *global* score of our source EHR system reflects its overall quality in the context of our evaluation.

Table 4 – Source EHR system scores

Vertex	Score
Object	C
Term	B
Concept	C
Global	**C**

Standardization

The standardization process was made during the loading of our clinical data warehouse for research. It was made at two different levels. At a first stage, we built an information quality firewall between the EHR and the CDW. Using the open source software Talend© Open Studio, we setup procedures to standardize the objects using a CTS[7] based information model. We built ETL scripts to correct objects based on a dictionary of 'dirty' and preferred terms stored into the CTS information model. At a second stage, we implemented two PERL scripts in order to map the local terminology preferred term with the standardized term. Up to 76% of the drug names present in the CDW were normalized successfully. Concerning pathogen normalization using NEWT, 99% of the pathogen names identified by an antibiogram were mapped to a NEWT term, which was manually validated.

The CDW physical information model was standardized using HL7 version 3 information models. The OMDF[8] platform was used to specialize the HL7-based conceptual models and generate the MySQL scripts in order to implement the CDW HL7-based information model corresponding to our domain.

Monitoring

We setup the necessary scripts to monitor the future load of data using Talend© Open Studio. We also setup the necessary alert routines that notifies of any unknown new concept loaded into the CDW in order to keep controlled clinical data warehouse information.

Discussion and Conclusion

The contribution of this work is three fold. First, this work enabled the HEGP hospital to provide a first attempt of measuring the distance between standardized information models and reference terminologies against its CIS after 10 years of production (it could also result in enhancing the information quality of their CIS). Secondly, it enhanced the quality of information within the CDW, which allowed building pertinent and coherent monitoring trends illustrating antibiotic resistance profiles over 10 years of data. Finally, it enabled the HEGP hospital to interoperate with other health institutes within the DebugIT project. Controlled vocabularies are a necessity to share data across Europe.

[7] Common Terminology Services: HL7 specifications for managing terminologies within clinical information systems
[8] Open Medical Development Framework: https://gforge.spim.jussieu.fr/projects/omdf-hl7/

We have introduced another method based on the literature work to assess information quality of electronic health records that takes into account a 'formal' framework to measure information quality, given the health care domain specificities: the IQT. We think this methodology abstract enough to be generalized. For instance, the use of an ontology could be preferred to the use of an information model to conceptualize a domain. In that case the conceptual vertex of the triangle could be an ontology.

We have successfully experimented this methodology in the context of the European project DebugIT. Not all of the experiment is automatized since it still requires the help of medical experts, but it does not invalidate the proposed methodology. The translational clinical data warehouse we built contains controlled objects, terminologies and concepts. We believe it is a first step to interoperability that cannot be avoided in the healthcare domain. It would be interesting to validate our approach on other EHR systems in order to better evaluate it. We also would like to investigate the use of our quality scores within a clinical decision support system.

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Understanding Effective Clinical Communication in Medical Errors

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Abstract

Clinical Communication failures are considered the leading cause of medical errors [1]. Minimizing communication problems among clinical team members could directly reduce medical errors and hence, increase patient safety and improve health care quality. Our main focus is, through knowledge representation approach, to develop an understanding of communication problems applied to health care settings. This will serve as the foundation to our long term goal of building an ontology-driven educational tool that will be used to educate clinicians about miscommunication issues and as a means to improve it.

Keywords:

Clinical communication, Knowledge representation, Model, Human-computer interaction, Medical errors.

Introduction

Medical Errors in health care are estimated to cost more than $5 million per year in a large teaching hospital [1]. The causes behind those errors are various; however, clinical communication is listed as the main cause of medical mishaps [2-5]. According to a report by the Institute of Medicine (IOM) [6], preventable health care-related injuries cost the economy from $17 to $29 billion annually, of which half are health care costs. On the societal level, the massive cost of medical errors affects the health care industry as well as the U.S. economy at large. In 2006, the IOM stated that at least 1.5 million preventable adverse drug events occur annually in the United States as a result of medication errors [7]. This remarkably high cost of injuries has a significant impact on individual's well being as well as the society. By understanding the causes of medical errors and efficiently evaluating possible solutions, preventable medical errors can be minimized and hence, improve patient safety and reduce health care costs.

In this research, we define communication as the exchange of ideas, messages or knowledge between two or more entities through oral and written forms, or signals. In health care, professionals carry dialogues using traceable mediums such as Electronic Medical Record (EMR) systems, paper chart or emails; and untraceable channels like face-to-face discussions. Communication problems arise when the instructions are incomplete or incoherent and therefore, incorrect tasks are performed which lead to medical errors. However, communication failures, whether traceable or untraceable, are hard to catch.

In 2003, a research was conducted to observe communication patterns between physicians, nurses and pharmacists, also known as clinical-to-clinical communication. Results suggested that through the use of technology and EMR to enhance communication better communication can be reached [8]. The use of technology to reduce medical errors is necessary however, the need to understand how and why medical errors occur as a result of miscommunication is essential. In another study carried out in Denver, some of the causes behind miscommunication were attributed to the complexity of health care structure and differences in education and training among health professionals [9]. Those results provide the necessary background for diagnosing the causes behind miscommunication between health professionals.

The role of communication in healthcare

The clinical communication space, which resembles total information transactions clinician time, accounts for the major part of the information flow in health care [10]. According to the Joint Commission on Accreditation of Healthcare Organizations, problems related to communication represent 60% of sentinel events reported [11].

A study carried in Australia shows that in a 16,000 in-hospital deaths, communication errors were found to be the leading cause, twice as frequent as errors due to clinical malpractice [4]. Results show that poor communication can lead to negative outcomes such as misunderstandings and medical errors and thus, poor patient safety [12]. Therefore, the need for better communication skills among health professionals is a must.

Clinical Information Systems

Computer-based systems, such as Clinical Decision Support Systems (CDSS) and EMRs, have facilitated evidence-based and patient care by reducing serious medication errors [13] and enhancing the delivery of preventive care services[14] [15]. However, about 34% of computer-based systems have shown insignificant progress in clinical practice [15]. One of

the major reasons for this inefficiency is, as the use of Health Information Systems (HIS) and Computer Information Systems (CIS) increase, new medical errors are introduced. The types of errors produced by both systems differ for each type; HIS mainly keeps track of administrative issues and CIS concentrates on patient-related data such EMRs. However, many errors from both systems can be related to miscommunication. Therefore, the communication model proposed addresses communication limitations in both HIS and CIS.

A previous study shows that there are two categories of errors that occur during human-computer interactions. The first is errors submitting and retrieving information to and from an information system and secondly, errors in the communication and coordination processes that (CIS) is supposed to support [16]. In order to improve clinical communication, human-computer interaction has to be considered as a major component of the communication process. We believe that CIS should facilitate communication between clinicians, ensure correct clinical data flow and most importantly, improve health care services to the maximum effect.

Methods

To our knowledge, there is no communication model that represents clinical communication. This research aims at developing a communication model that fits health care. Initially, we analyzed general communication models through identifying the strengths, limitations, overall applicability in health care for each model. Then, using literature reviews and domain experts, we identified medical error cases to indentify miscommunication factors. Table 1 shows a sample of selected cases, the scenario, and communication factors we identified. The table distinguishes between general communication models and the proposed model by displaying the coverage level of each model. Through the previous steps, we developed a communication model that can better represent communication in clinical settings.

A need for a communication model

As the largest industry in the United States in 2006, the health care industry provides about 14 million jobs [17]. This shows the diversity in education, training and culture among employees. Therefore, a communication model that articulately demonstrates the communication framework among clinicians is essential. We believe that a communication model is a significant step towards improving the concept of communication in health care. By demonstrating a communication model, there will be more opportunities to raise questions and to encourage more research in this field. The model will show the complexity of the process and hence, display the order and coherence of procedures. Moreover, a practical model will open more research doors to new discoveries and better approaches about enhancing clinical communication which is our ultimate goal.

We expect the model to go through cycles of modifications and refinements as more cases are reported. However, our research does not stop at the model; in fact the model is just the beginning point in a roadmap to increase patient safety. Using the model, we plan to build ontology of possible clinical miscommunication causes which would help healthcare professionals understand medical incidents and increase their awareness of effective communication. The cases collected enable classification of communication factors at a lower level taxonomy. The communication model classifies the communication barriers and hence, provides higher level categorization of the communication model. Both, cases studied and the proposed model will provide a vision towards building a communication ontology which is exhaustive and complete.

Proposed Model

To build the model, we used previously reported error cases, where miscommunication is the main cause behind the error. Through studying the relevant literature and analyzing reported cases, we believe that to build an inclusive model there needs to be two main subcomponents to clinical communication; Human-Human and Human-Computer communication.

We define human-human interaction in health care in the following scenario: a communicator tries to send a message through a given means of communication, while delivering the message some noise is usually introduced. The noise can occur due to external and/or internal factors.

External factors include interruption during communication and incoherent messages. Internal factors can be multitasking or assumptions made by a recipient. Those noise factors usually introduce distortion of some sort in the true meaning of the message and hence, it affects the overall efficiency of the communication process. The message is received by recipient but, the message is usually different from what was originally sent by communicator. Therefore we introduce a distortion variable 'Y' to the message; this variable can hold negative or positive values. A negative value means the message received is incomplete. A positive value means the message received had either more or different details than what was intended. Upon receiving the message, the recipient sends a feedback to the sender to ensure that the meaning received was the meaning intended by the sender. In some cases the message sent is the same message received however, miscommunication can still occur due to factors such as differences in training, cognitive factors. However, the feedback process is also viable to noise introduction and thus, more distortion could be added to the process.

As for human-computer interaction, the user submits a request through the interface; requests vary from entering data to a request to retrieve information. Upon receiving user's query, the computer system takes legitimate action to perform the requested set of actions. Once data has been extracted and formatted, the system displays the information to the user in a meaningful manner through the Graphical User Interface (GUI). Medical errors occur due to miscommunication between the user and the information system. Factors causing communication breakdown include GUI issues, user skills to enter or retrieve the right information, knowledge represented by the system and how it is interpreted by user, and miscellaneous factors represent access problems and ways to work around error messages.

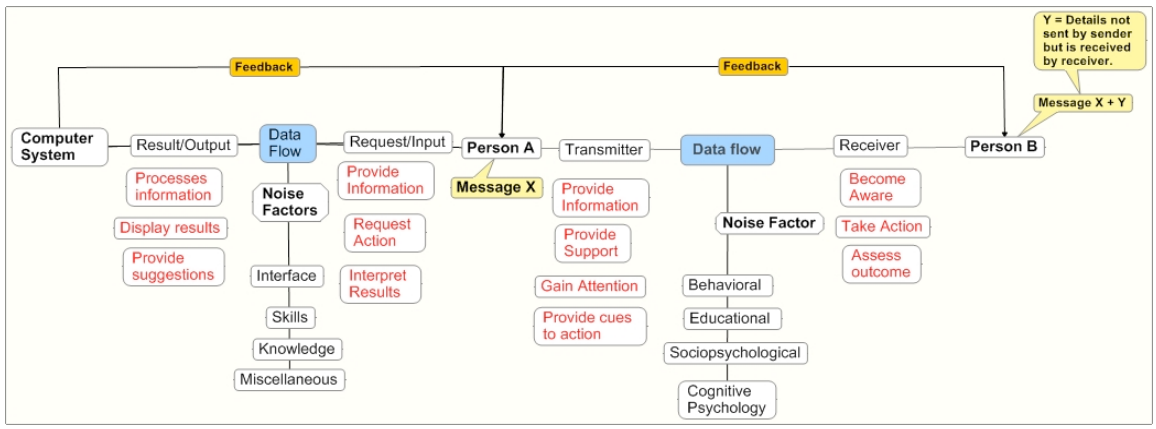

Figure 1- Proposed Communication Model with an emphasis on human-human and human-computer interaction

Comparing Communication Models

Table 1 shows 5 medical error cases we chose from the pool of cases. The cases were chosen carefully to represent the wide range of variability in miscommunication cases and they demonstrate our initiative to validate the model we proposed. We compared the proposed communication model against major communication models in other fields. Among those models were Shannon's, Schramm's, Riley's [18], Berlo's, Ecological, and Coorientation model [19-21]. The table displays a summary of each incident, factors leading to communication breakdown, factors covered by general communication models, and factors covered by the proposed model. The specific aim of this study is to provide a communication model that expresses the strengths and weakness of the communication process between clinicians.

Results

General communication models cover major communication aspects such as feedback, message medium and noise. However, the 5 cases show that in healthcare there are specific characteristics to communication. There are factors that are not expressed in general models. The model proposed, besides including more factors, has categories that are inclusive and well displayed which will facilitate future research.

Based on communication literature reviews, fragmented keywords were identified as communication factors for each case shown in the third column of the table 1. Then, factors from literature review were mapped with the current communication model to identify which factors, if any, are covered by which model, as shown in column 4. In some cases, some models do not have any overlaps with factors from the review. Another mapping was conducted between the literature factors and the model proposed, shown in last column. The proposed model includes taxonomy of the communication problem and hence, includes a higher level classification of the factors. For example, in case 1 the factor of lack of experience is mapped in the proposed model under educational factors. The proposed model has an advantage over current communication models in Human-Computer communication. The new model expresses Human-Computer interaction in more details than other models. Through real cases, the factors suggested have played an important role in communication between clinicians and computer systems.

Table 1 demonstrates the challenge in applying general communication model in health care. Through the five cases we studied in this paper, it can be concluded that other models can represent some of the problems but not all. The same cases show the ability of our proposed model to represent communication scenarios in health care. Therefore, we believe the results from this study support our model as an initial representative model to health care communication that requires more work to maximize cases covered by the model.

Discussion and Future Work

One of the obstacles to understanding clinical miscommunication is the scarcity of data. The absence of a mandatory reporting system has resulted in many medical errors occurring and not being reported. With the exception of Veterans Health Administration [27] and the Department of Defense, there are no nationwide reporting systems that mandate error reporting. Some of the reasons why such a system has not been implemented yet are the lack of anonymity, lack of knowledge on what to report, fear of blame, and most importantly lawsuits [28]. To our knowledge, very little research has been conducted to minimize clinical miscommunication. Researchers have explored the causes of miscommunication and ways to improve it [8, 9, 28-30]. We believe this research provides a new approach for physicians, nurses and other clinicians to improve communication within a single team.

Table 1- Medical Error Cases Analysis Guided by the Proposed Model

Case	Story [Reference]	Factors in communication literature	Factors in current Models	Factors in proposed Model
1	• Surgeon asks the anesthesiologist to give 10,000 Heparin. • The anesthesiologist hears the dose to be 2,000. Consequently, the Activated Clotting Time was low. The surgeon finds out the wrong dose of Heparin was given. The correct dose is given to the patient and a full recovery was achieved. [22]	• Assumptions • Ask Questions • Lack of Experience • Feedback	• Feedback (Shannon, Coorientation) • Experience (Schramm)	• Behavioral • Educational • Feedback
2	• Benny, 14-month old kid was admitted to the Care Unit. The nurse documents a verbal order as 0.7mg of Digoxin. • According to Benny's weight, the appropriate dose is 0.07mg. • When Digoxin was administered, Benny went into Cardiac Arrest and was announced dead. [23]	• Clinical Background • Training • Experience • Knowledge • Memory	• Culture (Berlo) • Social system (Ecological, Berlo, Riley) • Experience (Schramm)	• Educational • Cognitive Psychology
3	• A 47-year-old man was admitted and diagnosed with Pneumocystis jiroveci pneumonia (PCP). Two Biopsies were performed. • The intern finds a third biopsy in the hospital's EMR. The intern questioned her memory. • The team realized the third biopsy had been accidentally entered into this patient's record. • Dermatopathology department physicians and staff didn't have access to the hospital's EMR. [24]	• Human memory • Error Entering information to the system • Incorrect assumptions • Access to the system	• Experience (Schramm) • Feedback (Shannon, Coorientation)	• Behavioral • Cognitive Psychology • System skills • System knowledge • Miscellaneous
4	• An 85-year-old woman was admitted with a reported fall. • The surgery team decided that the patient is a candidate for nonsurgical treatment and noted in the EMR that the patient is able to weight-bear without pain. • The intern read the surgeon's note and found these comments ambulating odd. The team had evaluated the wrong patient. [25]	• Clinicians Feedback • EMR feedback • Memory	• Feedback (Shannon, Coorientation)	• Behavioral • Educational • System knowledge • Miscellaneous
5	• A 75-year-old woman admitted to the emergency department (ED) with chest pain. The patient could not recall of some of her medications. The physician printed the medication list from the EMR. • The patient developed a heart rate under 40. • On reviewing the patient's outpatient, the physician found a note stating the plan to discontinue some medications. [26]	• System design • System Interface • Usability skills	• Missing human-computer interaction	• System interface • System skills • System knowledge

The current communication model needs to be further verified and tested, through the analysis of more cases, in order to develop a more inclusive model. Case acquisition will come from literature databases such as Ovid database and Agency for Healthcare Research and Quality (AHRQ). Also, live observational study at the Critical Care Unit at the University of Missouri Hospital has been planned in an attempt to further identify the patterns and trends in clinical communication. The choice of Critical Care Unit is based on the fact that critically ill patients receive more services in short time spans which can be more error prone. Furthermore, critical care patients are prescribed twice as many medications as patients outside of the ICU which mean that the rate of preventable and potential adverse drug events is twice as high in ICUs and hence, higher chances of miscommunication occur in ICUs [3].

This ongoing project aims to utilize the data collected with domain expertise to build fully developed and exhaustive clinical communication ontology, which is in consistency with the early work [32]. Our effort would help healthcare professionals understand medical incidents and increase their awareness of effective communication. This ontology can serve as a classification methodology to communication problems in HIS. Also, as this ontology can be integrated with knowledge base systems to enhance clinical decision support systems. The long term plan is to utilize the built ontology to build an educational tool, that provides clinicians with the necessary information they need about clinical communication, its factors, and ways to improve it.

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Combining Relevance Assignment with Quality of the Evidence to Support Guideline Development

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Abstract

Clinical practice guidelines are used to disseminate best practice to clinicians. Successful guidelines depend on literature that is both relevant to the questions posed and based on high quality research in accordance with evidence-based medicine. Meeting these standards requires extensive manual review. We describe a system that combines symbolic semantic processing with a statistical method for selecting both relevant and high quality studies. We focused on a cardiovascular risk factor guideline, and the overall performance of the system was 56% recall, 91% precision ($F_{0.5}$-score 0.81). If quality of the evidence is not taken into account, performance drops to 62% recall, 79% precision ($F_{0.5}$-score 0.75). We suggest that this system can potentially improve the efficiency of the literature review process in guideline development.

Keywords:

Natural language processing, Machine learning, Clinical guidelines

Introduction

Clinical practice guidelines are produced by medical professional societies, governmental agencies, and the biomedical research community to assist clinicians in providing quality care [1- 3]. As part of the guideline creation process, queries are issued to MEDLINE® to retrieve citations relevant to critical questions supporting the guideline. Cited studies must be of high quality (typically, randomized clinical trials and systematic reviews) according to the evidence-based medicine (EBM) paradigm [4]. Currently, domain experts find such studies by reading large numbers of citations for each question posed, a process that is both resource- and time-intensive.

To reduce the amount of manual effort expended during guideline creation, we recently proposed an automatic method based on SemRep [5, 6] semantic processing for discriminating between relevant and nonrelevant MEDLINE citations for critical questions [7]. Although we suggest that the system can help streamline guideline development, it is unable to identify high quality clinical evidence. Others, however, have developed machine learning techniques for automatically recognizing such evidence [8- 10]. In this paper, we describe a system that combines our symbolic processing [7] with a statistical method [10] for selecting studies that are both relevant to questions and of high scientific quality. Retrieved citations are ranked: those which are both relevant and of high quality are put in the highest rank, while those which are nonrelevant and not of high quality are in the lowest. We tested the system on a class of questions for a guideline on cardiovascular risk reduction being produced by the National Heart Lung and Blood Institute at the National Institutes of Health.

Background

SemRep

The SemRep natural language processing system extracts semantic predications from biomedical text using linguistic analysis and domain knowledge in the Unified Medical Language System® (UMLS)® [11]. Processing begins with a partial syntactic analysis based on the SPECIALIST Lexicon [12] and MedPost part-of-speech tagger [13]. Simple noun phrases in this structure are then mapped to Metathesaurus concepts by MetaMap [14]. In final processing, underspecified dependency rules identify some of these augmented noun phrases as arguments of semantic predications asserted in the sentence. Such predications must be sanctioned by a relationship in the UMLS Semantic Network.

For example, from sentence (1), SemRep extracts the predications in (2), in which the arguments ("sibutramine," "Obesity," and "Patients") are concepts from the Metathesaurus, and the relations TREATS and PROCESS_OF are from the Semantic Network.

(1) Second phase of a double-blind study clinical trial on sibutramine for the treatment of patients suffering essential obesity

(2) sibutramine TREATS Obesity
Obesity PROCESS_OF Patients

Predications such as these are used to identify relevant citations for guideline questions.

Relevance

Analysis demonstrated that the distribution of predications representing the semantic components of questions is different in relevant and nonrelevant citations. We therefore wrote rules that match questions to predications [7]. For example, pertinent semantic components of questions in the cardiovascular guideline are risk factor, disorder, population, and action, and the question in (3) has the rules in (4) associated with it.

(3) What is the evidence that diabetes mellitus can be decreased in children?

(4) <Diabetes> PROCESS_OF <Children>
<Diabetes> NOT PROCESS_OF <Adults>
X TREATS <Diabetes>

These rules match SemRep semantic predications in the following way: "X" matches any argument, while items delimited by brackets in the rules represent variables to be matched to a specified domain of Metathesaurus concepts serving as arguments of predications. For example, "<Diabetes>" matches concepts such as "Diabetes Mellitus," "Diabetes Mellitus, Insulin-Dependent," and "Diabetes Mellitus, Non-Insulin-Dependent," while "<Children>" matches "Child," "Youth," "Boys," and "Girls."

If predications matching the rules in (4) are found in the SemRep output for a retrieved citation, it is relevant to the question; otherwise, it is nonrelevant. It is important to note that this processing does not answer the question (e.g. [15-19]), but merely identifies citations which can be used to determine an answer. The word *evidence* in the question implies that only high-quality evidence is sought.

Quality of the Evidence

The evidence-based medicine paradigm categorizes types of clinical evidence and ranks them according to their strength (quality) to avoid research bias. The Oxford Centre for Evidence-Based Medicine [20] proposed an influential categorization which states that the most rigorous scientific studies are systematic reviews and randomized clinical trials. The second component of our combined system identifies such studies, using machine-learning techniques trained on MEDLINE citations annotated by hand for high-quality evidence [21, 22]. An array of features, including text words, semantic features, and MEDLINE metadata are used by several classifiers augmented with boosting and ensemble techniques to mark each document encountered as either reporting high quality research or not. The classifier achieved an F_1 score of nearly 0.70 in making this determination in test documents [10].

Materials and Methods

Our technique for combining symbolic relevance processing with the statistical method for identifying high-quality research is tied to a particular guideline question. A PubMed query is issued to retrieve citations for that question. Relevance and quality of evidence processing are then applied independently to the retrieved citations and the results are combined so that each citation has a score both for relevance (1 or 0) and for quality of evidence (also 1 or 0). Citations are ranked into four disjoint groups based on these scores:

A. Relevant to the question and high quality of evidence (1,1)
B. Relevant to the question but not high quality of evidence (1,0)
C. Nonrelevant to the question but high quality of evidence (0,1)
D. Nonrelevant to the question and not high quality of evidence (0,0)

Citations in A have the highest probability of being true positives and those in D the lowest. We hypothesized that we could exploit the A group to retain only systematic reviews and randomized clinical trials in the list of relevant citations recommended to the guideline developers. To test this hypothesis we first calculated recall and precision on the A and B group combined and compared these metrics to those computed on the A group alone.

In constructing a reference standard for evaluation, we selected four questions from the guideline on cardiovascular disease risk reduction and issued a PubMed query for each. All queries were limited in PubMed to: Only items with abstracts, Humans, Meta-Analysis, Randomized Controlled Trial, and English. A further limit was imposed appropriate to the target population of the question. Questions, queries, and additional limits were as follows:

Question 1: What is the evidence for the effect of sibutramine on weight loss and maintenance in adults?

Query: sibutramine

Additional limits: All Adult: 19+ years

Retrieved citations annotated: 91

Question 2: What is the evidence that obesity can be decreased in children?

Query: Obesity/therapy[majr]

Additional limits: All Child: 0-18 years

Retrieved citations annotated: 100

Question 3: What is the evidence that hyperlipidemia can be decreased in children?

Query: Hyperlipidemia/therapy[majr]

Additional limits: All Child: 0-18 years

Retrieved citations annotated: 88

Question 4: What is the evidence that diabetes mellitus can be decreased in children?

Query: Diabetes Mellitus/therapy[majr]

Additional limits: All Child: 0-18 years

Retrieved citations annotated: 100

Retrieved citations were then annotated by the first and second authors as being relevant (or not) and high quality (or not). Limiting their analysis to titles and abstracts, relevant citations were those considered to be informative in answering the question. System output for Group A and for combined A and B were compared to the reference standard separately, and recall, precision, and F_1-score were calculated. We also calculated a weighted $F_{0.5}$-score (1.25*P*R)/(0.25*P +R), which calculates precision twice as much as recall, since guideline developers value precision more highly than recall.

Results

For evaluation, a citation had to be marked as both relevant and high quality in order to be considered a true positive, and, of the 379 total citations processed, 138 were so marked in the reference standard. We first consider overall results for all questions for Groups A and B combined. These two groups include all citations returned as relevant by the system, and are equivalent to not exploiting quality of the evidence processing. The system missed 52 (out of 138) of these, yielding recall of 62%. Of the 108 citations returned, 22 were false positives (either nonrelevant or not high quality), resulting in precision of 79%. The F_1 score was 0.69 and the $F_{0.5}$ was 0.75. The $F_{0.5}$ scores for the individual questions in Groups A and B combined range from 0.59 to 0.90. (See Table 1.)

Table 1- Questions and performance metrics for combined Groups A and B, N=Total number of citations. R = Recall, P = Precision

Question	N	R	P	F_1	$F_{0.5}$
Question 1	91	50%	82%	0.63	0.73
Question 2	100	52%	61%	0.56	0.59
Question 3	88	86%	90%	0.88	0.90
Question 4	100	76%	84%	0.80	0.83
Overall	**379**	**62%**	**79%**	**0.69**	**0.75**

As noted, citations in Group A are marked as both relevant and high quality by the system. In system output for Group A, 61 relevant citations were missed, resulting in overall recall of 56%. For all questions, the system marked 85 citations as belonging to Group A; of these, 8 were false positives, in that they were not both relevant and high quality, resulting in precision of 91% and an $F_{0.5}$ score of 0.81 for this group (an improvement of 6% over results for Groups A and B combined). The $F_{0.5}$ scores in Group A range from 0.67 to 0.92 for the individual questions. Although precision was higher in Group A alone than in A and B combined, lower recall caused the F_1 score to remain constant. (See Table 2.)

Table 2-Questions and performance metrics for Group A. N=Total number of citations. R = Recall, P = Precision

Question	N	R	P	F_1	$F_{0.5}$
Question 1	91	45%	96%	0.62	0.78
Question 2	100	42%	78%	0.55	0.67
Question 3	88	82%	95%	0.88	0.92
Question 4	100	72%	91%	0.81	0.87
Overall	**379**	**56%**	**91%**	**0.69**	**0.81**

Discussion

As shown in Tables 1 and 2, recall was always lower than precision and this is mostly due to SemRep missing predications. However, there were also mistakes made by the machine learning system when assigning high quality citations. Since it is hard to determine the real cause of machine learning errors, we give a SemRep example. (6) was the only predication generated for (5), which occurred in a relevant citation.

(5) This study demonstrates that plant stanols reduce LDL-C levels in children with hypercholesterolemia

(6) Hypercholesterolemia PROCESS_OF Child

The citation in which (5) occurred was not marked as relevant, primarily because "plant stanols" does not occur in the Metathesaurus, and thus SemRep could not extract the predication for stanols reducing LDL-C levels. Moreover, an inference based on domain knowledge would be required to determine that reducing LDL-C levels is related to decreasing hypercholesterolemia (hence making this citation relevant), and this is beyond the current capability of SemRep.

Our preliminary evaluation suggests that combining relevance assignment with quality of the evidence processing has promise in supporting guideline development. Although recall in the combined A and B group was 6% higher than in Group A alone, precision in Group A was 91% as compared to 79% for group A and B combined. The $F_{0.5}$-score rose from 0.75 (A and B) to 0.81 (group A). Guideline developers strive for high precision because of the added expense of reading additional citations. Although preliminary, our findings support the claim that considering citations only in group A sacrifices very few citations that are both relevant and based on high-quality studies. Additional strategies exploiting groups A, B, C, D might help guideline developers in other ways. The ranking inherent in this partitioning could be used to prioritize reading and conserve resources.

Group D (nonrelevant and not high quality), the lowest rank, may be useful for reducing the number of citations to be read during guideline development. Considering all questions, the system assigned 56 (out of 379) citations to this Group. Eleven of these were both relevant and high quality, as opposed to 77 out of 85 in the A group. It is unlikely to be worth developer time to read citations in Group D.

Group C presents a trade-off between sacrificing true positives and effort spent. The system assigned 215 citations to this

(nonrelevant but high quality) group. Of these, 41 were true positives according to the reference standard. This is a considerably high number; however, in order to find the true positives, developers would have to read 215 citations, which may not be cost effective.

Another consideration is that for some questions, developers are interested in case-controls, observational, and even serialized case report studies. For such questions, an appropriate partition would be A and B for true positives and C and D for true negatives.

This study is limited in that the evaluation was based on a small sample of four questions and was not conducted in the context of actual guideline development. Further, the method was tested on only one class of question and it remains to be seen how the incorporation of quality of the evidence processing will extend to other question classes.

Conclusion

In the context of clinical practice guideline development, we describe a system that combines symbolic semantic processing with a statistical method for selecting studies that are both relevant to guideline questions and of high scientific quality, the most valuable research for guideline developers. Evaluation revealed that exploiting the combined processing allowed us to improve overall performance by 6%. Finally, we described how this combined system might be useful to support guideline development.

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Theories, Models and Frameworks for Diagnosing Technology-Induced Error

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Abstract

Information technology has the potential to greatly streamline healthcare and reduce the chance of human error. However, there is a growing literature indicating that if systems are not designed adequately they may actually increase the possibility of error in the complex interaction between clinician and machine in healthcare (i.e. they may lead to technology-induced errors). In other domains the study of error has been guided by a variety of theories, models and frameworks for understanding human error. In this paper we argue for the need to consider and extend this work to the study of technology-induced error in healthcare. Insights from the software engineering, human factors and organizational behaviour literature will be described, including a set of models and frameworks that we have been using to guide our work in detecting and preventing technology-induced error in healthcare.

Keywords:

Technology-induced error, Evaluation, Theory, Models, Frameworks, Software engineering, Organizational behaviour, Human factors, Socio-technical theory

Introduction

The evaluation of health informatics applications is becoming an increasingly more important activity as the number of health information systems (HISs) that are being implemented in healthcare settings continues to grow. Historically, summative evaluation methods were used to determine if a HIS led to improved clinical outcomes, reductions in costs, or reductions in medical error rates (thereby improving patient safety) [1]. However, in recent years, researchers have also found that formative evaluation is essential to identifying other issues associated with a technology's use (such as socio-technical issues and technology-induced errors) [2,3,5]. No where is this more apparent than in the use of evaluation to study technology-induced errors. In the literature technology-induced errors have been defined as those sources of error that "arise from: (a) the design and development of technology, (b) the implementation and customization of a technology, and (c) the interactions between the operation of the new technology and the new work processes that arise from a technology's use" [4, p.154]. Unintended consequences are unexpected results of use of technology that "lack a purposeful action or causation" [6, p. 415]. Technology-induced errors are one type of unintended consequence arising from the use of HISs by clinicians [3,4,6]. Researchers have used many evaluation methods and approaches to identify the presence of technology-induced errors [2,3,6]. The evaluation methods used in the study of technology-induced errors range across a continuum of approaches from purely qualitative to mixed method and then exclusively quantitative approaches [7]. These methods have been used to evaluate technology-induced errors arising from the use of HIS software and devices at varying points in the software development lifecycle through to HIS implementation in healthcare organizations (including the customization of software applications, the selection of devices and the long-term maintenance of applications and devices in clinical settings) [7]. Although many evaluation methodologies have been used to identify sources of technology-induced error such as interface features and functions [2], database content [2,6] and workflows emerging from interactions between software, devices and organizational settings [6,8], these evaluation methodologies have only been able to identify specific types of errors at specific time points: (a) in software development [2], (b) prior to organizational implementation of software and devices [8], and (c) after organizational implementation of software and devices [6]. For example, some researchers have been able to identify potential sources of technology-induced errors during the software development lifecycle [2]. Other researchers have identified sources of unintended consequences after a system/device has been implemented in a real-world setting and the system/device is being used at point of care [see 6]. It is interesting and worthy to note that some of the same unintended consequences or technology-induced errors that have been identified by researchers studying applications and devices both before and after a system/device has been implemented in an organizational setting [3,6].

Therefore, there is a need to develop a more holistic understanding of technology-induced errors and how they propagate throughout a system [4]. This holistic understanding needs to take the form of models, frameworks or theories that span the entire software development process through to organizational implementation and maintenance of software and devices. Such theoretical work will help us to understand where errors come and how those errors are propagated throughout the HIS development, implementation and maintenance process [4]. Therefore, there is a need for researchers to describe the differing types of technology-induced errors and their unintended consequences (arising

from technology use) [4,6]. There is also a need to better understand the implications of software errors that arise during software design, development and implementation upon future clinician work at point of care (as has been done in other industries) [2,4,8].

Some researchers have suggested that error models can be imported from other industries (i.e. aviation, banking, nuclear power) [2,6,9]. Other researchers have indicated healthcare has unique features that do not allow for theories and models developed in other industries to be easily applied in healthcare settings [10,11]. For example, researchers have found that healthcare work is variable, dynamic, complex, emergent, involves a high degree of ambiguity, is inter-professional in nature, is highly professionalized, requires a high degree of coordination and is not easily deferred (unlike work undertaken in other industries such as banking, mining) [10,11]. Furthermore, some researchers have found [10], healthcare places additional pressures upon its workers (e.g. physicians and nurses) to provide continuity of care. As a result, models of error cannot be easily imported into healthcare due to the unique features of the setting and in some cases these models require modification or extension. This is consistent with other industries where theories, models and frameworks from other domain areas are imported and then modified in response to empirical testing for their applicability in another domain (e.g. theory from sociology and psychology has been applied, modified and extended through empirical testing in the management and aviation industries) [see 10, 13].

Therefore, there is a need to empirically validate models of error from other industries for their applicability to healthcare and the field of health/biomedical informatics. These models need to be empirically validated, falsified, extended and customized for healthcare and in some cases researchers need to develop new models for describing technology-induced error that are specific to the healthcare industry as has been done in other industries [10,12,13]. Such work is necessary in order to diagnose potential errors involving technology before they occur in real-world settings. Many of these frameworks, models or theories specific to health/biomedical informatics that have been published are still in their infancy from a theoretical, conceptual and empirical perspective. Research is needed to empirically test these models and more research is needed to determine if these models can predict error. Such developed and empirically tested models will allow health informaticians to engage in "targeted" testing of software, hardware and interactions between applications/devices that may lead to technology-induced errors in order to eliminate them before the application/device is introduced into a real-world environment. The authors of this paper intend to take the first step in this process by outlining the frameworks, theories and models that are currently being used in health/biomedical informatics that conceptualize technology-induced errors.

Health informaticians need to begin the process of developing frameworks, models and theories. Frameworks, models and theories once developed and tested could be used to prevent and predict future sources of technology-induced error (from software development through to the implementation and maintenance of systems). The authors of this paper conducted a search of Medline using the key phrases "technology induced error and framework", "technology induced error and model", "technology induced error and theory", "technology-induced error and framework", "technology-induced error and model", "technology-induced error and theory", "unintended consequences and framework", "unintended consequences and model", unintended consequences and theory", "e-iatrogenesis and framework", "e-iatrogenesis and model", "e-iatrogenesis and theory". Two authors reviewed each of the titles of the published articles and proceedings that were returned on each of the searches. If the title or abstract of the article or proceeding referred to a framework or model or theory and technology-induced error or unintended consequences or e-iatrogenesis then the full article was reviewed by two authors to determine if a framework, model or theory was indeed described (i.e. 191 citations were returned 6 were identified by the authors using the above mentioned criteria and the articles were downloaded and reviewed). All articles in Medline from its inception to the end of 2009 were searched using the above strategy. We also included models of technology-induced error that were published in health informatics texts up to and including 2009 to inform the work. The frameworks, models and theories from the health/biomedical informatics literatures that were identified and will be discussed in this paper. The frameworks, models and theories were grouped by the authors into four paradigms: software engineering, human factors, organizational behaviour, and multi-theory model and framework approaches.

Software Engineering Approaches

Software engineering has a long and established tradition of research documenting testing methodologies that can be used to empirically evaluate software applications, devices and interactions between applications/devices as they contribute to worker error rates. More specifically, the software engineering literature identifies that inadequate programming, requirements specification, design, customization, and beta testing can lead to software errors once an application is implemented in an organization. Many publications and texts provide details about the differing types of general software testing methodologies - arguing for the need to conduct testing early in the software development process in order to reduce costs associated with addressing software errors after an application has been implemented (i.e. the later an error is discovered in the software development and implementation process, the higher the costs associated with correcting the error(s) that arise from the software once it has been implemented). It must be noted that a strength of the models and frameworks from this literature are the empirical research supporting and the breadth and the applicability of these models to many industries where software/devices are being used to improve the effectiveness and efficiency of work processes [4].

The strength of the software engineering literature is also its weakness. Much of the literature is based on research done in industries where transactions are simplistic in nature (as compared to healthcare) and there are few urgent or life threatening decisions that have implications for individuals

(i.e. patients). Additionally, requirements specification approaches are tacit in nature and users' beliefs about their work practices are not easily elicited during the requirements specification process. For example, findings from the empirical literature indicate that [18, 20]: a) a work process does not always occur in the way that users think it occurs, b) the way users carry out activities may vary by user, and c) rules and procedures that involve an application/device may be "broken" by users or not followed.

Lastly, unlike other industries, health/biomedical informatics has been slower in its evolution and application to real-world settings. There are many reasons for this. In some cases there is an inability for healthcare to obtain the necessary funding to support software development and the complexities of designing and developing applications for the healthcare system. In addition to this, testing approaches from the software engineering literature have limitations as they do not take into account the challenges of providing services in urgent care healthcare settings (i.e. hospitals) where the stresses that an application/device must effectively respond to are significant -especially when a patient's healthcare is complex, urgent and requires intervention by multiple and differing health professionals. It is because of these limitations that health/biomedical informatics researchers have identified the need to develop frameworks, models and theories that attend to the complexities of patients and the organizations (i.e. hospitals, home care agencies and physician offices) that attend to them.

Human Factors Approaches

A variety of models of human-computer interaction can be applied to the problem of reducing technology-induced errors in healthcare. Eason [13] in an influential paper provides a framework where human-computer interaction can be considered in terms of levels, ranging from Level 1 interactions between individual users, to Level 2 interactions involving use of computer systems to carry out work tasks, to Level 3 interactions at the more complex layer of social and organizational interaction. This framework has proven useful in providing a rational and efficient approach to identifying where technology-induced errors may arise [15]. For example, in conducting analyses of systems such as medication order entry, at Level 1 certain interface features may induce users to make data entry errors (e.g. unclear or inconsistent user interface operations). Moving up to Level 2, the use of a system may be problematic once it is implemented in a real-world healthcare setting, where the user interaction (e.g. in entering a medication) may be interrupted during medication administration tasks involving patients. Finally, at Level 3 the system may introduce problems and errors if it interferes with the complex communication among healthcare workers.

A second influential error model referred to in the literature has been Reason's model of human error. Reason's [9,14] approach distinguishes between a "sharp end" and a "blunt end" where error may arise in complex human-computer interaction. It is at the sharp end that errors are made by humans, however, the origins of such errors may be at the blunt end of the continuum, that is, at the end involving the complex organizational processes, policies and environments that may eventually lead to error at the sharp end. In a paper by Keay and Kushniruk [15], Eason's framework [13] and Reason's model [9,14] of error were integrated with Eason's Level 1 interactions corresponding to Reason's sharp end, and Eason's Level 3 interactions corresponding to Reason's blunt end. In more recent work, Borycki et al. [16] have extended and elaborated Reason's model to include consideration of sources of error specific to healthcare informatics and technology-induced error that blends work in human-computer interaction and human error with theory from the organizational behaviour literature (and which is described in the next section).

Organizational Behaviour Approaches

Health/biomedical informatics researchers have suggested that there is a need to blend in works from the organizational literature to address the limitations of the software engineering and human factors literatures in developing theories, models and frameworks that can act as an aid to the study of technology-induced errors in healthcare organizations. Borycki and colleagues [16] have proposed a framework that can be used to diagnose technology-induced errors that draws on the organizational behaviour literature. The framework borrows from Reason's work in the human factors literature [9] and Orlinkowski's [17] work at the intersection of the organizational behavior and the information systems literatures. In this framework the researchers recognize that HIS are developed against a policy and regulatory backdrop that influences organizational functioning (e.g. hospital and vendor), vendor systems design and development of HIS and the procuring organization's (e.g. hospitals) selection and day to day operation of a system/device. The framework identifies that systems are designed using a model organization. Software requirements approaches and modeling techniques are used to gather data and describe organizational processes. These approaches and modeling techniques serve as the foundation for HIS design and development. In the organizational behavior literature, it is recognized that organizations are imperfect and that all model organizations do not have ideal processes [17], these processes may be error prone [9] and processes can be undertaken in varying differing ways [18].

Vendors who develop software based on the work processes found in a model organization [4,17] may inadvertently design and develop HISs that integrate errors into their software applications. In addition to this, vendors in the process of programming, designing and developing a HIS may introduce new types of errors (i.e. programming errors, errors arising from inadequate requirements specification and design). The model also recognizes that the organizational acts of procuring, customizing, implementing and maintaining such systems may introduce new opportunities for errors: those arising from a policy and regulatory backdrop, the model organization, the vendor, and the adopting organization's own customization and implementation processes. Lastly, when a new HIS is introduced during an implementation, users do not use the technology as vendors and healthcare organizations intended the technology to be used [16,17]. Each of these

layers – those at the policy and regulatory level, the model organization, the vendor and the adopting organization each have an opportunity to introduce new types of technology-induced errors and when the "holes" line up in the defensive layers of the complete system the "trajectory of accident opportunity" occurs) [9]. Borycki et al.'s [16] extension to health informatics recognizes that the causes of error can be located on the blunt end with the policy and regulatory environment and the model organization on which a design is developed to the sharp end where healthcare workers use the HIS at point of care in the procuring or adopting organization.

Another model that draws on the organizational behaviour literature is Leavitt's diamond model from the 1970's [19]. Leavitt's model may allow one to track the trajectory of accident opportunities, and inversely, it may also be useful at exploring the events of an accident in order to trace out the root cause of errors (i.e. the blunt end). Leavitt's model for organizational change is based on the principle that any change in one of the four elements, 'task', 'actors', 'structure', and 'technology' (in a later extension of the model also a fifth element, 'organizational environment') will propagate to the other elements of the organization in a domino reaction until a new, steady state is reached. Such changes may lead to new events taking place, new procedures, or unforeseen problems with a new technology, and so on. That is, compensating reactions will result as a consequence of introducing a change agent (also implying that changes will be visible in places where the change was originally introduced to the organization). In Brender [20], Leavitt's model for organizational change is integrated with Mumford's socio-technical work (participatory design, also from the 1970'ies) as a methodology for testing objectives fulfilment and hence for revealing the complementary reasons for why an organization does not achieve what it had anticipated from the systems development/change effort, while enabling root cause analysis of identified problems.

Diffusion theories from varying literatures have been a source of inspiration for many researchers from many domain areas (e.g. management, health/biomedical informatics) [6, 22-24]. Roger's text entitled "Diffusion of Innovations" [22] has provided insights to some researchers as to the varying factors that affect a technology's diffusion [6,22]. For example, Roger's [22] provides an overview of how communication channels influence an innovation, identifies the main attributes of a technology that influence its diffusion through a social system and identifies the intended and unintended consequences associated with the use of a new technology. Ash et al. [6] extend work documented in Roger's text [22] to healthcare. Ash and colleagues document the intended and unintended consequences associated with using a physician order entry system and develop a thematic hierarchical network model for the consequences of using physician order entry. The researchers use ethnographic observational and interview data and derive their model from the qualitative findings of their study [6].

Multi Theory, Model and Framework

Lastly, an Interactive Sociotechnical Analysis Framework [21] has been developed by researchers in health/biomedical informatics. Harrison and colleagues [21] draw upon multiple theories, models and frameworks to develop their model. Their work has its origins in the socio-technical, ergonomic, social constructivist and the technology-in-practice literatures which have long empirical tradition. The framework identifies there are relationships between health information technologies, clinicians, workflows and organizational environments. The developers of the framework suggest that new health information technologies (HIT) change existing social systems, interact with existing technical and physical infrastructures, the social system mediates HIT use, HIT use changes the social system and these interactions between the HIT and social system lead to technology redesign. The authors cite several empirical works to support their development of the framework.

Theories, Models and Frameworks: Diagnosing Technology-induced Errors

In our work in predicting and preventing technology-induced error in healthcare we have blended the use of many of the approaches described above [2,4,7,8]. For example, we have conducted usability and laboratory-based simulation studies explicitly targeted at Eason's level 1 interactions, involving think-aloud studies of users interacting with health information systems in isolation [2]. In our work we have been extending frameworks and models by applying simulation methods (involving video observation of health professionals interacting with systems to carry out simulated and real work tasks) corresponding to Eason's Level 2 interactions [8]. Likewise, Reason's model of error has led us to conduct analyses targeted at both the sharp and blunt ends of the error continuum. Using one strategy we have started with the occurrence of an error (at the sharp end) and then traced the error back to possible blunt end causes. In addition, we have also conducted preventative analyses of error, by beginning at the blunt end of organizational factors (and using the framework outlined by Borycki et al. [16] that extends Reason's work to healthcare informatics) and then progressively moving to the sharp end to assess the potential impact of organizational and policy choices on error at the human end.

Discussion

In this paper we have described a number of approaches to the study of human error that can be applied and extended to the prediction and prevention of technology-induced error in healthcare. We must ensure that the information systems we deploy in healthcare do not inadvertently add new forms of error. However, due to the complexity of healthcare processes and work activities, the potential for information technology to cause technology-induced error is a growing concern. In this paper we have argued that an eclectic approach to considering technology-induced error that draws on theories,

models and frameworks from a range of disciplines is needed. This will lead to a more principled and effective deployment of applications/devices.

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The nature of unintended effects of health information systems concerning patient safety: A systematic review with thematic synthesis

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Abstract

In order to understand the nature and causes through which Health Information Systems (HIS) can affect patient safety negatively, a systematic review with thematic synthesis of the qualitative studies was performed. 26 papers met our criteria and were included into content analysis. 40 error contributing factors in working with HIS were recognized. Upon which, 4 main categories of contributing factors were defined. Analysis of the semantic relation between contributing reasons and common types of errors in healthcare practice revealed 6 mechanisms that can function as secondary contributing reasons. Results of this study can support care providers, system designers, and system implementers to avoid unintended negative effects for patient safety.

Keywords:

Health Information System, Patient safety, Medical Errors

Introduction

Health Information System (HIS) is strongly recommended for improving patient care quality [1]. Evidence concerning the effect of these systems on patient safety is very important. After many years of applying IT systems in healthcare services and despite many advances in the development of safe technology, there are still growing concern about the impact of these systems on patient safety [2]. Results from various studies in this area show how HIS can cause or contribute to medical errors. These studies, however, have mainly reported upon specific HIS and/or specific settings, making it difficult to generalize their findings. In order to learn more general lessons, there is a need to classify reasons for the unintended side effects of HIS and their related mechanisms. Such an understanding can benefit patient safety and increase positive impact of IT applications in healthcare. Thus the critical question here is: How can HIS cause or contribute to error producing conditions in inpatient settings? In this study, factors behind the unintended negative effects of HIS were presented and classified in order to support care providers, system designers, and system implementers and to provide them a better understanding of error mechanisms and consequences in healthcare practices.

Methods

We performed a systematic literature review to answer the research question. PubMed, EMBase, and Cocharan Library were searched for the relevant literature 1995 to September 2009. To select the relevant literature, the terms "patient safety", "medical error" or "medication error" were electronically searched in abstracts and titles of the literature. These terms were in turn combined with: information technology, information and communication technology, computerized provider order entry, computerized physician order entry, electronic patient record, electronic medical record, radiology reporting system, and laboratory reporting system.

Primary search refinement

The search hit 911 items. The result of the search was refined by manually examining the titles and the abstracts of the selected papers at the same time. The items that were related to patient safety concerns and the possible role of HIS in their creation were primarily selected. The literature that could not be judged based on their title and abstract, were examined by their full text. More refinement of selected literature was performed considering the research question. Trying to answer the "How" question, we needed to use in-depth qualitative studies for our review. The process of search refinement is presented in Figure 1; and the important primary exclusion and inclusion criteria provided in Tables 1 and 2.

Secondary search refinement: assessing quality of qualitative studies

There is yet much debate on whether or not to apply qualitative rigor to assess the quality of qualitative studies. In this review, however, we took the view that the quality of qualitative researches should be assessed to avoid drawing unreliable conclusions. In the literature, different sets of criteria have been proposed as rigour of qualitative studies. We developed our criteria by combining the commonly used

set of qualitative research criteria [3-6] with those which have commonly been considered in evaluating quality of IT evaluation studies [7]. In this study, qualitative literature was included if the authors could answer all of the presented questions in Table 3 (the secondary inclusion criteria) with *yes*. More literature was included by examining the reference lists of the literature resulted from the secondary search refinement.

Table 1- Important primary exclusion criteria

- Related to dental care
- Non-English papers
- Reviews (point of views), commentaries
- Conference proceedings Telemedicine or Telehealth related publications
- Papers related to ethical and legal issue on using IT for improving patient safety
- Papers without abstracts, except one case which was included into our study (they were either reports, point of views, news, editorials, or interviews).
- Related to primary care and outpatient setting.
- Systematic reviews which were not addressing related issue to our research question (in case the subject was relevant their reference list were searched to include appropriate studies)
- Simulation studies
- Merely quantitative researches were excluded on the ground that qualitative researches are more appropriate to understand a phenomenon in depth and to answer our "How" question.

Table 2- Important primary inclusion criteria

Original papers reporting empirical researches in inpatient setting were included if:

- They had qualitative research methodologies[1].
- Studies with mixed qualitative and quantitative method.
- Studies on voluntarily error reporting by the system users
- Case reports and case studies were included if they presented enough information about the system being studied and the error happened in using the system.

Data analysis and thematic synthesis

Campbell *et al.* [9] extracted what they called the 'key concepts' from the qualitative studies they found about patients' experiences of diabetes and diabetes care. In a similar attempt to a systematic review of qualitative studies, Thomas et al.[10] extracted all result sections of the included papers into qualitative data analyses software and analyzed the data based on an already prepared scheme of coding. In this study, we extracted the concepts from the included studies' findings that were reported about the direct, indirect, or potential role of HIT on medical errors. Following Thomas et al.'s method, we then assigned the extracted concepts into Atlas-ti 5.5.9 software for further qualitative data analysis. In case it was necessary, we used more information of the included literature to clarify the context of different pieces of extracted information.

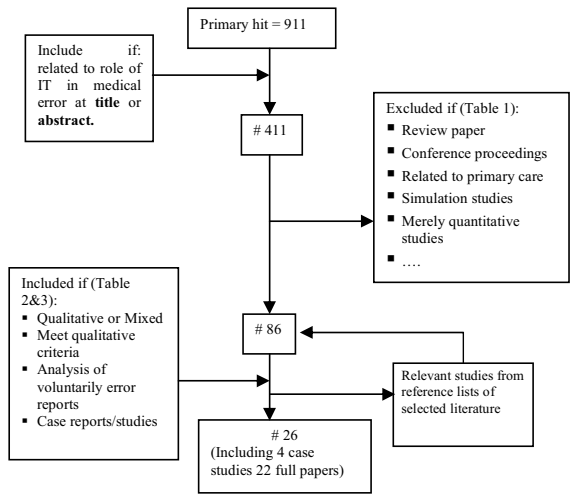

Figure 1- The search refinement process.

Table 3- Secondary inclusion criteria

1. Is there explicit theoretical framework and/or literature review?
2. Are aims and objectives clear?
3. Is the context of study clearly described (e.g., organizational setting, the evaluated system's detail and other systems in use)?
4. Is the study sample (e.g., system users) and how it recruited clearly described?
5. Is data collection method clear?
6. Is it possible to identify study findings from those of the other studies' in the paper?
7. Is the data analyses method clearly described?
8. Are attempts made to establish the reliability or validity of data analysis (e.g., reflexivity, triangulation, member checking, saturation in the field, and an audit trail)?
9. Are sufficient original data included to mediate between evidence and interpretation?

The extracted texts were coded for two types of contributing *reasons* (primary and secondary) of medical errors. More than 150 codes were created for the primary contributing reasons. In the process of thematic synthesis, the primary contributing reasons were reviewed frequently until 40 contributing *factors* (denoting the categories of similar primary contributing reasons that could be collected under specific causal themes) and 4 contributing *categories* (denoting the categories of family codes that could be organized under major causal

[1] Qualitative study was defined based on Strauss and Corbin [8] as "any kind of research that produces findings not arrived at by means of statistical procedures or other means of quantification".

themes of contributing factors) were created. The data was also coded with respect to identifying reported secondary contributing reasons (i.e., *mechanisms* through which primary contributing reasons were reported to produce error in healthcare practice). More contributing mechanisms were recognized by analyzing the semantic relation between the contributing factors and the common types of error in healthcare practice (i.e., mistakes, slips, and latent errors). In this study, we did not investigate the frequency and severity of the errors.

Results

Four case studies and 22 qualitative or mixed method studies were analyzed [11-36]. Four major categories were recognized out of 40 contributing factors: workflow problems, communication problems, technical problems, and user-related problems. Some of the contributing factors were reported to produce error directly (direct mechanism of error). The majority of the contributing factors however worked through *contributing mechanisms*. Figure 2 represents the semantic relation between the contributing factors at different levels with common medical errors.

Contributing categories

Workflow Problems

Working with HIS could hamper or block the normal flow of care work and as a result caused error in healthcare practice. Such workflow problems in working with HIS were reported due to increasing workload of care providers [11, 12, 20, 21, 25, 29-31, 35], or slowing down time intensive care work [11, 20, 21, 23, 25, 26, 28, 29, 31]. The use of information systems was reported to change inappropriately the structure of healthcare work and/or to increase the steps required to fulfill a healthcare task inappropriately [20, 21, 25, 35]. Many studies reported on HIS applications' failure to support intermediary tasks and shared responsibilities between care providers [16, 20, 25, 35]. Moreover, HIS reportedly failed to support non-routine and complex care processes [21, 31]; or it supported only a part of a care process and as a result created coordination problem between the automated part and paper-based part of the process [13, 25, 28, 29, 31, 34]. The workflow was also disrupted whenever a system forced its users to perform unnecessary extra-checks on one single part of a care process [11, 31, 32]. Extending the functionality of the software designed for one healthcare professional group (e.g., pharmacists) in order to support another group of professionals (e.g., physicians) also caused workflow problems [25, 35]. In the literature, many workflow problems were reported because of mismatches between the components of a process designed into HIS and the component of the process in the real care practice. Such mismatches were reported between HIS and its users in the way a care time [11, 20, 21, 26, 28, 35], a care unit [20], and a care process sequence [12, 25, 26] were defined. In addition a problem was reported when a system was not updated with new changes in healthcare practice [21]. Many recent studies have also reported the role of unsafe compensating strategies being adopted by care providers (i.e., workarounds) in order to improve problematic workflow as potential contributing factors for medical error [16, 17, 21, 25, 27-29, 31, 36].

Communication problems

HIS can contribute to or cause error by generating problems in the process of communication and information exchange between care providers. Working with information systems was reported to interfere with the communication between care providers [12, 18, 25, 28, 29, 35], or between the care providers and the patients [26, 35]. Information systems could also produce problems in the process of information mediation due to, for example, lack of feedback mechanisms between communicating care providers [12, 28, 29, 31, 34]. In addition, communication problems occurred in cases where HIS restricted appropriate registration of patient information, for example because of an insufficient /inflexible coding scheme [17, 21, 34]. Problematic information presentation was frequently reported as an important error contributing reason in the literature. Problems of this kind were reported due to fragmented presentation of data over different screens [20, 30] or over different patient care information systems [28-30], due to presenting too much information for systems users [28, 29], and because of problems in finding and retrieving already stored information [21, 29]. Moreover, interoperability problem between care providers as well as data loss were reported to happen in situations where care providers had to work with electronic and paper-based systems at the same time [28, 29, 33, 34]. Likewise, communication problems were reported in case patient information was not updated in information systems [17, 29, 35].

Technical Problems

Many studies have reported technical shortcomings with HIS that could directly or indirectly lead to error in healthcare practice. These problems were frequently reported to be in the form of a software glitch [13, 14, 18, 33] or due to applying outdated hardware [12, 33]. Problems in the design of user interface were also frequently reported in the literature. They were reported to be either in the form of inappropriate screen layout, forms, fonts, and colors [11, 18, 20, 24, 31], or inflexible data entry options [20, 21, 23, 35], or look alike on-screen forms [18]. Such design flaws could for example facilitate juxtaposition errors. Likewise, design problems such as inappropriate/insufficient order set [18, 20, 23], using inappropriate terminology in the system [18], unclear log in/off processes [20, 35], and unspecific alarms [21, 31] were also among the frequently reported error facilitating technical problems. Problematic ergonomics of HIS was reported as a contributing factor to erroneous practice [11, 21, 35] as well. Shortage of technical support in working with HIS, for example in case of networking problems or problems with system accessibility [21, 35], or when the system is down or has crashed [20] were of commonly recognized error contributing technical shortcomings in the literature. Moreover, working with nonintegrated or partially integrated information systems were reported to produce medical error [17, 19, 20, 30].

User-related problems

Some of the error contributing reasons were related to the way users worked with HIS and are hence called user-related

problems here. These problems were frequently reported to occur if users were not trained and educated enough with respect to the proper way of working with IT applications [12, 18, 21, 30, 31]. Another frequently reported problem of this kind was recognized to be system entry mistakes by users [11, 13, 14, 17, 20, 24, 33]. Users' cognitive ability to handle complex care processes was reported to be reduced or hampered if for any reason they developed negative emotions towards the IT systems [12, 21, 30-32]; or because they developed over-dependence to HIS [12, 21]; or because their social relationship with their colleagues and/or patients was intruded by HIS [11, 26, 31]. Users' role in error producing conditions dominated whenever they had to work with information systems in an interruption-driven and/or hectic environment [15, 22, 28]; or they had to work with paper-based and electronic systems at the same time [20, 29, 33]. User-related problems also reportedly took place if they did not comply with policy and procedure in working with HIS [13, 21, 26].

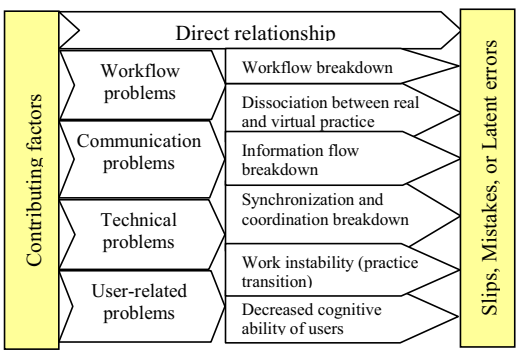

Figure 2- Semantic relation of medical errors with error producing mechanisms. Note that there is no one-to-one relation between the primary and secondary contributing factors.

Contributing mechanisms

Six error contributing mechanisms were recognized upon the contributing categories. The first mechanism, *workflow break down,* will be triggered if the construct of healthcare work is broken down as the result of applying HIS. The second mechanism works whenever *dissociation between real and virtual practice* happens. There should be a one-to-one connection between the components and stages of a care process designed into an information system (virtual practice) and the components and stages in real practice. The virtual-real connection is dissociated if for example patient information is not updated in the system or a wrong digital ID is allocated to a patient. The third mechanism will function if by using HIS *information flow is broken down* and the right information is not delivered to the right care providers at the right time and in the right place. The fourth mechanism will be initiated in case using HIS *hampers coordination and synchronization* between healthcare providers throughout the healthcare work. The fifth mechanism will be instigated if working with HIS *decreases the cognitive ability* of the care providers to cope with healthcare situations (e.g., due to increasing cognitive load). The sixth mechanism will work in case a care practice has developed a fragile and context specific configuration (*work instability*) as a result of interaction between a system and its users. In such a condition any unexpected change in practice can lead to error.

Discussion

The overview provided in this paper can benefit safe system design, implementation and use. The contributing factors and mechanisms are not specific for one system or one implementation site and hence important. More research however is required to point out where and how specific hands-on should be applied to decrease the unintended errors.

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A system for solution-orientated reporting of errors associated with the extraction of routinely collected clinical data for research and quality improvement

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Abstract

Background: We have used routinely collected clinical data in epidemiological and quality improvement research for over 10 years. We extract, pseudonymise and link data from heterogeneous distributed databases; inevitably encountering errors and problems. Objective: To develop a solution-orientated system of error reporting which enables appropriate corrective action. Method: Review of the 94 errors, which occurred in 2008/9. Previously we had described failures in terms of the data missing from our response files; however this provided little information about causation. We therefore developed a taxonomy based on the IT component limiting data extraction. Results: Our final taxonomy categorised errors as: (A) Data extraction Method and Process; (B) Translation Layer and Proxy Specification; (C) Shape and Complexity of the Original Schema; (D) Communication and System (mainly Software-based) Faults; (E) Hardware and Infrastructure; (F) Generic/Uncategorised and/or Human Errors. We found 79 distinct errors among the 94 reported; and the categories were generally predictive of the time needed to develop fixes. Conclusions: A systematic approach to errors and linking them to problem solving has improved project efficiency and enabled us to better predict any associated delays.

Keywords:

Computerized medical records system, Data quality, Databases, Semantics, Controlled vocabulary, Computers.

Introduction

Internationally, routinely collected clinical data from primary care electronic patient record systems (EPR) is used for research and quality improvement [1]. However, many of the research databases only draw their data from a single vendor; thereby circumventing many of the difficulties due to variation in the way that national and international standards are implemented in different brands of EPR system. By way of contrast the Primary Care Data Quality (PCDQ) programme has worked with large datasets drawn from different vendors some using different classification systems and generating their own local codes to supplement standard taxonomies: truly heterogeneous distributed databases [2]. The largest PCDQ study drew data from 2.4 million patient records [3]; current studies work with databases of just under 1 million records drawn from six different brands of EPR system but extracting several hundred variables [4].

The difficulties in extracting data from heterogeneous distributed sources are well known [5] and standard methods and toolkits for measuring the validity and utility of electronic patient record systems have been proposed [6]. The difficulties arise because of the different architectures of the heterogeneous distributed systems, the local autonomy of these systems, problems in representational diversity of the same clinical concept, and the potential lack of precise semantic meaning. None of the classification systems within the UK have definitions, making it possible for meaning to vary between professional groups and over time [7]. There may be a trade-off for vendors between achieving functionality and strict adherence to guidance on requirements of EPR systems. Difficulties can then arise because standards are not strictly implemented.

We frequently encountered data extraction problems, which we historically reported in terms of what data were missing from our response files rather linking our problem to the underlying cause. We carried out this study to see if we could develop a system of solution-orientated error reporting, which improved our problem solving and predicted likely time to resolution.

Method

We carried out a literature review on the standard bibliographic databases to identify structured approaches to data extraction techniques from heterogeneous distributed databases. We narrowed our search to clinical data and databases. We tried to identify any current approaches to identifying and resolving data extraction errors apply prospective and retrospective statistics with dynamic validation as data are being extracted [8].

Our literature review initially focussed on the UK National Health Service methods of date extraction. We also looked for proprietary tools for data extraction provided by EPR vendors. We found two generic approaches to enable enquirers to execute queries and extract data from different types of general practice computer systems using a common query lan-

guage. The two alternatives are the MIQUEST (Morbidity Information and Export Syntax) HQL (Health Query Language) data extraction tool and the proprietary Apollo SQL interface. PCDQ uses the MIQUEST data extraction tool.

We then collected information about the experiences of five data collectors during 2008 and 2009. Interviews with the collectors, observations, documentation reviews and test data extraction queries were used as information gathering techniques. The study exports included detailed descriptions of errors, frequencies of occurrence and comments on specific issues, system installations and system versions. A post-hoc exploration process was carried out.

We constructed an initial list of the errors encountered and classified the errors according to their effect on the data collection process. This included; information about whether the query would execute at; the stage each query would run to, and whether it produced partial or no results at all. We then reviewed and categorised the observed data collection issues based on their impact.

We subsequently redefined the data collection issues to create a briefer but nevertheless descriptive functional IT component approach to facilitate problem solving.

Finally, we reclassified the improved list of errors based on our need for a system which enabled understanding of whether certain groups of errors could be resolved by the collection team or not; and finally whether they were vendor specific. This led to the creation of a taxonomy of errors for our data collection problems.

We then created an on-line resource for the PCDQ data collectors. The on-line problem reporting form was designed to capture the key information needed to diagnose the IT component which was responsible for any errors.

The studies carried out during the development of our taxonomy were ethically approved, and only used pseudonymised data.

Results

Errors during the Data Collection Process

We identified 94 problems with the data extraction from the four major UK GP electronic patient record (EPR) suppliers: EMIS PCS, EMIS LV, INPS Vision and iSOFT Synergy. These four EPR systems account for over 90% of GP EPR market for England [9].

Problems of different levels of severity and impact were identified and initially mapped to a set of groups in a purely clinical use driven approach. The frequency of the type of problems encountered is summarised in Table 1. Errors were reported in the following categories: (A) MIQUEST – the data extraction tool did not work, or the query code failed at some point, (B) The MIQUEST specification was differently implemented on one of the brands of EPR systems. For example the word "CHOSEN" returns different response files, (C) Clinical System and database would not return information, (D) Supporting Software and operating system, (E) Hardware and Infrastructure, (F) Generic/Uncategorised and/or Human Errors.

We documented the cumulative frequencies for each issue based on each individual collector's recordings and assigned them to any category they applied to.

Multiple mappings

This type of direct mapping did not allow for an optimised approach to error solving. We found that 56 of the 94 errors (60%) could be assigned to multiple categories as shown in Figure 1; a limitation of our initial categorised reporting.

Table 1 - Stage Process Categorisation Frequencies

Category(/ies)	Frequency	Number
B	21%	20
D	11%	10
D or E	11%	10
B or D	9%	8
B or D or E	9%	8
A or B	7%	7
A or C	6%	6
A or B or C	5%	5
E	4%	4
C	3%	3
B or C	3%	3
C or D	3%	3
B or E	2%	2
B or F	2%	2
F	1%	1
C or E	1%	1
C or D or E	1%	1
Total Errors: 94		

Post processing of the error list

We initiated another round of result interpretation to identify the generic functional IT standings of each specific issue and generate a list with strictly targeted errors that could be classified to one of our newly defined categories.

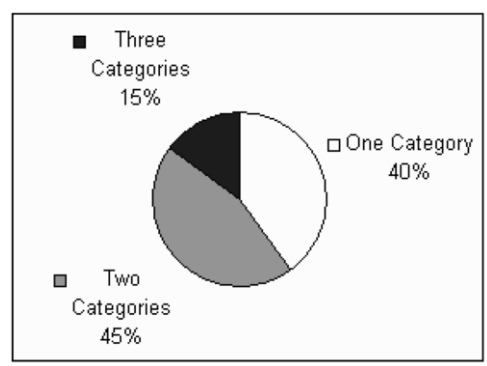

Figure 1 - Frequencies for Multiple Categories

Taxonomy of errors

We then investigated whether the errors identified could be mapped to a single root cause – recognising that this may involve careful analysis as to which IT component was responsible for the error encountered. We connected each of the redefined issues to the respective group described in Table 2. The new definition allowed for identifying the point of contact as well as an estimate on the delay for solving individual cases.

The list was structured from the data collectors' experiences in the field, response time average and contact points.

Table 2 - Component Oriented Approach

Code	Description	Resource Responsible	Delay Estimate
A	Data Extraction Queries and Process	Collector	Up to 2 weeks
B	Extraction System (Translation Layer/Proxy)	Extractor / Vendor	From 1 month
C	Top Level System and Database (Original Schema)	Software Vendor	From 1 month
D	Underlying Software, Networking and OS (System and Communications)	Technician	Instant to 1 month
E	Hardware Layer and Infrastructure	System Vendor	From 2 weeks
F	Human Errors	Technician / Extractor	Up to 2 weeks

We completed our direct mapping of each individual case to one category through several iterations; based on comments and feedback from collectors, IT resources and documented processes. This enabled us to summarise all the errors into the categories and export metrics as in Table 3.

This process, involved merging a total of 15 error descriptions with closely related ones. This created an accurate assignment to the various categories of secondary level processing.

Of the 79 final individual error types, category C (Clinical EPR System) was most frequent and found in 30 of these 79 problem categories – requiring input from the vendor. This was followed by D (Network and Operating System) and B (Data Extractor Specification) with 16 and 14 occurrences respectively. Categories A (Query Content), E (Hardware) and F (Other Human Errors) had 6 and 7 error types recorded for each. Around 40% (30/79) of the problems could be solved by phoning software support for the particular brand of EPR system, 20% by actions from the data collector, and 10% by senior team member. 30% could not be resolved by the team in the expected timeframe and required some external input. The majority involved external resources and required changes to the underlying hardware or technical intervention with the onsite systems; albeit usually delivered remotely by the vendor.

Table 3 - Taxonomy of Errors and Frequent Cases

Category Most probable errors	Issue Count Occurrences
A	7
Query code incompatible with current data	6
Query execution order and ID conflicts	5
B	14
Query timer issues	12
Unable to interrupt query execution	9
C	30
Uninterruptible response copying process	49
Query response filetype / output format	12
D	16
DB size and other filesizes incorrect	32
Client login without sufficient rights to Extractor	10
E	6
Disk space limitations	11
Query execution taking too long	10
F	6
Query execution/queue removed by third party	11
Malfunctioning/Non functioning Report server	6
Total individual cases: 440	**Distinct Issues: 79**

An online structured system for the initial reporting of errors was implemented. We used a project management platform and divided the tracking mechanism into several sub-systems for different projects (QICKD [4], IAPT (an evaluation of Improved Access to Psychological Therapies), Osteoporosis, and Diabetes studies) but with the same underlying format for cross reporting. A set of optional and required fields, allowed for immediate connection to a predefined taxonomy.

Practical examples of errors and solution orientated reporting

We report exemplar errors in each of the seven areas and the action taken and time taken to solve them:

(a) Data extraction queries and process problems: One brand of EPR vendor creates its own local codes to plug what it perceives as gaps in the standard (Read code) hierarchy. Unless queries collect these local codes this data area is deficient. Smoking data provides a good example - where sometimes local codes have accounted for >10% of the data. The solution took under two weeks, involving query re-writing and exploring with clinic doctors how these patients were represented in the EPR system.

(b) Extraction system errors: The INPS Vision and EMIS PCS systems can take several minutes to extract large response files during which the session cannot be interrupted. We prevented this by logging in another session on the same workstation on the proviso that login details are held. We asked that these details be provided so that restarting the extraction would require less time. Interference from support staff would often take hours or require a revisit.

(c) Top level system and database errors: Systems are not designed to handle large-size result files. EMIS LV in particular, is negligent for not having sufficient free database and

disk space which is an essential prerequisite for data extraction. This often resulted in system crashes if it was utilised for clinical purposes at the same time. We made sure at least 100MBytes are free, to avoid interruptions and system restarts that would take 30 minutes or more.

(d) System and communication errors: Due to insufficient user privileges, execution of queries is sometimes impossible. We used accounts with >Level 4 access to MIQUEST. Also, the interface would sometimes incorrectly indicate the current load. We were proactively ensuring that we had enough resources than the stated, to prevent having the support staff sort it for us with a 15 minute to 1 hour addition to the collection.

(e) Hardware and infrastructure errors: iSOFT Synergy and Premiere are both vulnerable to complex query sets when an external reporting server is not being used. We found that even in cases where a reporting server was installed, we had to use the live clinical system because of poor maintenance and data that were not up-to-date or incorrectly linked.

(f) Human errors: Experience has shown that human errors were also commonplace even in some instances where communication had been successful. On occasion, queries had been removed from the system by practice staff unknowingly, where researchers had scheduled set execution times or where practice staff needed to execute internal queries or maintenance tasks (the data extraction tasks get lower priority than the system maintenance processes).

Discussion

Principal findings

Data extraction techniques are widely used to answer research questions from routinely collected clinical data. Problems are faced during data extraction. Most appear to be associated with the way specific data extraction engines have been implemented by the different EPR system vendors. The adoption of this error taxonomy would enable consistent reporting to system manufacturers and potentially improved efficiency in data collecting.

Implications of findings

Our system imposed a much more analytical approach to error reporting and handling from data collectors. Errors were assigned to all categories. Although the incidents were not equally distributed, they were correctly proportioned based on the influence of each individual category (and system element) to the overall extraction and anonymised patient record collection process. The process allowed us to be more accurate, fast and proactive. For example, the common error of queries being randomly interrupted was originally handled as a query writing issue. Statistically, and based on our classification and findings, there are less chances of this error feedback because of a syntax or vocabulary error and the failure output is almost directly connected to automated backup processes on the reporting server or other maintenance issues. On another example, the traditional way of handling long-running queries was to generate subsets even in cases where the practice systems had a specific (in most cases easy to resolve) issue. With our process, we would classify the error, check the most probable causation and proceed with the collection without rescheduling a visit which involved writing vendor-specific subset queries in-between, using valuable study time and resources. Also, the taxonomy helped us provide feedback to the EPR vendors (and MIQUEST) as in a recent example, new data together with the inclusion of post-collection validation error information pointed to a vendor bug with a false return of text data type ACR values instead of numeric ones, resulting in gaps inside the collected data. This was flagged, the developers were notified and a fix was introduced prior to our next collection. We found that the duration of this process was less than our estimate for rewriting the queries, deploying and executing them as well as any changes to our analysed flat-file generation mechanisms for converting the inconsistent data type.

We followed a set of principles for our own research projects and found that early steps and precautions also allowed for minimised error frequency. For example, the use of mechanical processes for query writing, code execution and system maintenance minimised errors in categories A and F (we followed the commonly used reusable code principle via component based engineering for our processes), whereas documented solutions to usual problems on software-level (for categories B, C and D) allowed for error solving by the collectors themselves. Finally, articulating the least acceptable hardware features and specifications before a data provider joined a study minimised the impact of any issues with the infrastructure (category E).

The error classification through the taxonomy we implemented makes error reporting a solution-orientated approach. It allows for the flagging of the nature of any obstacles combining precautions as well as immediate action thenceforth. Problems which were frequent 12 months ago no longer feature on our error list, these include but are not limited to: Some human errors, disk space issues where feedback would be inaccurate, crashes on the server because of lengthy or problematic queries and shared folder issues where the mapping of local drives needs to be set up by staff with sufficient privileges.

This process provided team members the confidence to approach vendors or explain the limitations of hardware or software to healthcare providers participating in research.

Comparison with literature

We identified a dearth of literature on error reporting. Though much is written about how data from EPR systems are expected to have a central role within healthcare commissioning, and quality improvement [10].

There are generic IT approaches to problems with data extraction: namely the resolution of possible data conflicts occurring in the database integration process; incompatibilities between databases, differences in data types; and copies of the same information stored in different databases [11]. There are examples of logging mechanisms able to identify errors either in extraction itself or the underlying EPR system data (for example, the miscoding of family history as heart disease resulting in apparently 25% of practice population as having this diagnosis) [12]. The above reveal the need for a structured error handling process. The literature recognises the problems with heterogeneous distributed databases as well as the cost and

effort for overcoming them without a standard well-defined and designed process [5,11].

The UK national data quality programme PRIMIS+ discussion board illustrates how data extraction problems extend widely; but does not incorporate any sort of error taxonomy [13].

Limitations of method

We found that on rare occasions the translation of an issue that can be connected to multiple categories has a slight change on its meaning (not on its effect, however) when redefined for our functional approach.

Also, for a number of problems we had to analyse feedback from the data collectors several times, in order to define the most appropriate category definition and the course of action that required the least effort (in terms of man-hours or external resources involved).

Based on our need for immediate logging of the problems and comments about them, we had to update the list as the extractions progressed and collections were rescheduled.

The design of the online system for error reporting allowed us to propagate knowledge on the effect and effort in resolving issues across several projects by setting principles and user-access rights for different teams in several locations connected to the same central repository. An approach that can widely be used for cross-platform access with direct assignees, minimising the time spend for both administering and providing solutions in timely manner.

Call for further research

Based on our findings, the implementation of a shared reporting system adopted by the individual EPR system vendors can help the secondary use of routinely collected data by allowing for faster solutions and therefore interpretation and use of the output data.

Conclusion

This approach has enabled us to achieve higher levels of successful problem reporting and solving. Its method could be replicated in other projects. We recommend the use of this taxonomy for error reporting for any type of study whether using primary or secondary care data.

System vendors should be more aware of the potential impact of non-standard interfaces. Better structured systems, which more strictly implemented standards, would reduce the time spent in crisis managing problems when extracting data. A national or international system of error reporting would allow sharing of workarounds is urgently needed. Adoption of a standardised method of solution-orientated error reporting would help EPR vendors identify and address errors in data extraction from their systems.

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Toward a Human-Centered Voluntary Medical Incident Reporting System

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Abstract

Voluntary medical incident reports are a valuable source for studying adverse events and near misses. Underreporting and low quality of reports in local organizations, however, have become the impediments in identifying trends and patterns relating at the local, regional and national level. Human factors on usefulness and ease of use have shown their important role in acceptance of voluntary reporting systems. To understand and identify the obstacles of quality reporting, we employed a set of human-centered analysis methods to examine one-year voluntary medical incident reports of a University Hospital. We found about 30% of the reports labeled as "miscellaneous" and "other", and their real incident types or error descriptions were identified through an in-depth recoding. Human-centered analyses show that the pre-defined reporting categories could serve well for the voluntary reporting need if reporters' tasks were better represented on user-friendly interfaces. We suggest that a human-centered, ontology based system design for voluntary reporting is feasible which could help improve completeness, accuracy, and interoperability among national and international standards.

Keywords:

Medical incident, Reporting system, Human-centered, Interoperability.

Introduction

Medical incident reporting system, where error data are collected in a properly structured format, is suggested a useful mechanism for the detection of patterns, discovery of underlying factors, and generation of solutions[1]. Such a system as a source of adverse event repository would allow patient safety researchers to categorize, trend, and analyze data, increasing knowledge about medical mistakes and generating common solutions. Voluntary incident systems are a valuable, major source for this purpose. However, there is a clear dissatisfaction with the current voluntary systems [2-5]. Incomplete and inaccurate reports are misleading and not usable for further analysis.

Despite a large amount of studies suggest instituting a "just culture" that encourages learning, non-punishment [6-15], few studies have investigated the system difficulty and inefficiency regarding ease of use, ease of understanding and their relations with the level of details in reporting[10, 16-18]. To date the research addressing the inefficiency of medical incident reporting system has been limited and fragmented, with findings not always broadly disseminated. Although general rules of human-centered design have been introduced in many other fields, currently there is a lack of design framework for medical voluntary incident reporting systems to effectively collect, catalog, and analyze the reports.

Human factors, an important role in voluntary incident reporting systems, greatly affect the reporting rate, completeness and accuracy of the incidents [19, 20]. For example, classification and definition used in incident reporting systems determine whether an event is recognized or ignored [21, 22]. The people, who report, are generally working under time critical and multi-tasking conditions, and often do not have either the time or sufficient information to create a complete and meaningful report of the incident. If "other" or "miscellaneous" is offered as an option, it is often chosen [23]. It is critical to know what the needed categories are and how they would promote the quality of reports, users' acceptance in voluntary reporting systems.

To understand the current status of voluntary reporting systems in term of completeness, accuracy and degrees of expressiveness, and to identify the technical barriers toward a human-centered design, we proposed to study a set of voluntary reports acquired from the University of Missouri Health Care System (UMHC). UMHC is one of the most comprehensive health-care networks in Missouri, with approximately 500 staffed beds and 19000 patient admissions annually, offering the finest primary, secondary and tertiary health-care services. In 2002, in response to the Institute of Medicine report[24], UMHC developed a web-based voluntary reporting system, the Patient Safety Network System (PSN), which collects adverse events, near misses reported from 5 facilities located in mid Missouri[25].

Goals, Operators, Methods and Selection rules (GOMS) have been widely applied to model user's behavior and system evaluation. As a theory of Human-Computer Interaction (HCI), GOMS models can be classified as predictive, descriptive, and prescriptive[26]. GOMS model can be used to predict the time it will take a user to perform the task. GOMS can be used to describe the way a user performs tasks on a system and can be used to prescribe because it can serve as a guide for developing training programs and help systems. Keystroke-Level Model (KLM) is a simplified version of GOMS.

KLM aggregates all perceptual and cognitive function into a single value for an entire task[27].

In particular, we are interested in those incident reports with wrong or mislabeled categories and uncovering the underlying reasons of incorrect category selection. This process may help us develop a new set of incident type or event categories to better serve reporting needs and be compatible with the Common Format(AHRQ) and International Classification of Patient Safety (WHO)[28, 29]. This paper demonstrates our process and results regarding consistency and reliability of the voluntary incident reports. Base on the analysis, we have proposed our recommendations for upgrading institutional voluntary reporting systems through a human-centered, national/international standard compatible design, and for effectively maintaining historical data.

Materials and Methods

We obtained a total of 2919 de-identified, unique (duplicate copies were combined) voluntary incident reports generated in a 12-month period during 2005-2006 from the Office of Clinical Effectiveness (OCE) at UMHC. The reports are stored in MS Access and password protected on a secured server. The PSN is a web-based electronic reporting with tutorials and explanations on harm scores usage provided on the same webpage. Regardless of the choice of anonymity, each reporter must complete a factual and objective report in the PSN system immediately following an adverse or near-miss event. The OCE periodically holds a peer review process, which identifies the basic or causal factors with focuses primarily on systems and processes, not individual performance.

In this system, adverse events/incidents are defined as "any potential deviation from policies, procedures and standards regarding patient care, or a clinically related adverse or unexpected event causing injury or the potential for injury to any person"[30]. This could include an unexpected adverse outcome related to the natural course of the patient's condition or an outcome unrelated to the patient's condition. Near-miss events are defined as "an adverse event that could have resulted in an accident, injury or illness to a patient but did not through chance or timely intervention."[30]

Data Structure & Reporting Flow

The voluntary report database contains one table with 26 required fields. Each case has been automatically assigned a unique event ID. Of the data fields represented on user interface, Five (up to seven) fields, including patient age, report date, event date, patient unit ID, patient unit ID, are typed in by reporters. Report data and event date can be either typed in or selected from a calendar. Most fields require reporters to select from pre-defined menus displayed as drop down lists, radio groups, check boxes, etc. The fields displayed in predefined menus include harm score, incident type, error description and brief description. Event description is a short narrative to support the selected harm score. The harm score is a subjective rating of severity from 0(no clinical changes) to 5(death). Each harm score corresponds to a different number of items provided to reporters as a reference for evaluating the severity of events[30]. For a typical reporting process, one has to go through "answer initial questions", "event common questions", "event details", and "report summary", totally four interfaces to complete a report. For all reports, reporters may choose to report them anonymously or retain their IDs. After submission, hospital administrators, service medical directors or departmental managers review the reports and fill in the solution, review, and additional information fields. Therefore, all reports we studied were previously reviewed and responded by domain experts.

Procedure

First, we conducted a systematic content analysis on all the reports using a comprehensive coding interface which aggregates event information on one page and offers a coding space for researchers [23, 31]. Content analysis is an effective method of identifying key concepts and building up the conceptual hierarchical structure of concepts [32]. Content analysis is especially necessary in such a voluntary reporting process because there might be a great variety of term usage in reporting a case. Similarly, the selections of harm score, incident type or error description may lack consistency due to individual's understanding and therefore affect usefulness of the reports for patient safety research [33]. The content analysis was conducted by two data analysts who completed the work independently and performed a cross checking for achieving a higher consistency among harm score, incident type and error description.

Second, we further conducted an in-depth analysis on a selective type of cases (346 patient fall cases) to reveal the factors which might have caused the inconsistency and incompleteness of the reports. We selected fall cases to examine for two reasons. (1) according to the hospital policy, all falls are required in the PSN system [30]. Therefore, this type of incident has a mandatory nature within a voluntary reporting system. (2) Patient fall, as a typical category in voluntary reporting systems, represents the quality and taxonomy granularity in the current system. Fall cases are usually more frequently reported in incident reporting systems than in patient charts. This is in consistency with other group's study [5]. In our study, fall is defined as a sudden, unintended, uncontrolled downward displacement of a patient's body to the ground or other object (such as bed or commode) at a lower level. The fall excludes the falls resulting from a purposeful action or violent blow [34].

Third, for exploring the feasibility of transforming the hospital on-site reporting categories into a compatible format recommended by WHO International Classification of Patient Safety(ICPS) [29] and AHRQ Common Formats [28], we developed a prototype using a set of questions with a step-by-step structure for fall incident reporting. The reporting categories were mapping results between the PSN fall terminology and the national/ international standards. We then compared the estimated execution times of two interfaces between the PSN and our prototype by using KLM, which predicts task execution time from a specific design and specific task scenario. Following Kieras's method [27], two experienced reporters conducted KLM analysis of reporting a typical fall case based upon two interfaces.

1. Choose one or more representative task scenarios.

2. Have the design specified to the point that keystroke-level actions can be listed for the specific task scenarios.
3. For each task scenario, figure out the best way to do the task, or the way that you assume users will do it.
4. List the keystroke-level actions and the corresponding physical operators involved in doing the task.
5. If necessary, include operators for when the user must wait for the system to respond.
6. Insert *mental operators* for when user has to stop and think.
7. Look up the standard execution time to each operator.
8. Add up the execution times for the operators.
9. The total of the operator times is the estimated time to complete the task.

"Click mouse", "move mouse", "move hand to mouse/keyboard", "time needed for mental preparation", "type keys" were calculated. System waiting W (how long the system takes to respond) was not considered as the system speed was great.

Results

Our content analysis shows the majority non-anonymous reporters were registered nurses (66.2%). Other reporting professionals such as unit clerks, physical therapists contributed a total of 5.0% in the reports. Figure 1 shows the percentage distribution. The inter-coder reliability was good and reached at 82% between two data analysts (κ=0.83).

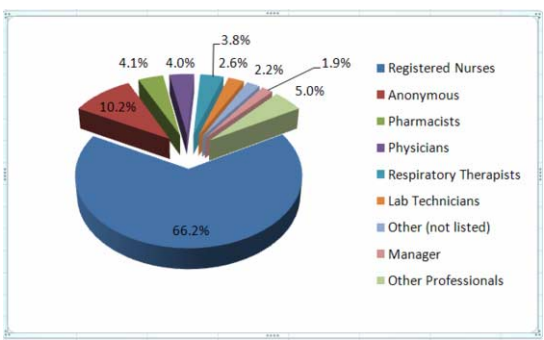

Figure 1- Distribution of Reporting Professionals in the PSN system

The incident type leads each reporter to further describe the error using predefined error descriptions and a free text entry. The major incident types are miscellaneous (32.8%), medication/IVs (23.7%), procedure/test/treatment (16.5%), fall (11.9%), equipment/device (5.9%), skin impairment (0.9%). The Error Description field is a pre-defined list designed for quickly summarizing the incident, where the major data entries were "other" (41.3%). We noticed that the field only allows reporters to select one item associated with the Incident type.

The big portion of "miscellaneous"(32.8%) in the incident type field and overwhelming percentage of "other" (41.3%) in the error description field indicate the reports lack of accuracy, completeness and affect the utility of the reporting system at large. There were 25.3% of the reports labeled with both "miscellaneous" and "other" in the two fields simultaneously. This means that the reports were completely not categorized by the original reporters. To investigate the case, investigators need to carefully examine all pieces of information and summarize out the exact category for the case.

We indentified 360 (12.3%, n=2919) fall cases among the unique 2919 medical incident reports after all the cases were cross checked and rectified for the "miscellaneous" and "other" cases. We then examined the PSN terminology used in fall reporting, which includes fell from bed/stretcher/table, fell while ambulating, sitting at side of bed, sitting in chair, toileting, transferring, unwitnessed, and other. Over one third of the cases (36.1%, n=130) belongs to unwitnessed case. This "unwitnessed", as an index for aggregating cases, does not provide more information than "miscellaneous" or "other" of other fields. As a result, we successfully revealed "unwitnessed" from reporter's free text description and replaced it with detail-oriented categories (a table not included due to space limits). We assigned "unwitnessed" as a secondary category attached to fall locations.

As shown in Table 1, the prototype with structured step-by-step questions greatly reduced the time needed for mental preparation, typing, and the total action though mouse clicks and mouse & hand moves are slightly increased. This implies that the prototype may increase reporting speed, yet it is subjected to more rigorous user testing with both new and experienced users.

Table 1- Comparison of KLM Analysis Results between the PSN system and Prototype

Action	Standard Operator	PSN system		Prototype	
		Count	Second	Count	Second
Click mouse	B (0.1 Sec)	30	3.00	34	3.40
Move mouse	P (1.1 Sec)	30	33.00	34	37.40
Move hand to mouse/keyboard	H (0.4 Sec)	11	4.40	19	7.60
Time needed for mental preparation	Tm (1.35 Sec)	139	187.65	90	121.50
Type keys	0.28 Sec/key	143	40.04	87	24.36
Total		353	238.09	264	194.26

As a result of mapping between the PSN categories and the national/international standards, seven major categories for fall were created. They are (1)sitting in chair; (2)fell while ambulating; (3)sitting at side of bed; (4)transferring(with assistance); (5)toileting; (6)location + unwitnessed; (7)fell from bed/stretcher/table, and (8)special (not included in the above situations). All the major 7 categories were clearly mapped between ICPS and Common Formats. This compatible taxonomy was used to successfully code 95.6% fall cases. Only 4.4%, coded as "special", cannot fit well in all the other six major categories.

Discussion

The content analysis revealed the overall status of the PSN reports in terms of consistency, accuracy and degree of expressiveness. "Miscellaneous" and "Other" cases were unmatched (mismatched) reports of incident types and error descriptions in the database. Through analyzing the short event summary, which contains the justification of harm score selection, we found that those "miscellaneous" or "other" cases usually can be coded by the categories existing in the system. This may because (1)those reporters were not experts in classification and may select the "safe" categories such as "other", "miscellaneous" due to their time limits or unfamiliarity with the classification for incident type or error description. (2) Only seven major incident types were available in the system and reporters selected "other" or "miscellaneous" when the incident could not properly fit into the description. For example, a patient fall with bleeding may be reported for both "bleeding" and "fall", since the system did not allow reporters to select more than one categories, which might result in "miscellaneous" or "other". (3) In addition, there were a few cases not fit into any existing categories, for example, an "organizational management" delay. In such a case, "other" or "miscellaneous" might be the best choice. If predefined categories do not match reporters' mental model of incident type, it may result in underreporting, incomplete or inaccurate issues. Moreover, reporters may also wish to capture varying levels of details. Therefore, each high-level category (broad concepts) ideally should contain more details through low-level categories (narrow concepts). This strategy may guide reporters to identify an optimal granularity as well as build an interoperable system at the local, regional, and national level. The reasons abovementioned direct designers of voluntary incident reporting systems to better understand the reporters' cognitive characteristics, term requirements on the interface level.

A human-centered design should fully consider both new and experienced users. In such a system, new users will not feel confused even without reading the tutorial whereas experienced users are able to find accelerators to expedite the reporting speed by using short-cuts, default values or preferred interfaces. According to the KLM analysis results, our prototype holds promise in reducing time needed for mental preparation and total steps. For example, (1) the current system requires users choose between "anonymous" and "un-anonymous" radio buttons. Since most reporters use "anonymous" reporting (no release of their work ID), new designs should offer a check box for "un-anonymous" and thus simplify the interface meanwhile make "anonymous" a default value. (2)Auto-completion features would increase the efficiency of pull-down menu selection, which is not offered in the current system. This is especially true when hundreds of names are listed in the menus. (3)Since most cases were reported with 24-48 hours, some convenient time/date stamp buttons (e.g. today, yesterday) could be very useful for reporters to click, rather than manually typing in the day and time or selecting from a calendar, which is laborious and prone to typos. (4)A holistic view that contains all entries of an individual report on a single page would be easy for reporter to conduct final editing and confirmation, rather than forcing reporters to flip pages back and forth to verify. (5)A navigational bar as an indicator of progress towards the completion of a quality report should be offered. This will improve system transparency to users and allow user to estimate if time slot is adequate to finish a report.

Designers for voluntary incident reporting system should notice the balance between efficiency and expressiveness of data entry. Current voluntary reporting systems are mainly template based, which increases data entry speed. Meanwhile, it may have the unintended effect of homogenizing incident descriptions with a loss of detail. For example, rather than asking reporters to recall an entire incident and type a long, time consuming free text description. A set of procedure-based questions, with conditional skips according to previous answers, would guide reporters better through the entire recall process. Moreover, an additional free text box would be offered in case any information not included in those questions deemed valuable for reporting. We suggest an intelligent interface for voluntary reporting based on existing data repository that can predict term requirements and offer intelligent guesses during data entry.

To further our study, we will employ heuristic analysis, user testing to examine the feasibility of our prototype, and apply an ontological approach to maintaining historical data without disrupting current users or altering the meaning of historical data. This pilot study based on an institutional voluntary reporting system contributes to a human-centered framework for voluntary reporting and promotes its migration towards a unified, interoperable reporting format.

Limitations

Accessing to medical incident reports generated in other institutes would definitely increase generalizability of the results. Collaborations between institutions are highly needed. Some inaccurate, incomplete data may be further rectified and analyzed through reviewing the corresponding patient charts. Due to the anonymous and retrospective nature, we are not able to interview the original reporters.

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Enhanced Notification of Infusion Pump Programming Errors

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Abstract

Hospitalized patients receive countless doses of medications through manually programmed infusion pumps. Many medication errors are the result of programming incorrect pump settings. When used appropriately, smart pumps have the potential to detect some programming errors. However, based on the current use of smart pumps, there are conflicting reports on their ability to prevent patient harm without additional capabilities and interfaces to electronic medical records (EMR). We developed a smart system that is connected to the EMR including medication charting that can detect and alert on potential pump programming errors. Acceptable programming limits of dose rate increases in addition to initial drug doses for 23 high-risk medications are monitored. During 22.5 months in a 24 bed ICU, 970 alerts (4% of 25,040 doses, 1.4 alerts per day) were generated for pump settings programmed outside acceptable limits of which 137 (14%) were found to have prevented potential harm. Monitoring pump programming at the system level rather than the pump provides access to additional patient data in the EMR including previous dosage levels, other concurrent medications and caloric intake, age, gender, vitals and laboratory results.

Keywords:

Adverse drug events, Infusion pumps, Patient harm

Introduction

Ninety percent of hospitalized patients receive intravenous medications (IV) [1] and many are delivered by infusion pumps which can provide from 0.1 to 9999mL volumes over a wide range of infusion rates [2]. The pumps are usually programmed by nurses who enter the dose and rate for the specific drug that may be used for adults or premature infants. Function keys on the pumps are used to set dosages as mg/hr, ml/hr, mcg/hr, mcg/kg/min, units/hr, etc.

Adverse drug events (ADEs) were the most common cause of patient harm reported by the Harvard Medical Practice Study [3] and medication errors are the leading cause of ADEs [4]. The Institute of Medicine reported that one medication error occurs per hospitalized patient per day [5]. Patient harm occurs more rapidly and is more severe when ADEs are caused by IV medications [6]. Intensive care patients are at especially high risk for pump programming errors due to the potency and narrow safety margins of the drugs they receive and the fact that many are given via infusion pumps. Old infusion pumps provide dose calculation functions and free-flow protection. Still, 35% to 60% of ADEs involve pumps [1, 2] and most were the result of incorrect programming [2,4,7-9]. New smart pumps have drug libraries of acceptable dosages and infusion rates and provide soft and hard alerts when the pumps are programmed outside of acceptable ranges. [2,10]. Despite the obvious potential of smart pumps to prevent patient harm, there are conflicting reports of their ability to do so without additional capabilities and interfacing to electronic medical records (EMR) [10,11]. We report the development and use of a "smart system" on our EMR to reduce ADEs by enhanced notification of infusion pump programming errors that can be used alone or in addition to smart pumps.

Materials and Methods

Background

Intermountain Medical Center in Salt Lake City, Utah, USA is a 456-bed teaching hospital affiliated with the University of Utah School of Medicine and replaced LDS Hospital in November, 2007 as Intermountain Healthcare's Level One trauma facility. The key feature of the hospital information system is the integrated EMR that contains most clinical information including bedside charting of administered medications. The coded data in the EMR facilitates the development and use of clinical decision support programs to analyze the data and constantly monitor patient care. In 2005, we started the development of a computerized system connected to our EMR to help reduce ADEs caused by infusion pump programming errors.

System Description

The infusion pumps in the ICUs at Intermountain Medical Center currently do not have the smart pump capabilities. We developed an application using a USB to RS232 converter that we connected to the RS232 ports of each pump (Figure 1). The USB side of the converter is connected to a USB hub which is connected to the bedside computers. A program on the bedside computers queries each pump every second and any initial drip rates or changes are sent to a central server. A Java program

(DIAServer) on the central server allows nurses to associate each administered medication to a specific patient and pump in the EMR. When a drip rate change at the pump arrives at the server, the program queries an oracle table to see if it is a monitored medication and if so, checks the table to see if the rate violates the initial or change limits. Maximum initial and rate change limits were defined by a committee of critical care pharmacists, physicians, and nurses for 23 high-risk drugs commonly used for ICU patients. If the rate violates the limits, the program waits 30 seconds to allow the pump programmer to recognize and correct the error. If the rate continues to violate the limits, a message is sent to another JAVA program (AlertServer) on the central server to activate an alert of a potential pump programming error. That program also constantly listens on a TCP/IP port for messages sent from the bedside and nursing station computers which "check-in" with the server every 10 minutes. The server contains a table with the nursing units, room numbers, and IP addresses of each computer. If a computer has not checked-in during the previous hour, that computer is marked as "out of service" and removed from the table and a message is sent to the pagers of the on-call staff to determine the status of the computer. As computers are brought back online, a message is sent to the server. This process ensures that when alerts are sent, the AlertServer program can determine which unit the patient is in and send the message to all the computers in the same unit over the TCP/IP connection.

Another Java program loaded on the bedside and nursing station computers runs as a service in MS Windows. When this program receives the "activate" alert message from the server, it sends a Java frame to the terminal that fills the whole screen. The background of the frame alternates between blue and black every three seconds (Figure 2). The room number and pump number are displayed large enough to be seen from 20 to 25 feet away. There are two ways to turn off the visual alerts sent to all the computers in the unit; 1) fix the dose rate at the pump to within the limits, 2) close the alert window on the computer. If clinicians simply close the alert window on the computer, they have to acknowledge and terminate the alert (overridden alert). The alert also creates a log which is stored and sent via email to the clinical pharmacist. The log includes the patient's encounter number, time of the alert, medication, dose rate, previous dose rate, device number, order number, bag number, and room number. The program also logs how the alert was turned off and the clinician's comments and name.

Pump Use

The pump alerts were implemented in the ICUs at Intermountain Medical Center on November 1, 2007 right after it first opened. When a nurse hangs a medication bag for a patient and programs the pump the first time on the

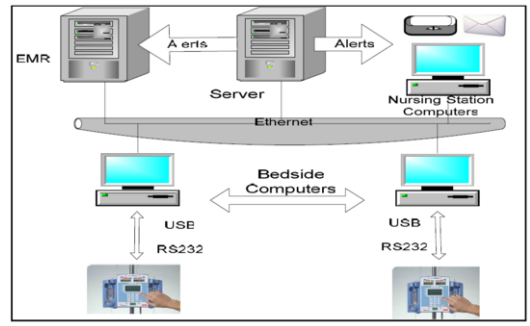

Figure 1 – Diagram of the enhanced infusion pump alerting system.

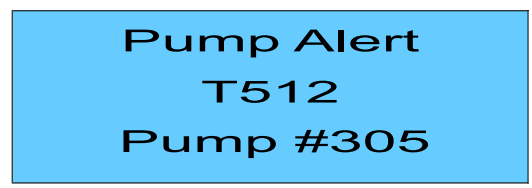

Figure 2 –Example of visual alert sent to every computer in the same unit as the patient.

first bag of the first order, the "initial start" rules are evoked. Any subsequent changes to the pump for that drug are monitored by the "rate change" rules. If the pump is turned off for 60 minutes, the initial start rules are used. While some pumps allow multiple infusions through a single pump, only one infusion per pump is allowed in our ICUs.

Evaluation

A critical care clinical pharmacist (RC) followed up on every pump alert in the 24 bed shock/trauma ICU (STICU) from November 1, 2007 through September 15, 2009 and determined the cause and potential outcome. Pump alerts were classified in the alert log as "fixed" or "overridden" by the nurse. Fixed alerts were those where the programming error was acknowledged and the pump was reprogrammed so the dosage was within acceptable limits. Overridden alerts were acknowledged by the nurse but not changed at that time. Overridden alerts were followed up and discussed with the programming nurse to obtain more information. Alerts were classified as "potential harm" if the clinical pharmacist determined the initial pump settings would have resulted in an incident report of a potential ADE.

Results

During the 22.5 month study, 3,865 unique patient encounters were in the STICU for a total of 13,648 patient days (average 3.5, range <1 - 183 days). Fifty-six percent of the patients were male and 4% were less than 20 years of age, 22% from 20-40, 32% from 41-60, 30% from 61-80 and 12% were older than 80. Most of the patients were admitted due to sepsis, acute respiratory distress syndrome, stroke, trauma and other

critical illnesses. Those patients received a total of 434,163 (average = 112) doses of over 500 different types of medications.

For the 23 different drugs monitored by the alert protocols, the patients received 31,102 different doses of which 25,040 (81%) were delivered via an infusion pump (Table 1). A number of doses of propofol, furosemide and labetalol were given as bolus doses and not via a pump. For the other 20 monitored drugs, all were given via a pump. Of the 25,040 pump doses, 970 (4%, 1.4 alerts per day) generated an alert due to pump settings that were outside of the acceptable ranges. Follow up for each alert found that 137 (14%, 10 per 1,000 patient days) were judged to have prevented potential patient harm. All of the alerts judged as patient harm in this study were the result of obvious infusion pump programming errors. For all but two of those alerts, the pump settings were fixed at the time of the alerts. For two overridden alerts, nurse follow up found that while the nurse overrode the alert they changed the doses to within the acceptable ranges within a few minutes. As seen in the table, the number of generated alerts was usually associated with the total number of drug doses administered. Thus, the more a drug was used, the greater the chance a pump's settings would be incorrect. Of the administered doses, dopamine generated the highest percent of alerts (30%), but none were judged to have caused potential harm. In contrast, only 2% of the fentanyl doses generated alerts, but 71% were judged to have prevented potential patient harm.

The number of alerts generated and the number of alerts resulting in potential patient harm varied during each month of the study (Figure 3). Likewise, there was no pattern as to which bag number was associated with the alert or the potential harm. There were only 33 alerts resulting in potential patient harm when the first bag of the drug was programmed (range 1-53). Thus, 104 of the 137 were the result of catching incorrect dose rate changes.

Discussion

Unlike prescribing and dispensing errors that can be detected and prevented by pharmacists or nurses, incorrect pump programming provides little time to discover and correct the error. This study showed that many doses of high-risk drugs are administered to patients who may be the least capable of tolerating additional harm. The drugs we found to cause the most alerts and potential patient harm are consistent with another recent study of smart pumps and ADEs [11]. Some drugs like fentanyl, norepinephrine, insulin and dopamine generated more alerts in this study because they were titrated more frequently and resulted in more dosage changes to the pump. An insulin drip protocol used in our STICU checks blood glucose levels every 2 hours and could result in a rate change every 2 hours. Dopamine generated a lot of alerts because it is titrated often and alert follow up found that some nurses felt that if they were not getting a patient response soon enough, they would increase the dose for a few minutes to get a response. These types of alerts provided opportunities for process control and nursing education.

Table 1 – Generated alerts and potential harm identified by the enhanced notification of infusion pump programming errors in STICU from Nov. 1, 2007 – Sep. 15, 2009.

Medication	Administered Doses* No.	Generated Alerts No. (%)	Potential Harm No. (%)
Fentanyl	6109	129 (2)	92 (71)
Insulin	5908	314 (5)	29 (9)
Propofol	5257	123 (2)	4 (3)
Norepinephrine	2313	27 (1)	-
Heparin	1505	73 (5)	4 (6)
Amiodarone	1000	22 (2)	-
Dexmedetomidine	550	21 (4)	1 (5)
Vasopressin*	485	34 (7)	5 (15)
Furosemide	372	69 (19)	2 (3)
Diltiazem	318	12 (4)	-
Dopamine	281	84 (30)	-
Dobutamine	207	19 (9)	-
Phenylephrine	193	13 (7)	-
Epinephrine	192	21 (11)	-
Lorazepam	134	5 (4)	-
Milrinone	62	2 (3)	-
Nitroglycerin	40	-	-
Labetalol	34	1 (3)	-
Eptifibatide	32	-	-
Nitroprusside	25	1 (4)	-
Midazolam	12	-	-
Bivalrudin	6	-	-
Isoproterenol	5	-	-
Total	25040	970 (4)	137 (14)

** Doses administered via an infusion pump.*

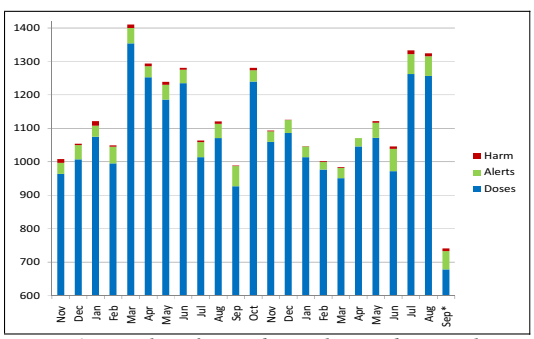

*Figure 3 – Number of pump doses, alerts and potential patient harm during the 22.5 month study. *Only 15 days.*

However, amiodarone is a drug that should only have the dose changed once or twice during the course of therapy. Many of the amiodarone alerts were caused by nurses giving bolus doses through the pump. Giving bolus doses through pumps is considered dangerous, is discouraged and we also educated nursing when it was detected.

The fact that the number of alerts and corresponding bag numbers varied throughout the study indicates that a variety of patient factors and work related distractions often result in pump

programming mistakes. Thus, the potential harm comes from the mechanism of the drug and the often non predictive series of events that lead to the programming errors. Fentanyl caused the most potential harm because of its narrow safety limits and propensity to cause respiratory arrest. A typical alert resulted when a physician wrote an order for extubation and to change the fentanyl drip down from 100mcg/hr to 75mcg/hr. Upon extubation, the patient experienced some complications that required additional treatment and delayed the fentanyl dose change. The nurse then quickly turned the fentanyl drip down to 75mcg/hr. Thirty seconds later all the screens in the ICU begin to flash with a pump alert for that patient. Several nurses and a pharmacist responded to the alert and found the pump running at 75mLs/hr or 750mcg/hr. With the 30 second delay built into the program and the time to respond to the alert, the patient received an extra 8.5 mcg of fentanyl. Before the pump alerts, this likely would have gone unnoticed long enough to require re-intubation and/or caused other physiological harm to the patient. In addition to respiratory arrest, many of these drugs, dopamine, norepinephrine and epinephrine can cause cardiac arrest, a neurological coma (insulin) or serious bleeding (heparin).

As shown in the table, most of the pump alerts did not result in patient harm. This is also consistent with other studies that found medication errors associated with infusion pumps were frequent, but most would not have resulted in patient harm [1,10,11]. One of those studies reported that current smart pumps would fail to generate meaningful improvement in patient safety until they can be interfaced to electronic medical records, computerized provider order entry and bar coding [11]. One of the first studies on the use of smart pumps did not find a statistically significant difference in ADE rates or severity when smart pumps were used [10]. Nurses could bypass drug libraries and override soft alerts. Nurses were found to only use the drug libraries between 31% to 75% of the time due to the extra time required to use the library. Conversely, a study at a pediatric hospital showed that ADEs dropped 75% when smart pumps were implemented [12]. However the direct role of the smart pumps is unclear since standard drug concentrations and improved medication labels were introduced at the same time and ADE rates were dependant on voluntary incident reporting. A study at Vanderbilt reported that smart pumps appeared to prevent errors involving heparin [13] and another study suggested that smart infusion pumps should be the standard for safety in intensive care [14]. The fact that the smart pump libraries automatically switch to the appropriate concentration and measurement units should reduce the potential for error by eliminating the need to make unit conversions. Moreover, a benefit of smart pumps and our smart system is the ability to examine the alert logs and monitor overrides and potential harm. Constant overrides can indicate the need for logic changes or further education and potential quality intervention. One of the reasons we had such a high alert rate with dopamine was because of how the alerts were initially set up. The dose increase limit was originally >= 5 mcg/kg/min. The cardiovascular group always increased by 5, so changing it to > 5 mcg/kg/min reduced those false alerts.

Advantages of a Smart System

Since the smart system logic occurs at the patient level and not at the pump, any coded patient data in the EMR can be included. We have an insulin alert that checks for concurrent total parental nutrition (TPN) in a different pump. If the TPN is turned off and the insulin is continued, an alert notifies nurses of the calorie and insulin inconsistency. In addition to concurrent drug therapy alerts, logic can include patient age, gender, renal function, weight, pregnancy status, vital signs such as blood pressure for patients on propofol, laboratory prothrombin times for patients receiving heparin or glucose results for patients receiving insulin. Smart pumps currently only have access to the current medication and acceptable dosage ranges, but not drug specific rate increase limits. Most of the potential patient harm detected in this study was due to dose rate increases rather than programmed dosages outside of initial dosages ranges.

It takes extra time to switch smart pumps to dose-checking mode and then access the drug library. Nurses find shortcuts for tasks they view as extra work or don't understand the potential patient harm [10]. In a smart system, no extra nursing time is required at the pump and the initial and rate change settings are always monitored. Likewise, adding or changing alert logic in a smart system can be done in the single knowledge base that monitors all infusion pumps in the hospital. This replaces the need and cost of having to have each pump reprogrammed. However, newer wireless smart pumps allow the logic changes to take place at one location and then sent to multiple infusion pumps.

Since pumps may be used in different types of nursing units, some smart pumps prompt the programmer for the specific care area the patient is in. The smart system automatically checks the room of the patient preventing the potential incorrect programming of the unit. For example, there are two vasopressin dosage settings in our logic. The STICU and the cardiovascular ICU use vasopressin differently. Thus, the smart system automatically selects the correct ranges. Likewise, the dose limits for heparin and insulin in our smart system are based on very specific unit protocols and require additional data from the EMR.

When smart pumps detect that cardiac drugs are running out, they can be programmed to go into Keep Vein Open (KVO) to reduce the drug rate, but keep the vein open. But, if not detected, the drug will eventually run out. Our system goes into KVO and also sends a unit-wide alert if it is not detected within 45 seconds.

Another benefit of our smart system was improved nurse charting of medications in the EMR. On occasion, nurses would delay the medication charting of the changes of the drugs on a pump. Nurses soon found with the smart system, if they did not chart a change in drugs before hanging and programming the new drug, the new dosages would usually generate an alert. Initially, nursing acceptance of unit-wide alerts was questioned. Nurses soon recognized the value of the alerts as potential harm was detected and prevented. Nurses now accept the alerts and appreciate the backup. Due to the visibility of the unit-wide alerts, nurses are not more prone to be careless and become dependent on the alerts.

Limitations

We installed the pump alerts in the new STICU when it first opened, and did not have any baseline ADE data for

comparison. However, our goal was to catch and reduce pump programming errors and not ADEs in general. Also, some of our drug limits could be considered as liberal. The current logic is set up to catch the obvious programming errors and giving bolus doses through the pumps. Thus, some additional patient harm was not detected by our alerts.

While the 30 second delay built into the logic increases nurse acceptance by allowing them to catch and correct an obvious error before the alerts are generated, it also exposes the patient to some degree of potential harm. While we detect the "nurse catches", we did not include them in the permanent alert log. Thus, we cannot report how often nurses caught their own errors within the 30 second delay.

One study found that 59.8% of their smart pump alerts were underdoses [15]. We only monitored and reported programming errors due to pump settings greater than acceptable limits (overdoses). Thus, we did not include underdoses for drugs like heparin that can also result in patient harm by not achieving the intended therapeutic drug levels. Likewise, we only monitored 23 different high-risk drugs in this study. There are seven additional drugs commonly administered via pumps in our ICUs that we could add, but we do not expect a large decrease in potential harm relative to the increase in alerts. The potential for "alert fatigue" should always be included in discussions to implement decision support of patient care.

Conclusion

We found our smart system prevented a number of pump programming errors from resulting in patient harm. Nurse and physician acceptance is extremely high and the system is being enhanced and installed in other hospitals.

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Extraction of Adverse Drug Effects from Clinical Records

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Abstract

With the rapidly growing use of electronic health records, the possibility of large-scale clinical information extraction has drawn much attention. We aim to extract adverse drug events and effects from records. As the first step of this challenge, this study assessed (1) how much adverse-effect information is contained in records, and (2) automatic extracting accuracy of the current standard Natural Language Processing (NLP) system. Results revealed that 7.7% of records include adverse event information, and that 59% of them (4.5% in total) can be extracted automatically. This result is particularly encouraging, considering the massive amounts of records, which are increasing daily.

Keywords:

Adverse effect, Side effect, Drug trial, Natural language processing (NLP)

Introduction

The use of Electronic Health Records (EHR) in hospitals is increasing rapidly everywhere. They contain much clinical information about a patient's health, including the frequency of drug usage, related side-effects, and so on, which facilitates unprecedented large-scale research. Nevertheless, extracting clinical information from the reports is not easy because they are written in natural language. This study specifically examines adverse effects and event information buried in EHR.

Why is Adverse Effect Information needed?

For each approved drug, adverse effects are investigated through multiple phases of clinical trials. Clinical trials usually target only a single drug. Consequently, it is difficult to capture detailed effects resulting from multiple drug administration.

Real patients sometimes take multiple medications (e.g. prophylactic administration), leading to a gap separating the clinical trials and the actual use of drugs by patients. For ensuring patient safety, it is extremely important to bridge that gap.

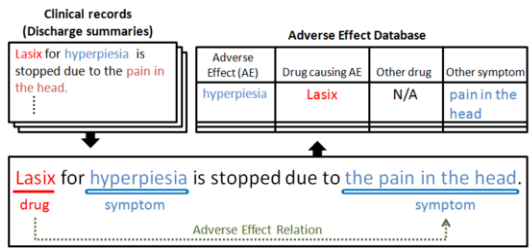

Figure 1- Proposed approach

Adverse Effect Extraction

For such situations, we have started a project to extract adverse effect information from clinical records. As the first step, this paper presents examination of the following two questions.

(1) How much adverse information is included in records? To investigate this, we manually checked the information included in hundreds of records

(2) How to extract the information? Manual checking of all records takes too much time. Therefore, we attempted automatic extraction. We regard the adverse effect extraction task as including two sub-tasks (STEP 1) "term identification" and (STEP 2) "relation extraction."

STEP 1: Term identification: First, the system identifies drug and symptom expressions in records. This task is almost equivalent to the Named Entity Recognition (NER) task in NLP. We use a state-of-the-art NER method: conditional random fields (CRF) [1].

STEP 2: Relation identification: Then the system identifies which effect is related to which drug (adverse effect relation between a drug and an effect). We use both a pattern-based method and machine learning (SVM[2]) based method.

Through STEP 1 and STEP 2, a pair of a drug and an adverse effect is extracted along with other information (other drugs and symptoms) and is stored in a database (Fig. 1).

Although experiments described in this paper are related to Japanese medical reports, the proposed method does not depend on a specific language or domain.

Specific Research Questions

The specific goals of this study were the following:

1. To investigate how much adverse effect information exists in the clinical records (described in Section 2; *Materials*)

2. To investigate the accuracy with which the current technique (automatically) was able to extract adverse effect information (described in Section 4; *Experiments*)

Materials

This section introduces the materials (clinical records) used for this study, and reports summary data related to the adverse effects contained in the material.

Clinical Records (Discharge Summaries)

The materials of this study are 3,012 discharge summaries[1], which are reports generated by medical personnel at the end of a patient's hospital stay. The summaries were gathered from all departments of the University of Tokyo Hospital[2]. Because it costs much time to survey all summaries manually, we split the summaries into two sets: SET A, which contains keywords related to adverse effects (a keyword set is presented in Table 1); and SET B, which contains no keywords. Consequently, we obtained SET A consisting of 435 summaries, and SET B consisting of 2,577 summaries. Regarding SET A, we manually checked all of them. For SET B, four annotators checked small parts (randomly sampled) of them. Cases of ambiguity were resolved through discussion. We regarded even a suspicion of an adverse effect as positive data.

Quantities of Adverse Effects in Summaries

The results are presented in Fig. 2. For SET A, 53.5% (=233/435) of summaries described adverse effects. For SET B, 11.3% (=6/53) summaries described adverse effects. The ratio of SET A: SET B was 435:2577 (SET A=14.5%: SET B=85.5%). To sum up the results, we estimated that at least 7.7% (=0.145×0.535; only SET A) of summaries contain a description of adverse effects. Even considering that the result includes merely a suspicion of adverse effects, the summaries are a valuable resource for assessing adverse effects.

Annotation for Machine Learning (SET A Only)

To use a machine learning method, we also added tags to records. This annotation is limited to SET A because the other set (SET B) included few descriptions of adverse effects. The annotation includes information of two types: (1) term annotation, and (2) relation annotation.

(1) Term Annotation: Term annotation includes two tag types: (a) an expression for a drug, and (b) an expression for an effect. The definition is presented in Table 2. We annotated 1,045 drugs and 3,601 possible effects.

(2) Relation Annotation: Adverse effects were annotated. We represent the effect as a relation between a drug <d> and a symptom <s>, which is represented as a "relation" attribute. Table 3 shows several examples, wherein "relation =1" indicates an ID of a drug – adverse effect relation, which is a unique number in the text. We annotated 460 relations.

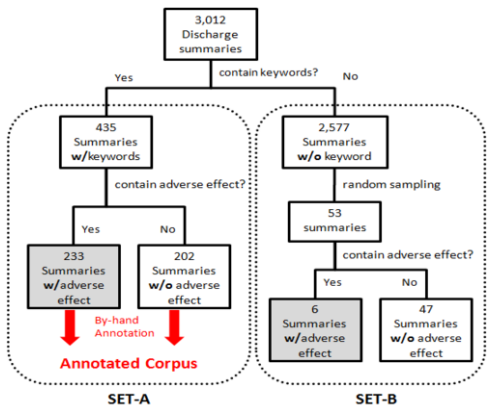

Figure 2 - Data Configuration

Table 1 - Set of Keywords

Stop, stepped, Change changed, adverse effect, side effect

Table 2 - Markup Scheme (Tags and Definitions)

Tag	Definition (Examples)
s (symptom)	An expression of disease or symptom: e.g. *endometrial cancer, headache*. This tag covers not only a noun phrase but also a verb phrase such as "<s>*feel a pain in front of head*</s>".
d (drug)	An expression of medication of administration of a drug. Some examples are *Levofloxacin, Flexeril*

Table 3 - Annotation Example

<d relation="1">*ridora*</d>*resumed because it is associated with an* <s relation="1"> *eczematous rash* </s>
<d relation="1">*ACTOS(30)*</d> *brought both* <s relation="1">*headache*</s> *and* <s relation="1">*insomnia*</s>

* If a drug has two or more side effects, then they share the same ID. For example, *ACTOS* has two symptoms in the following:

Methods

The prior section explained that 7.7% of the records contain adverse-effect information. This section describes the standard two-step NLP used to extract information automatically.

[1] That amount roughly corresponds to summaries accumulated in one month at the University of Tokyo Hospital.

[2] All private information was removed from them. The definition of private information was referred from the HIPAA guidelines.

STEP 1: Term Identification

First, terms in records are identified. This task is similar to Named Entity Recognition (NER). Therefore, we use a state-of-the art NER method (conditional random fields (CRFs)), which has been shown to provide high performance for many tasks, such as part-of-speech tagging [1], text chunking [3], information extraction [4], and named entity recognition [5]. The detailed manner is described in a previous report [6].
In learning, we use standard parameters[3] and features as presented in Table 4. The only difference between the previous studies and this method is the dictionary feature.

STEP 2: Relation Identification

Then, the system decides which drug caused which symptom. For this identification, we compared two methods; a pattern based method, and a Support Vector Machine (SVM) based method.

Table 4 - Features for Term Identification

Lexicon & Stem	Target word (and its stem) and its surrounding words (and stem). The window size is five words (-2, -1, 0, 1, 2).
POS	Part of speech of TW and its surrounding words (-2, -1, 0, 1, 2). The part of speech is analyzed using a POS tagger[4].
DIC	A fragment for the target word appears in the medical dictionary MedDRA/J [7] consisting of covered 47,665 terms (lower level terms), and a drug name list (30,085 terms), which comes from drug package inserts [8].

Table 5 - Relation Identification Algorithm

```
1: procedure Relation_Identify (D, S, K, n)
2: for each drug d in D do
3:     for each symptom s in S do
4:         for each symptom k in K do
5:         pattern_based_identifier (d, s, k, n)
```

* *D* is a set of drugs in the target record; *S* is a set of symptoms in the record; *K* is a set of keywords shown in Table 1; *n* is the parameter of the pattern (window size)

Pattern based relation identifier: The procedure is presented in Table 5. The system judges whether each extracted term pair (*d* and *s*) has an adverse effect relation or not. The judgment is based on heuristic-rule-based patterns (Table 6).

Table 6 - Patterns for Relation Identification

*d*s*k*	*s*d*k*	*k*s*d*
*d*k* s*	*s*k*d*	*k*d*s*

"*" represents a wildcard for *n* words, where *n* is a parameter of window size

[3] *f*=3 *c*=1.5 window size=3
[4] http://chasen-legacy.sourceforge.jp/

For example, given the example in Figure 3, the pattern "*d*k*s*" identifies an "*ACTOS-edema*" relation. Although the pattern is simple, it might suggest the difficulty of the task.

SVM based relation identifier: The SVM based method utilizes features as shown in Table 7 instead of patterns. The features come from words from a drug and a symptom. For example, we regard "*but stop for relief of the*" as a "word chain" feature in the Figure 3. For training, we regard a pair of a drug and a symptom sharing the same relation id as a positive sample, and the other pairs as negative samples. We utilized an RBF kernel, which has two parameters (C and gamma). We checked the performance with various parameter settings.

Table 7 - Features for Relation Identification

Symptom Lexicon	A symptom term
Drug Lexicon	A drug term
Word Chain	A series of words between a symptom and a drug.
Distance	A distance (the number of characters) between a drug term and a symptom term.

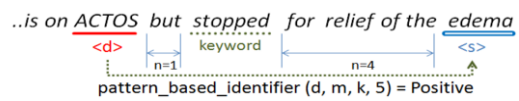

Figure 3 - Relation Extraction Example

Experiments

We investigate performance of two types: (1) term identification, and (2) relation extraction. The experimental design is portrayed in Figure 4.

Experiment 1 (Term Identification)

Experimental Setting: We collected 435 Japanese discharge summaries, as described in Section 2.

Evaluation: We conducted experiments in a ten-fold cross validation manner. The performance is evaluated in the precision, recall, and *F*-measure attributable to the standard NE manner.

Results: Table 8 shows that we obtained all scores of more than 80%. This accuracy is higher than the Japanese NE task result (shown in IREX [10]) in which the best system's accuracy is *F*-measure of 0.68. That result indicates that the term identification in records is easier than the other tasks.

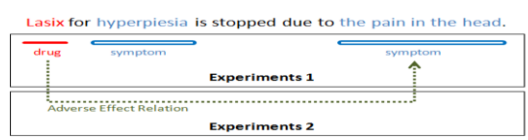

Figure 4 - Experimental Design

Table 8 - Term Identification Results

	Precision	Recall	*F*-measure
s (Symptom)	0.855	0.802	0.828
d (Drug)	0.869	0.813	0.840

Experiment 2 (Relation Identification)

Experimental Setting: Because this experiment specifically examines relation identification performance, we adopt an oracle setting, wherein terms in a text are identified correctly.

Evaluation: The evaluation manner is identical to that in Experiment 1; ten-fold validation, precision, Recall and *F*-measure. We compared two methods: pattern-based (PTN) and SVM based (SVM). We checked the performance of various parameters. The F-measure curve in SVM is shown in Figure 5. We checked the possible combinations of two parameters and picked up the highest f-measure points (Table 9).

Results: Both PTN and SVM F-measures were lower than 0.65, indicating this is difficult task. Especially, SVM obtained a significantly lower performance than PTN (p=.05). One of the reasons is the amount of training data (especially positive data) is too small to capture the complex phenomena.

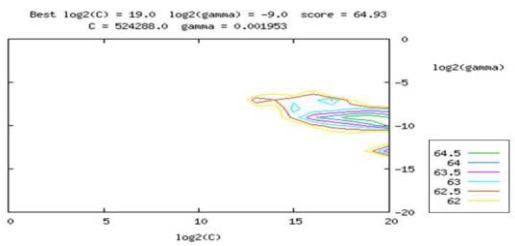

Figure 5 - F-measure in Various Parameters (C & gamma)

Table 9 - Relation Identification Results

	Precision	Recall	F-measure
PTN	0.411	0.917	0.650
SVM	0.576	0.623	0.598

Discussion

The experimental results revealed two salient facts.

1. How much information related to adverse effect is included in discharge summaries?

From the material, we infer that about 7.7% of the summaries contain information related to adverse effects.

2. To what extent are adverse effects extracted automatically?

The overall accuracy is estimated using the combined accuracies in experiment 1 and experiment 2: (accuracy of syndrome identification) × (that of drug) × (that of relation identification). Table 10 shows the result. Although the accuracy is insufficient (see precision 0.30), the proposed method (both SVM and PTN) could control the balance of precision and recall (Figure 6), which enables several practical applications appear promising: automatic mining under a high-precision setting, or pre-processing for human checks under the high-recall setting.

Table 10 - Results of Overall Accuracy

PTN	Precision	0.301 (=0.855 × 0.869 × 0.411)
	recall	0.597 (=0.802 × 0.813 × 0.917)

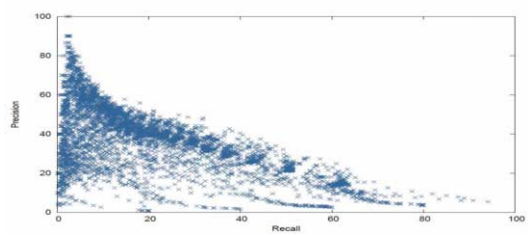

Figure 6 - Precision & Recall curve in SVM

Remaining problems

Training data: Compared with term identification, relation identification has low accuracy, which degrades the overall accuracy. Usually, the relation identification is solved using a machine learning approach (see a series of shared tasks [8]), we use that approach only slightly because adverse effects are rare events in records (the positive data are few).

Future studies should (1) increase training data to incorporate machine-learning techniques, or (2) apply another technique that works with small samples, such as active learning.

Variants: Another problem is orthographic variants. A typical example is "*WBC decrease*", "*WBC depression*" or "*reduced WBC*" that share the same concept, but which have different expressions. Such variants engender serious problems in the symptom-aggregating process. In the future, normalizing techniques are highly desired.

Demonstration System

The presented system is available on the web (Figure 7). The annotation guidelines and sample corpora are also downloadable.

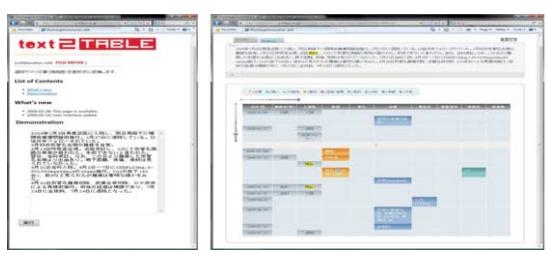

Figure 7 - Demonstration System

** free text input in the left window is converted into a database structure in the right window. http://luululu.com/text2table*

Related Work

Adverse Event/Effect Database

To date, several adverse effect databases are manually maintained, such as ARRS and GPRD.

The Adverse Event Reporting System (ARRS) is a famous adverse event database that is designed to support the FDA's safety program for all approved drugs. Reporting of adverse events from the point of care is voluntary in the United States. The current version of AERS contains 4,000,000 reports. The General Practice Research Database (GPRD) is a large database of medical records (over 3.6 million patients in the UK).
Compared with the large databases described above, the data in this study are few and have low reliability. However, the automatic technique is highly desired considering the rapidly growing use of new medicines. We believe that the proposed automatic approach will be useful.

Related Natural Language Processing Studies

1. *Term Identification*
Recent term identification uses machine-learning techniques such as Support Vector Machine (SVM) [2] and CRF [1]). Because of such trends, such techniques are also used in a clinical context [11,12]. We use the same approach as that in a previous study [11]; it effectively works with our corpus.

2. *Relation Identification*
Relation identification has drawn much attention from various fields: Information Extraction (IE) fields such as MUC [13] and ACE [14], semantic relations (such as Semantic Relation tasks at SemEval2007 [15]) and Protein–Protein Interaction ontology. In all fields described above, machine-learning-based approaches using annotated corpora are popular.
This study deals with low-frequency phenomena (adverse events). Therefore, machine-learning approaches suffer from a paucity of positive data. As described in the *Discussion* section, we must solve this problem.

Conclusion

The method described in this paper extracts adverse drug events from texts in records. First, we annotated 435 discharge summaries with adverse effect information. Then, using the corpus, we investigated how much the current NLP system extracted the information. The results revealed that 7.7% of the records contain adverse event information; 59% of them (4.5% in all) were extracted (recall 59%; precision 30%). This result is encouraging, especially considering the massive and continually accumulating amounts of records. In the future, a high precision method is highly desired.

Acknowledgments

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SeReM^2 - A Meta-Model for the structured Definition of Quality Requirements for Electronic Health Record Services

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Abstract

Quality assurance is a major task with regard to Electronic Health Records (EHR). Currently there are only a few approaches explicitly dealing with the quality of EHR services as a whole. The objective of this paper is to introduce a new Meta-Model to structure and describe quality requirements of EHRs. This approach should support the transnational quality certification of EHR services. The Model was developed based on interviews with 24 experts and a systematic literature search and comprises a service and requirements model. The service model represents the structure of a service whereas the requirements model can be used to assign specific predefined aims and requirements to a service. The new model differs from existing approaches as it accounts for modern software architectures and the special attributes of EHRs.

Keywords:

Electronic health record, Service, Quality, Requirements, Meta-model

Introduction

The idea of comprehensive Electronic Health Record had its origin in the early 90s and was first - amongst others - discussed by Waegemann (see e.g. [1]). Since that time a great number of projects and efforts were dedicated to the development of this basic idea. This fact has still not changed but the recent past shows that more and more of the research that was conducted is introduced in real life environments. Particularly Scandinavian countries are on the cusp of introducing EHR systems or at least parts of it (e.g. Denmark [2, 3]).

The success of such an EHR introduction is – apart from the mere technical questions – strongly dependent on the definition and fulfillment of a variety of different requirements on a functional and non-functional level. The definition respectively the coordination of such requirements is extremely difficult. This is due to several factors such as different norms and standards, legislation, different strength or heterogeneity of stakeholders within a country etc.

The general question in this context is: How can the quality of EHR services be defined? Basically, quality can be defined as the degree to which a set of inherent characteristics fulfills requirements (technocratic definition) [4]. But the actual definition and characterization of EHR quality poses a problem, as the large heterogeneity in existing requirements or tacit knowledge makes it difficult to define a consolidated set of characteristics that has to be fulfilled.

As the conceptual design and prototypical implementation were in the center of interest till the recent past, there aren't many initiatives so far that focus on the quality neither of EHRs nor on quality of EHRs as a whole. Quality approaches such as the ones from CCHIT [5] or EuroRec [6] have a very strong functional focus; the IHE again solely focuses on interoperability. Other more generic approaches such as FURPS+ [7] or the ISO 9126 [8] do not account for the specific requirements of EHRs.

The paper presents a Meta-Model to describe and structure quality requirements for EHR services. The model serves as a basis during/after requirements engineering as well as for potential quality certifications. It should increase, amongst others, transparency and comparability between systems and aims at an increase of the quality of requirements description and structure. Furthermore, potential users should be supported during the selection process of different EHRs. The approach also accounts for the particular characteristics of modern EHRs such as service oriented architectures, heterogeneous requirements, different vendors or interoperability.

Methods

The Meta-Model for quality requirements that is described in this paper was developed as part of an extensive research project that started in 2007 with the aim to support transnational quality certification of EHR services. The Meta-Model is part of a comprehensive framework including a large requirement repository (> 1200 EHR specific requirements), a language to formally represent the structural model, a thesaurus and a model to categorize requirements, a process model etc. To develop the model an expert survey and literature analysis in the middle of 2008 was conducted.

Data collection - Literature analysis

To collect all relevant publications for the data analysis PubMed, IEEExplore, Google and ACM Digital Library were used. The search was targeted towards publications on software quality and software certification with regard to electronic medical records in general.

The following initial list of keywords or keyword combinations was used: software, quality, software engineering, certification, software model, Health Record, Standards, EHR certification and EHR quality. This initial list of keywords was obtained by selecting relevant MeSh-Terms. Through the analysis of the documents found during the process further keywords and document sources were discovered and subsequently used. In total 400 sources were found of which 63 sources were relevant for this work.

Data collection – Expert survey

The expert survey was designed as qualitative problem-centric interviews. 50 Experts from the domains of legislation, standards, norms, data security, industry and science were initially selected. An expert was defined as a person that works in the field of clinical information systems for more than 3 years and is actively involved in the development (design/implementation) of Electronic Health Records. In total, 26 experts all over Europe (special focus on German-speaking and English-speaking countries) were questioned about general as well as detailed requirements regarding quality certification of EHR services. We applied the concept of theoretical saturation to both, the literature analysis as well as the expert survey, meaning that we stopped the research as the analysis of interviews and documents did not yield fundamentally new results.

Data analysis

Documents that were retrieved were analyzed by two independent reviewers. In the first step documents were roughly judged regarding quality and content. This was done by selecting scientifically published (peer-reviewed conferences, journals etc.) documents only and analyzing their abstract. Reviewers afterwards discussed their results to match all discrepancies in selection that occurred.

Selected documents as well as the results from the expert survey were analyzed in detail. Techniques of qualitative content analysis as described e.g. in [9] or [10] were used to derive quality requirements for EHR services.

Results

The following paragraphs describe the different elements and sub-models of the Meta-Model as well as general Meta-Model constraints. The Meta-Model is divided in two interdependent sub-models, a service model and a requirements model. This separation better reflects/distinguishes the structure of a service from its requirements. The service model is therefore used to describe the structure of an EHR service, whereas the requirements model is used to structure the requirements of EHR services. It is important to notice that the Meta-Model is not aiming at the definition or selection of specific requirements for an EHR service, but rather as a method to structure requirements.

Initial Situation and Model Constraints

To be able to represent EHR services, their structure and requirements using a Meta-Model the actual complexity of EHR services with regard to their structure had to be reduced resulting in different constraints, definitions and relations.

Summarizing these results a service is defined as an application program that runs on a (hardware) device using different communication means and transmitting various content by these means. Services may use other services to provide certain functionality. For this purpose services communicate with other services bi-directional, exchange information and compute information. Infrastructure neither communication infrastructure nor devices are of interest with regard to the current Meta-Model. Also Services that are needed to execute EHR services (e.g. operating system) are not part of the Meta-Model.

Service Model

The Service Model is used to describe the EHR service with its basic structural components aiming at the later, structured assignment of requirements. The Service Model defines an EHR service as the sum of the services that it consists of respectively that it uses to provide certain functionality. It is not regarded as a monolithic entity (see Figure 1). Such an approach is particularly important for the representation of applications that are based on service-oriented architectures where services may use different and sometimes even changing services in different physical or logical locations to provide functionality.

The root element of the Service Model is a certain service. Different structural elements and sub-elements (such as Application-Logic-Element, User-Interface-Element etc.) are assigned to this root element depending on the components a service consists of. All possible Elements that may be assigned are displayed in Figure 1. These structural elements are used as containers to assign different elements from the requirements model and subsequently specific requirements (see Requirements Model below). All structural elements of the service sub-model are categorized either as external or internal visible from the viewpoint of the service.

When a specific service is modeled using the service model not all of the structural elements need to be used. This is solely dependent on the requirements that are modeled for a service (see chapter Example of use). Figure 1 describes the Service Model and contains all structural elements defined (see also Figure 2).

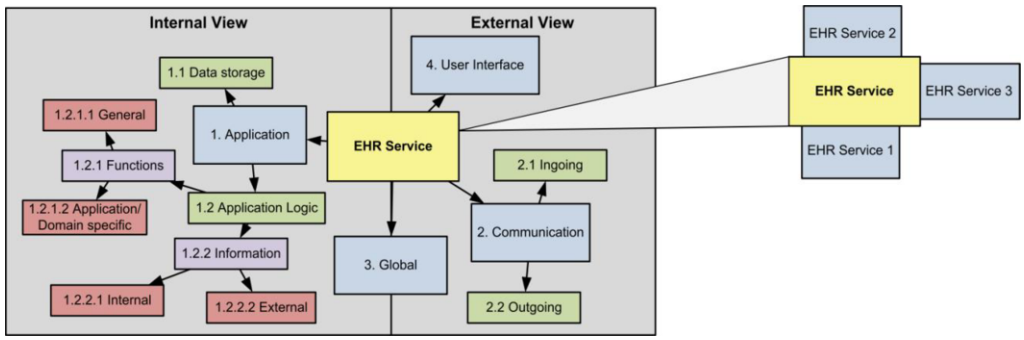

Figure 1 - Service Model

The EHR Service consists of / uses different services to provide its functionality (in this case three). The Arrows define a hierarchical order within the structural elements of the model. Colors represent the hierarchical layers. All structural elements are either part of the internal or external view except the Global-Element

Requirements Model

Whereas the service model describes the structure of a service, the requirements model describes and structures specific requirements that were selected for a certain EHR service. The basic idea of the Requirements Model is to define requirements on different levels of abstraction and to link dependent requirements.

The model consists of four basic elements: quality objectives, generic requirements, implementations and metrics. These elements are mainly determined by the content they represent and their sensitivity with regard to change during lifetime of a service. See Figure 2 for the elements of the Requirements Model and their relationships.

Quality objectives

These elements mainly have two functions they define long lasting objectives regarding the quality of a service and they are used to group generic requirements and other quality objectives. Quality objectives can be assigned to more than one other quality objective if applicable. A Quality objective needs to have at least one generic requirement to be assigned.

Generic Requirements

A generic requirement is used as a container for actual requirements that are assigned to an EHR service.

The main purpose is to describe a certain requirement with the objective of stating what has to be implemented / fulfilled by the service. One or more implementation elements can be assigned to a generic requirement. If a generic requirement has no implementation elements assigned then it is necessary to assign at least one metric.

Implementations

Implementation elements contain rules or references to certain existing rules such as standards or norms which describe how generic requirements must be implemented. Every implementation element must link to at least one metric element.

Metrics

Metrics are again rules or references to rules that in this case describe procedures how requirement elements respectively implementation elements can be checked for their fulfillment. Metrics do always have a certain type. So far a metric may be of one of the following types: value, presence, rate and combined type.

Sensitivity regarding the change of Requirements

As all elements were described regarding content and structure so far it is also of major importance to reflect the elements against the background of change during the lifecycle of an EHR service.

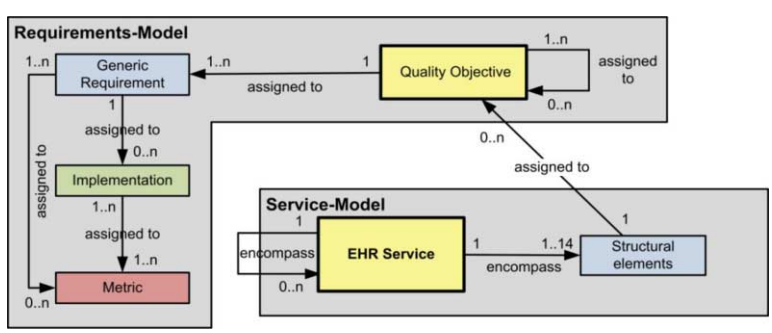

Figure 2 – Summary of all Elements and Interdependencies

With regard to requirement changes quality objectives are intended to face much smaller changes over time therefore they are highly suitable to describe medium and/or long-term aims. Generic requirements are subject to greater changes and represent medium-term aims. Implementations are suitable to describe the current state of the art and subsequently short-term aims. Figure 3 illustrates this matter schematically.

The requirements model, the service model and their interdependencies are summarized graphically in Figure 3.

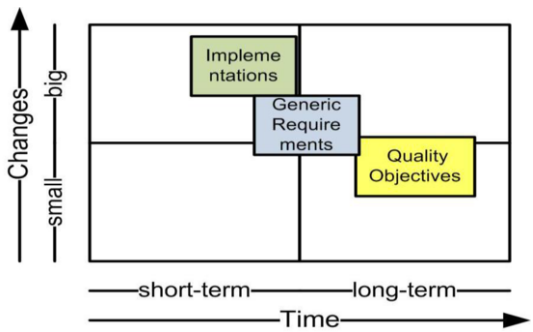

Figure 3 - Requirement Model Elements in Dependence of Time and Change

Example of Use

To illustrate the use of the Meta-Model a brief example is shown in Figure 4 and Table 1. The EHR service that is modeled is a Diabetes Diary which features a glucose meter import service, a web portal for additional data entry / display and a chart service to plot the results gathered as well as other services not mentioned here (see Figure 4). The services that compose the diary are not offered by the same organizations. The diary and the web portal belong to organization C, the chart service is offered by organization A and the Import service by organization B who also offers the glucose meter.

The import service which is displayed in the figure in detail as part of the diary does not make use of all structural elements of the service model. As the import service doesn't have a user interface or doesn't store data the corresponding structural elements are not modeled for the service.

Other services offered by the diary do have a user interface such as the web portal service. Therefore the structural element 'User Interface' is modeled for the portal service. Table 1 contains exemplary and randomly selected user interface requirements for such a service taken from the requirements repository which was also established as part of this project. The requirements are structured according to the requirement model (QO – Quality Objective; GR – Generic Requirement; IP – Implementation). Table 1 points out that all requirements used have a unique, service-independent ID to identify them.

The unique and service-independent identification is especially important for the comparison and consolidation of different services and their requirements.

Table 1 – Exemplary and randomly selected requirements for the User-Interface-Element of the Portal Service
(Legend: QO – Quality Objective GR – Generic Requirement; IP – Implementation)

Requirements Web Portal Service User Interface
QO - The interface should be user friendly (UI57)
GR - The user interface should be context sensitive (UI12)
QO - Forms should be user friendly (UI32)
GR - Forms should be structured (UI39)
GR - The user interface should be consistent (UI19)
IP - Icons should be unambiguous and conform to industry standards (UI86)
IP - The fonts should be consistent and easily readable (UI124)
IP - Screen item placement should be predictable (UI432)
GR - The user interface should be customizable (UI213)
IP - Font size should be customizable (UI17)
IP - Icon placement should be customizable (UI83)

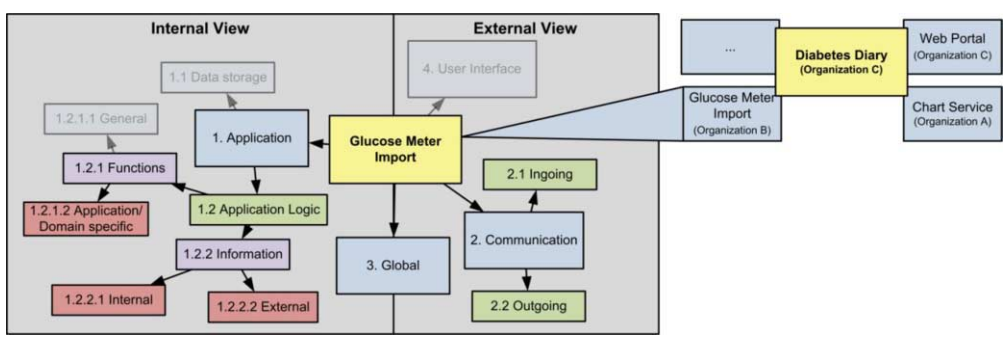

Figure 4 - Brief Example for the Service Model of a Diabetes Diary Service
Structural elements colored in grey (e.g. User Interface) are not used / applicable for this service

Discussion

SeReM^2 as presented in this paper is a Meta-Model that supports quality assurance as well as requirements engineering during the lifecycle of an EHR service. In comparison to existing EHR specific certification approaches such as the ones from the CCHIT [5] or EuroRec [6] or general software quality approaches e.g. Dromey [11], Boehm [12], FURPS+ [7] or the ISO 9126 [8] our approach features significant differences/advantages.

Complex structures and increased transparency

In general it is easier to represent complex service structures especially those based on service-oriented architectures. Interdependencies of different services that provide certain functionality are transparent.

It is not necessary to mix requirements of different services. Composed services can clearly be separated in terms of their requirements but not completely separated.

The afore mentioned approaches do not regard a service as the sum of different other services and therefore do not or only in a limited way offer these possibilities.

Better maintenance and comparability of requirements

Due to the classification of requirements in different levels of granularity the change process during the lifecycle of a service is better supported. Requirements can be discussed and changed on different levels improving the integration of different stakeholders in the definition and maintenance of requirements.

Comparison of different services and their requirements is supported as requirements are more structured. This is particularly true as requirements are split in different levels.

Existing approaches mainly categorize requirements but do not differentiate within requirements.

Selected further advantages

The model supports the inheritance of requirements for different services. This is the basis for requirements patterns for specific services such as web portal service. The model can be used to represent both, the requirements and the attributes of a service.

Limitations and drawbacks

So far the Meta-Model was used to model and structure requirements for a system run by the TILAK (Tyrolean Federal Hospitals) which is used by general practitioners to retrieve doctor's letters, laboratory and radiology findings. It is also used as a basis for the development of an EHR certification approach within ProRec Austria and is used to model requirements for the selection of specific EHR services by the Wiener KAV (Vienna Hospitals Association). So far all tests were successful but to fully proof the model more tests especially with complex systems are indicated.

At the moment there is also little tool support to implement the model for real system. The majority of the modeling tasks have to be carried out manually.

The approach does not support the user with guidelines regarding the categorization and actual structuring of specific requirements.

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Exploiting UMLS Semantics for Checking Semantic Consistency among UMLS concepts

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Abstract

Objectives: To quantify semantic inconsistency in UMLS concepts from the perspective of their hierarchical relations and to show through examples how semantically-inconsistent concepts can help reveal erroneous synonymy relations. Methods: Inconsistency is defined in reference to concepts from the UMLS Metathesaurus. Consistency is evaluated by comparing the semantic groups of the two concepts in each pair of hierarchically-related concepts. A limited number of inconsistent concepts was inspected manually. Results: 81,512 concepts are inconsistent due to the differences in semantic groups between a concept and its parent. Four examples of wrong synonymy are presented. Conclusions: A vast majority of inconsistent hierarchical relations are not indicative of any errors. We discovered an interesting semantic pattern along hierarchies, which seems associated with wrong synonymy.

Keywords:

Unified medical language system, Semantic consistency.

Introduction

Capsule of adrenal gland is an anatomical concept found in the Foundational Model of Anatomy (FMA) and the NCI Thesaurus. In the FMA, it is defined as a subclass of *Capsule*. Once integrated in the Unified Medical Language System (UMLS), *Capsule of adrenal gland* (C1181304) appears as a child of the concept *capsule (pharmacologic)* (C1181304), for which "*Capsule*" is also a name. Of course, *Capsule* is an ambiguous name used by both anatomy and pharmacology specialists. In fact, a search for "capsule" in the UMLS yields 4 concepts (Table 1). Surprisingly, none of these concepts pertains to macroscopic anatomical structures.

The issue here is both the absence in the UMLS of a concept for the membranous layer surrounding an organ and the wrong association in the UMLS Metathesaurus of this meaning with the pharmacologic concept *capsule (pharmacologic)*.

We stumbled upon this error while exploring the UMLS Metathesaurus for creating lists of drug form terms in preparation for the i2b2 Challenge in Natural Language Processing for Clinical Data on Medication Extraction[1]. We were surprised to find anatomical concepts such as *Capsule of adrenal gland* in the descendants of the concept *Solid Dose Form* (C1378566).

Table 1-Four concepts for Capsule in the UMLS

Name	CUI	Sem. Type	Sem. Group
capsule (pharmacologic)	C0006935	Biomedical or Dental Material	CHEM
Capsule Dosing Unit	C1706433	Quantitative Concept	CONC
Capsule Shape	C1704652	Qualitative Concept	CONC
Microbial anatomical capsule structure	C1325531	Cell Component	ANAT

Quality assurance in biomedical terminologies is an active field of research [1]. Various research groups have investigated quality in the UMLS, addressing issues including terminological cycles [2], ambiguity of concepts [3, 4], concept categorization [3, 5]. Consistency across hierarchies has been addressed by [6], while [7] have studied the consistency of Metathesaurus relations against Semantic Network relations. More recently, the semantic groups have been used for analyzing the consistency of Metathesaurus relations [8]. Most closely related to our work is a study of the validity of concepts associated with multiple semantic groups [9]. Our current work uses the same approach to assess the validity, not of single concepts, but of pairs of hierarchically-related concepts.

The objective of this paper is to quantify semantic inconsistency in UMLS concepts from the perspective of their hierarchical relations and to show through examples how semantically-inconsistent concepts can help reveal erroneous synonymy relations. The specific contribution of this paper is to leverage the semantic groups for identifying inconsistencies and to consider not only the semantics directly ascribed to a concept, but also the semantics it inherits from its ancestors.

[1] https://www.i2b2.org/NLP/Medication/

Background

The Unified Medical Language System® (UMLS®) [10] includes two sources of semantic information: the Metathesaurus® and the Semantic Network. The UMLS Metathesaurus was assembled by integrating some 150 source vocabularies. It contains more than 2 million concepts, i.e., clusters of synonymous terms coming from multiple source vocabularies identified by a Concept Unique Identifier (CUI). More than 36 million relations are recorded between these concepts. Several types of relationships among concepts are recorded in the Metathesaurus: parent / child of (PAR / CHD) and broader / narrower than (RB / RN) essentially correspond to hierarchical relations, while the other relationships are associative. More than 7.5 million hierarchical relations are represented in the Metathesaurus.

The Semantic Network is a much smaller network of 135 Semantic Types (STs) organized in a tree structure [11]. Each Metathesaurus concept is assigned at least one ST. Groupings of STs, called semantic groups (SGs), represent subdomains of biomedicine such as "Anatomy", "Chemicals & Drugs", and "Disorders" [12]. Each ST belongs to one and only one SG.

Version 2009AA of the UMLS was used in this study, after removing cycles from hierarchical relations in the Metathesaurus.

Methods

Computation

We say that a UMLS concept is *inconsistent* if the following two conditions hold for the concept:

- it belongs to two different semantic groups (except CONC) either directly or via its ancestors;
- it does not have any inconsistent ancestor (i.e., the inconsistency of the concept is not due to inheritance, it is original).

Therefore, to compute all inconsistent concepts, we need some method to find all the ancestors of a concept and their semantic groups, and check the inconsistency of each ancestor.

A naïve method to find all the ancestors of a concept and their semantic groups can be described as follows:

1. for each concept, compute all its ancestors;
2. for each ancestor, check that it is not inconsistent;
3. if no ancestor is inconsistent then check for each pair of ancestors whether they belong to different groups; else quit.

However, there are over 2,000,000 concepts in the Metathesaurus and some of them have too many ancestors (over 800); and thus it may not be practical to generate all of them at Step 1 above. Note that, to check the inconsistency of each ancestor at Step 2, we can apply the three-stage method above recursively: for each ancestor, find its ancestors and their semantic groups, and check the inconsistency of its ancestors, and so on.

Considering that a slight modification of the UMLS graph or a slight modification of the definition of inconsistency requires a new sequence of computations from the very beginning (that is, we may not reuse the previous results), we need to find more efficient methods that do not require programming efforts from the user and that can handle recursion.

We introduce a new method for computing inconsistent concepts: first, we divide the set of all UMLS concepts into smaller sets (e.g., of size 20,000); then, for each set, we compute in parallel all ancestors of its elements in the whole UMLS graph that are not inconsistent. Therefore, we compute the inconsistent concepts, as we compute their ancestors and check their inconsistency.

We have realized this method using a computational methodology, called Answer Set Programming (ASP) [13, 14]. The idea is to define the ancestors of concepts, and the inconsistent concepts by means of (possibly recursive) rules, and then call an existing ASP system (e.g., the ASP solver CLASP) to find inconsistencies based on these definitions. Figure 1 shows a sample ASP definition of inconsistency for a set of concepts. Since recursion is allowed in ASP, we can define hierarchical relations (e.g., descendant); we do not have to enumerate all descendants in advance. Furthermore, since ASP has default negation (not), we can define original inconsistencies without generating all paths to their ancestors.

Evaluation

One of us (OB) performed a detailed review of 200 inconsistencies involving the semantic groups "Anatomy" and "Chemicals & Drugs", groups in which the "capsule" error was originally observed. In addition, we performed a casual inspection of the four major groups of inconsistencies in order to identify categories of inconsistencies.

```
% define the ancestors C2 of a concept C1 in set n
descendant(C1,C2) :- childOf(C1,C2), set(n,C1).
descendant(C1,C2) :- descendant(C1,C), childOf(C,C2).

% define the concepts C with some inconsistent ancestor C1
descendantOfInconsistent(C) :- descendant(C,C1), inconsistent(C1).

% identify the groups G (except conc) that a concept C belongs to,
% such that C is not a descendant of an inconsistent ancestor
groupOfConcept(C,G) :- hasCategory(C,T), hasGroup(T,G), set(n,C), G != conc.
groupOfConcept(C,G) :- not descendantOfInconsistent(C), descendant(C,C1), hasCategory(C1,T), hasGroup(T,G), G != conc.

% a concept is inconsistent if it belongs to two different groups G and G1
inconsistent(C) :- groupOfConcept(C,G), groupOfConcept(C,G1), G<G1.
```

Figure 1- Defining inconsistencies in ASP

Results

Quantitative results

We identified 334,396 inconsistent concepts. Out of these concepts, 81,512 concepts are inconsistent due to the following reason: the semantic group of the parent differs from that of the source concept, and no ancestor of the concept is inconsistent. For example, the concept *Anti-purkinje cell antibody* (C0443893) is one of these 81,512 concepts: its semantic group is "Chemicals & Drugs", whereas its parent *Purkinje Cells* (C0034143) belongs to the semantic group "Anatomy"; furthermore, no ancestor of *Anti-purkinje cell antibody* is inconsistent.

The distribution of the number of inconsistencies by semantic group of the source concept is listed in Table 2. Two semantic groups, "Disorders" and "Physiology", represent less than 25% of all UMLS concepts, but concentrate 80% of the inconsistencies. This map of inconsistencies can be further refined by looking at the semantic group of the parent of inconsistent concepts in reference to that of the source concept. The number of inconsistent *child_of*[2] relations by semantic group of the source and parent concepts is listed in **Error! Reference source not found.**. For example, 10,732 inconsistent *child_of* relations involve a concept from the semantic group "Disorders" as the child and a concept from the semantic group "Anatomy" as the parent. Note that the number of inconsistent *child_of* relations is slightly higher than the number of inconsistent concepts, since a given concept can be involved in several inconsistent *child_of* relations.

Table 2-Distribution of the number of inconsistencies by semantic group of the source concept

	SG (source)	# conc	%
ACTI	Activities & Behaviors	750	1%
ANAT	Anatomy	809	1%
CHEM	Chemicals & Drugs	3482	4%
CONC	Concepts & Ideas	--	
DEVI	Devices	2463	3%
DISO	Disorders	30704	38%
GENE	Genes & Molecular Sequences	158	0%
GEOG	Geographic Areas	22	0%
LIVB	Living Beings	995	1%
OBJC	Objects	1084	1%
OCCU	Occupations	134	0%
ORGA	Organizations	236	0%
PHEN	Phenomena	4257	5%
PHYS	Physiology	34366	42%
PROC	Procedures	2052	3%
	Total	*81512*	*100%*

[2] We use a generic *child_of* relationship to represent the various kinds of hierarchical relations in the Metathesaurus (child and narrower than).

Wrong synonymy relations

Including the "capsule" error, four errors of the same type were identified by manual review of pairs of concepts with inconsistent *child_of* relations, two of which involve the semantic groups "Anatomy" and "Chemicals & Drugs".

Capsule. The concept *capsule (pharmacologic)* (C1181304), presented in the introduction, belongs to the semantic group "Chemicals & Drugs". Its parents include anatomical concepts such as *Membranous layer* (C2338391), as well as drug concepts (e.g., *Pill* (C0994475)). Analogously, mixed semantics is found among its children, with anatomical concepts such as *Capsule of adrenal gland* (C1181304) and drug concepts including *Oral Capsule* (C0991533). In order to address the wrong synonymy in *capsule (pharmacologic)*, a distinct concept should be created for the anatomical capsule, with a semantic type from the semantic group "Anatomy".

Retina / Retinol. The concept *Retina* (C0035298) from the semantic group "Anatomy" has two types of parents. On the one hand, there are concepts from the semantic group "Chemicals & Drugs", such as *All-Trans-Retinol* (C0087161) and *Aldehydes* (C0001992). On the other, there are concepts from the semantic group "Anatomy", including *Wall of eyeball* (C0929391). Except for some lexical resemblance, it is unclear what caused this error. However, there seems to be a wrong synonymy issue, because three of the children of *Retina* are also from the semantic group "Chemicals & Drugs" (e.g., *Retinal | bld-ser-plas* (C1972646)), while most children are anatomical concepts (e.g., *Retinal Neurons* (C2350331)).

Two additional examples of wrong synonymy involving other semantic groups than "Anatomy" and "Chemicals & Drugs" were identified in this study.

California plant / state. The concept *California* (C0006754) belongs to the semantic group "Geographic Areas." Its parents include *Pacific States* (C0524818) from the same group and *Geraniaceae* (C0996910) from the semantic group "Living Beings." (*Geraniaceae* is a family of plants comprising, among others, Geranium). Analogously, the children of *California* include other geographic areas (e.g., *San Francisco* (C0036152)), as well as plants (e.g., *California macrophylla* (C1891810)). This is another example of wrong synonymy. A distinct concept should be created for the plant family *Geraniaceae*, with a semantic type of Plant, from the semantic group "Living Beings."

Transdermal / Skin Patch. The concept *Transdermal Patch* (C0991556) from the semantic group "Chemicals & Drugs" has two types of parents. On the one hand, there are several drug concepts, including *Patch drug form* (C0994894). On the other, parents such as *Lesion* (C0221198) belong to the semantic group "Disorders." Moreover, the same mixed semantics can be observed among the children of *Transdermal Patch*, including the drug *Nicotine patches* (C0358855) and the clinical finding *Café-au-Lait Spots* (C0221263). The issue here is probably wrong synonymy related to "patch". A distinct concept should be created for the clinical finding *Skin Patch*, with a semantic type from the semantic group "Disorders."

Table 3 - Number of inconsistent parent relations by semantic group of the source concepts (rows) and parent concepts (columns) (NB: The abbreviations of the semantic groups are defined in Table 2)

src\target	ACTI	ANAT	CHEM	DEVI	DISO	GENE	GEOG	LIVB	OBJC	OCCU	ORGA	PHEN	PHYS
ACTI	0	0	1	1	238	0	0	13	17	102	18	81	121
ANAT	0	0	175	2	264	20	0	16	157	14	0	15	120
CHEM	1	188	0	193	59	72	1	1618	484	15	1	39	177
DEVI	0	6	1443	0	6	2	0	1	693	10	56	3	0
DISO	485	10732	82	94	0	9	1	167	28	333	2	3008	2492
GENE	0	12	66	0	25	0	0	18	4	1	0	3	25
GEOG	2	0	0	0	0	0	0	3	14	0	0	1	0
LIVB	44	12	306	1	225	0	1	0	53	254	3	12	97
OBJC	21	36	480	434	19	0	17	24	0	21	6	24	0
OCCU	13	1	1	0	6	0	0	50	2	0	6	4	12
ORGA	16	0	0	0	1	0	4	172	3	18	0	0	0
PHEN	42	27	107	1	1118	1	2	122	14	73	1	0	322
PHYS	101	6804	20412	224	2590	760	0	650	83	7210	0	824	0

Other types of inconsistencies

In addition to wrong synonymy, several other types of inconsistencies were observed. In contrast to wrong synonymy, the other inconsistencies could be expected, since the UMLS is **not** an ontology of biomedicine, but rather a terminology integration system, which, by design, does not impose a semantic model to the terminologies it integrates [15].

Many terminologies such as the Medical Subject Headings (MeSH) organize their concepts for a particular purpose rather than based on ontological principles. For example, the hierarchical organization of MeSH descriptors supports information retrieval. In other words, MeSH hierarchical relations often reflect "aboutness" rather than subsumption [16]. One such example is the relation from the Japanese version of MeSH between *Orphan Drugs* ("Chemicals & Drugs") and *Drug Industry* ("Organizations").

The absence of formal distinction between types and roles in the semantic network can lead to inconsistent usage. For example, *Sheep milk* is considered food ("Objects"), while its parent concept *Milk* is considered a body substance ("Anatomy").

We also found cases where concept categorization (i.e., the semantic type assigned to the concept) is arguable or inconsistent across similar concepts. One such example is *Animal Disease Models*, categorized as a disease model ("Disorders"), while its parent concept *Animal Model* is (wrongly) categorized as an animal ("Living Beings").

Finally, differences in granularity between hierarchically-related concepts are at the origin of some of the inconsistencies. For example, *Iodothyroglobulin* ("Chemicals & Drugs") and *Thyroid colloid* ("Anatomy") are definitely related, but their relationship – between molecular and macroscopic structures – is mereological in nature (part-whole) rather than taxonomic (is a).

Our casual review of four large sets of inconsistencies revealed that inconsistencies in these groups were essentially homogeneous within a group. We examined inconsistencies from the pairs of semantic groups with the largest number of inconsistent relations (10-20,000 per group). These are DISO-ANAT, DISO-PHYS, PHYS-PROC and PHYS-CHEM.

Most inconsistencies from DISO-ANAT come from the integration of the clinical synopses from OMIM in the UMLS. In a clinical synopsis, disorders are grouped under anatomical structures (e.g., *Mouth Neoplasms* under *Oral cavity*). The corresponding relations, i.e., *Mouth Neoplasms* to *Oral cavity*, have been integrated as *child_of* relations in the UMLS, leading to this type of inconsistency.

Inconsistencies from DISO-PHYS generally correspond to pairs of hierarchically-related concepts in which the parent represents a quality being observed in a clinical observation (e.g., *Texture of hair*), categorized with a semantic type from the semantic group "Disorders" and the child one possible value for this quality (e.g., *Coarse hair*), categorized with a semantic type from the semantic group "Physiology."

Inconsistencies from PHYS-PROC and PHYS-CHEM are related to the hierarchical organization of concepts in LOINC, i.e., how LOINC groups laboratory tests and clinical observations into classes, resulting in links between observations (from the semantic group "Physiology") and chemical analytes (e.g., class of sodium plasma tests) or procedures (e.g., class of observations related to organ transplantation).

In these four groups, the large numbers of inconsistencies are generally not indicative of errors, but reflect the fact that, although used to form hierarchies, these relations are not hierarchical in nature (i.e., not is-a). Consistency checking based on the semantic groups assumes that the *child_of* relations are subsumption relations, which is not the case here.

Discussion

UMLS semantic framework

With its multiple layers, Metathesaurus concepts, semantic types from the Semantic Network and semantic groups, the UMLS provides a unique framework for checking semantic consistency. Semantic consistency between the Metathesaurus

and the Semantic Network requires valid relations between concepts, valid relations between semantic types and accurate categorization of the concepts with semantic types. In contrast, inconsistency is indicative of a problem with at least one of these elements, but further analysis is required to pinpoint the problem causing the inconsistency. Additionally, semantic consistency between the Metathesaurus and the semantic groups (through the semantic types) is predicated upon the validity of the disjunction axioms added to the Semantic Network by the semantic groups.

As we have argued in the past [7], taking advantage of the UMLS semantic framework in the editing environment used by the Metathesaurus editors would help expose semantic inconsistencies at the time of editing and would likely reduce the number of such inconsistencies in the Metathesaurus release. Using the semantic groups rather than the semantic types for consistency checking seems appropriate in the context of terminology integration (as opposed to ontology development).

Lessons learned

One of the lessons learned from this analysis is that the approach we propose for identifying inconsistencies lacks specificity. In fact, we showed that a vast majority of inconsistent hierarchical relations are not indicative of any errors, but simply reflect the use of hierarchical relations for knowledge organization purposes.

Interestingly, we discovered that the four instance of wrong synonymy we identified exhibit a pattern of "semantic rupture" along the hierarchical structure of the terminology. By semantic rupture, we mean that, along one hierarchy, the source concept belongs to a given semantic group, its parent concept does not, but one of the parents of the parent belongs to the same group as the source concept. For example, in the "capsule" example presented earlier, the source concept is *Capsule of adrenal gland* ("Anatomy"). Its parent is *capsule (pharmacologic)* ("Chemicals & Drugs"), one parent of which is *Membranous layer* ("Anatomy"). We hypothesize that such pattern of semantic rupture might be a good marker for wrong synonymy and we plan to test it in future work.

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Empirical Analysis of the Reduction of Medical Expenditures by eHealth

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Abstract

This paper aims to examine reduction of medical expenditures by utilizing the system of Nishi-aizu Town, Fukushima Prefecture. The town office has been implementing it since 1994 and keeps receipts on medical expenditures of its approximately 4,000 residents paid by National Health Insurance for 5 years from 2002 to 2006. We select (1) users; and (2) non-users of the e-health system, and by comparing their medical expenditures, we examine: (i) difference in medical expenditures between two groups; and (ii) negative correlation between medical expenditures and the length of usage of the e-health system. We find that total medical expenditures of users are larger than those of non-users, whereas by restricting to lifestyle-related illnesses such as high blood pressure, cerebral infarction, strokes, and diabetes, medical expenditures of users are found to be smaller than those of non-users. The results we obtained here provide the rigorous economic foundation of the e-health system.

Keywords:

e-health, Telemedicine, Medical expenditures, Lifestyle-related illnesses, Regression analysis.

Introduction

Medical expenditures in Japan have been increasing steadily, amounting to 32.4 trillion yen (US$ 324 billion) in FY (Fiscal year) 2006. More than half (51.1%) of all expenditures are for persons over 65 years old. Japan is aging rapidly; the current percentage of the elderly (over 65) is more than 20%, and is expected to increase further in the near future. In order to cope with this situation, various policy measures have been taken, including requiring patients to bear more of their own medical costs. Japan has a well-organized universal public health insurance system; due to increasing medical expenditures and deficits in the medical insurance budget, however, the percentage of costs reimbursed by public health insurance has been falling. The elderly have thus been forced to pay more of their medical expenditures.

Another measure to reduce medical expenditures is to focus on prevention of diseases: the healthier people become, the fewer medical costs are required. One example is to enhance consciousness toward health and efforts to prevent illness. To this end, the government has taken initiatives such as the "Health Japan 21 Project." Recent campaigns against Metabolic Syndrome are another example, as this condition is thought to increase risks of hypertension or hyperlipidemia. The campaigns against Metabolic Syndrome include recommending regular physical exercises and monitoring of diet and nutrition. Prevention of illness through health maintenance is an important measure to reduce medical expenditures.

This paper focuses on the utilization of IT (Information Technology) to maintain health. We examine the e-health system, which monitors the health condition of the elderly at home by transmitting users' health-related data, such as blood pressure, ECG (Electrocardiogram), and blood oxygen, to a remote medical institution via a telecommunications network (see [4]). At present, more than 100 Japanese local governments are using such systems, using a total of more than 12,000 devices – more than any other country. The system is equipped with a simple device that records an elderly person's condition or a patient's illness in graphs that are then used for diagnosis and consultation. Reports sent by the medical institution also help users to enhance their daily health consciousness and maintain good health. These positive effects have been identified through field surveys in [4-6].

The e-health system in Japan has already passed the experimental stage, and is entering the diffusion stage. The government expects the e-health system to reduce medical expenditures and enhance the provision of public health and welfare. The authors have been conducting research on economic evaluation of the e-health system, by estimating the system's benefits in terms of WTP (Willingness to pay) and comparing benefits with costs (see [2, 3, 5-7]). Without confirmation of the e-health system's cost-effectiveness, the system's future sustainability cannot be guaranteed.

In this paper, we make an attempt to prove a statistically significant relationship between medical expenditures and the introduction of the e-health system by examining the case of Nishi-aizu Town. Reasons for this region's selection are: (i) the town has been making full use of the system since 1994; (ii) Nishi-aizu is the second town in Japan to introduce the e-health system, and since then the system has been the core of its health, welfare, and medical services; (iii) the authors conducted field research on this town in 2000, 2001 and 2006; and (iv) data on Nishi-aizu's medical expenditures is readily available. The town office has medical receipts paid of National Health Insurance for its 3000 residents for recent five years from 2002 to 2006 (for Nishi-aizu Town, see [1]).

The paper format will be a section explaining the basis of Nishi-aizu e-Health system, and then a section explaining how we construct the data for a survey analysis, and the method of analysis. The next section provides characteristics of sample, which based on our survey data. After that, the results of survey are presented, followed by rigorous statistical analysis by making use of Ordinary Least Squares method (OLS). Brief concluding remarks are stated in the final section.

Data and Methodology

Selection of Sample

As stated earlier, this paper examines the relationship between medical expenditures of Nishi-aizu's residents and the e-health system. According to the Japanese medical insurance system, which is organized and operated by the Ministry of Welfare and Labor, all people must be covered by one of several social health insurance systems. This paper focuses on people in Nishi-aizu who are covered by "National Health Insurance," since data on medical expenditures through this system are handled by local governments. National Health Insurance is not only for self-employed individuals such as farmers or owners and employees of small- and medium-sized firms, but also people who already retired.

One of the purposes of this paper is to compare medical expenditures between two groups such as (i) users and (ii) non-users of the e-health system from medical receipts of Nishi-aizu Town. Samples of two groups are selected according to the following way.

1) User group

We selected 412 users from the list of registered users in the town according year they registered. The total number of users and that selected as the sample is shown Table 1. Then we send questionnaires to them and 311 replies were received. Finally, after checking the replies, 199 replies remain as significant. The rate of valid reply is 48.30%.

2) Non-user group

We selected 450 residents who are covered by National Health Insurance out of total 3,528. Questionnaires were sent to 450 and we received 239 replies. Again by checking the replies, we had 209 significant replies. The rate of significant reply is 46.44%.

In sum, the total number of residents selected as the sample becomes 408. We checked their receipts from those stored in the town office, and total number of receipts of 3,528 residents who are covered by National Health Insurance is 160,000 for five years. It took 8 days for 18 students to picks up those of 408.

Receipt Data

The receipts of National Health Insurance of each month are kept at the town office, in which the data such as name and address of medical institution, birth date, name of disease, date of initial-visit, medicine, and score (amount) of medical treatment are described. In this paper, we use the following data: (i) name of resident, (ii) birth date, (iii) either regular outpatient treatment or hospitalized patient treatment, (iv) name(s) of major disease(s), (v) date of initial treatment, (vi) number of days needed for treatment, and (vii) cost of medical treatment.

Table 1 – e-health users

Year start using the system	Total number of users: Male	Female	Total	Users selected as sample
1994	9	11	20	20
1995	13	11	24	24
1996	8	14	22	22
1997	30	36	66	66
1998	13	15	28	28
1999	4	6	10	10
2000	8	11	19	19
2001	3	3	6	6
2002	6	7	13	13
2003	91	88	179	95
2004	53	69	122	95
2005	6	6	12	12
2006	2	0	2	2
Total	246	277	523	412

Characteristics of Data

The age distribution of users and non-users is shown in Table 2. As for users, more than half are age of 70s, while for non-users more than one third. Most of samples are age of 60s, 70s and 80s.

Table 2 – Age distribution of users and non-users

	User	Non-user	Total
40 - 49	2	0	2
50 - 59	14	23	37
60 - 69	45	67	112
70 - 79	92	76	168
80 - 89	46	37	83
Over 90	0	6	6
Total	199	209	408

According to Table 3, about 45% of users and 40% of non-users replied they have some kind of chronic diseases. The former has the higher rate than latter because suffering chronic diseases is strong incentive to use e-health service. This coincides with the property of other regions.

Table 4 indicated years of using the e-health system, and except less than one year, the numbers of users are not different in terms of years of use.

Table 3 – Having chronic diseases

	User	Non-user	Total
Yes	90	81	171
No	72	90	162
No reply	37	38	75
Total	199	209	408

Table 4 – Years of using e-health

Years of use	Number of user	
Less than 1year	6	3.0%
1-3	38	19.1
3-5	45	22.6
5-7	35	17.6
7-10	39	19.6
Over 10	36	18.1
Total	199	

Table 5 shows the relation between age and years of use. The longer the use, the older the users become. This is rather natural, longer use implies those users become old. Table 6 indicates the frequency of using the e-health service. Nearly 40% of users use it every day, while 24% use 3-4 times a week. More than 70% use at least one a week.

Table 5 – Years of using and average age

Years of use (years)	Average age (years)
Less than 1	71.3
1 - 3	68.9
3 - 5	70.3
5 - 7	74.8
7 - 10	74.0
Over 10	76.4

Table 6 – Frequency of using

Almost everyday	76	38.19%
3 - 4 times a week	47	23.62
1 - 2 times a week	20	10.05
1 - 2 times a month	23	11.56
Not use	25	12.56
No reply	8	4.02
Total	199	

Hypotheses and Model Specification

According to data discussed in the previous section, at first the following four hypotheses are presented.

- Hypothesis 1: Users of the e-health system have lower medical expenditures of lifestyle-related illness than those of non-users.
- Hypothesis 2: Users of longer practicing the e-health system have lower medical expenditures of lifestyle-related illness than those of non-users.
- Hypothesis 3: Users of longer practicing the e-health system reduce medical expenditures larger than those who use it shorter years if they extend usage one more years.
- Hypothesis 4: The e-health system there has more effect to people who have diseases than those who do not.

We tested these hypotheses based on the model as follows:

$$y_{it} = \alpha + X'_{it}\,\beta + u_{it}$$
$$u_{it} = \lambda_t + v_{it} \qquad (1)$$

where y_{it} denotes the medical expenditures of life-style related diseases, X_{it} indicates each characteristics such as sex, age, education, employment (dummy variable), number of family living together, income, and chronic diseases (dummy variable). We utilized the panel data analysis with one-way fixed effect model where λ_t denotes the year dummy, because the system of calculating medical expenditures is changed every 2 years. Also, individual effect, or dummy might cause serious multicollinearity with each characteristics, so we control only time effect.

Results

Hypothesis 1

Table 7 shows the result of estimation of hypothesis 1 by taking medical expenditures restricted to lifestyle-related illnesses as a dependent variable. The explanatory variables are Sex, Age, Education, Employment (dummy variable), Number of family living together, Income, Chronic diseases (dummy variable), and Use dummy (e-health user). Variables which provide significant effect at the 1 % significant level are Sex, Age, Income, Chronic diseases, and User dummy; and number of family living together at the 5% significant level. The results of this estimation can be interpreted in the following way, in which one medical score is equivalent to 10 yen (US$ 0.1).

- Medical expenditures of e-health users are smaller than those of non-users by 15,688 yen (US$ 156.88) per year. This amount is 21.2% of average annual medical expenditures.
- Medical expenditures of residents with chronic diseases are larger than those without it by 33,440 yen (US$ 334.40) per year.
- Medical expenditures increase 2,197 yen (US$ 21.97) per year when they become one year older.
- Higher income residents have lower medical expenditures than low income group.

Table 7 – Result of estimation (Hypothesis 1)

	Coef.	Std. Err.	
Sex	1467.36	473.55	***
Age	219.67	29.12	***
Education	309.45	315.10	
Employment	95.86	501.79	
No. of family living together	289.24	126.34	**
Income	-19.09	4.08	***
Chronic Diseases	3344.00	476.34	***
User dummy	-1568.79	478.90	***
Constant	-10517.63	2378.58	***
Number of Obs.	1545		
R2 adjusted	0.0819		

***, **, and * indicate the 1%, 5%, and 10% significant level, respectively.

Hypothesis 2

Next, we present the second result by making use of OLS. In this estimation, we take medical expenditures of lifestyle-related illnesses as a dependent variable, and as for independent variable, sex, age, education, employment (dummy variable), number of family living together, income, chronic diseases (dummy variable), and years of e-health use. The estimation result is summarized in Table 8. Variables which provide significant effect at the 1 % significant level are (i) sex, age, income, chronic diseases, (ii) number of family living together at the 5% significant level, and (iii) years of e-health use at the 10% significant level. Again these results can be interpreted in the following way:

- Medical expenditures of lifestyle-related illness can be reduced by 1,133 yen (US$ 11.33) per year, if they extend using the e-health system one more year. The amount of reduction is 1.5% of average annual medical expenditures.

Table 8 – Result of estimation (Hypothesis 2)

	Coef.	Std. Err.	
Sex	1542.36	474.40	***
Age	223.57	29.65	***
Education	302.22	315.90	
Employment	127.48	503.50	
No. of family living together	257.77	126.99	**
Income	-19.24	4.09	***
Chronic Diseases	3315.44	477.95	***
Years of e-health use	-113.32	66.18	***
Constant	-11250.42	2411.04	***
Number of Obs.		1545	
R2 adjusted		0.0780	

***, **, and * indicate the 1%, 5%, and 10% significant level, respectively.

Hypothesis 3

The elasticity, which is is a rate of decrease according to the 1% of increase of years of use, becomes larger, as shown in Table 9. In other words, for users who utilize e-health for more years, additional one year use decreases more medical expenditures than for those who use it for less years.

- This implies that elasticity increases according to years of its use, and the years one uses the system, the larger the reduction in medical expenditures becomes. This is an amazing result and verifies effectiveness of the e-health system.

Table 9 –Elasticity (Hypothesis 3)

Years of e-health use	Elasticity
Non-user	0
0 – 2	-0.01323
2 – 4	-0.04161
4 – 6	-0.07279
6 – 8	-0.09959
8 – 10	-0.12806
10 – 12	-0.15044
Over 12	-0.18321

Hypothesis 4

Nishi-aizu Town distributed the devices according to the following criteria:

(i) Senior people with diseases

(ii) The senior who are recommended by doctors

(iii) People other than the above categories who have chronic diseases or recommended by doctors.

The town office recognizes effects of its e-health system, and especially, it expects the effect to people with chronic diseases. Here we attempt to verify whether the e-health system there has more effect to those than people who do not have chronic disease.

The result of this estimation is indicated in Table 10, which implies that variables such as sex, age, and income are significant in the estimation for people without chronic diseases, while variables such as the number of family and user dummy in addition to above variables of people without chronic diseases. Especially, the dummy variable for people without chronic diseases is not significant, which means that there is no significant difference in medical expenditures between users and non-users. For the estimation of people with chronic diseases, its p-value is less than 1 %, which indicates that there is great difference between two groups. In other words, we cannot identify the difference between two groups for healthy people, while the system has great effect to people with chronic diseases. Our estimation shows that the difference in medical expenditures is 37,942 yen (US$ 379.42). According to this result, the principle of distribution of the device to people is verified.

Table 10 – Result of estimation (Hypothesis 4)

	Without chronic diseases		With chronic diseases	
	Coef. (Std.err.)		Coef. (Std.err)	
Sex	1424.65	**	1681.68	**
	(553.25)		(815.62)	
Age	281.14	***	112.32	**
	(32.95)		(52.40)	
Education	13.26		511.28	
	(390.09)		(508.33)	
Employment	565.58		-592.03	
	(579.25)		(879.79)	
No. of family living together	110.53		588.46	***
	(145.50)		(222.25)	
Income	-14.40	***	-26.23	***
	(4.75)		(7.19)	
User dummy	65.60		-3794.18	***
	(557.77)		(827.54)	
Constant	-14725.31	***	324.68	
	(2720.33)		(4177.35)	
Number of Obs.	755		790	
R2 adjusted	0.0933		0.0485	

***, **, and * indicate the 1%, 5%, and 10% significant level, respectively.

Conclusion

This paper analyzes the relationship between medical expenditures and the e-heath system, which connects senior people at home and medical or health institutions by transmitting vital data via the telecommunications network. Even though the e-health system is simple, it contributes to promote health of senior people. This paper aims to verify empirically whether and how much it contributes to promote senior people's health by examining the system of Nishi-aizu Town, Fukushima Prefecture in Japan. The town office keeps receipts on medical expenditures of its approximately 4,000 residents in a paper form paid by National Health Insurance for 5 years from 2002 to 2006.

First, we can estimate from OLS that users' average annual expenditures per person related to lifestyle-related illnesses is smaller than that of non-users by 15,688 yen (US$ 156.88). This amount is about 21.2% of average expenditures of non-users. Second, if users utilize the system one more year, then the above expenditures decrease about 1,133 yen (US$ 11.33) per year, which is about 1.5% of the average expenditures. We also find that the amounts of the above decrease become larger, if the experience of using the system is longer. Finally, the e-health system there has more effect to those than people who have diseases.

Nishi-aizu Town used to suffer high death rates due to life-style-related illnesses, and it introduced the e-health system as a part of projects such as "Promoting Total Care", and "Challenge to 100 Years Old." The efforts of residents as well as staff engaged in these projects for nearly 20 years achieved medical expenditures significantly smaller than the national average. It should be noted that behind this success lies close collaboration of networks of health, medicine, and welfare. Nishi-aizu's experiences thus establish a model to reduce medical costs and improve health of the residents of other regions.

The increase in medical expenditures is common phenomena all over the world. There are two measures to cope with this; the utilization of IT in medical area and prevention from being illness (or maintain health). The e-health system can solve these issues. The results we obtained here provide the rigorous foundation of the e-health system.

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Using a Business Rule Management System to Improve Disposition of Traumatized Patients

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Abstract

We propose a business rule management system that is used to optimize the dispatchment on a mass casualty incident. Using geospatial information from available ambulances and rescue helicopters, a business rule engine calculates an optimized transportation plan for injured persons. It automatically considers special needs like ambulances equipped for baby transportation or special decontamination equipment, e.g. to deal with an accident in a chemical factory. The rules used in the system are not hardcoded; thus, it is possible to redefine them on the fly without changing the program's source code. It is possible to load and save a rule set in case of a catastrophe. Furthermore, it is possible to automatically recalculate an already planned operation if it becomes clear that the rescue vehicles assigned are needed by a person with life-threatening injuries.

Keywords:

Mass casualty incidents, Online systems, Decision support systems

Introduction

Even though mass casualty incidents occur only rarely, they present a major challenge for medical personnel. While the number of injured complicates a fast decision on how to treat individual persons, dispatchment has to be done quickly in order to save lives. Thus, efficient means to support humans in managing mass casualty incidents are sought for.

In Germany, the EMS (Emergency Medical Service) is organized municipally [1]. Every municipality has its own infrastructure. Often they are using central PSAPs (Public Safety Answering Point) to dispatch rescue operations. These headquarters answer the emergency calls and assign vehicles and personnel provided by different local organizations such as hospitals or private emergency medical services. To improve communication among these headquarters and different organizations, special networks like the "Trauma Network North-West" have been founded [2]. These networks make it easier to organize transports of injured people to hospitals in neighboring areas. However, the methods used by this network only suit a limited number of patients.

In the case of mass casualty incidents, the patients are brought to a special place to conduct triage. After being prioritized, seriously injured persons are transported first [3]. This simplified system is not good enough because it does not consider special needs of the patient. A baby for example needs a specially equipped ambulance and a hospital that is able to treat it appropriately [4]. Besides, the available transportation should be used in the best way possible.

The requirements to a dispatchment system are similar to decisions done in business environments. We hence suggested using rule based systems to support the assignment of injured people to available vehicles or helicopters and their transfer to hospitals.

This paper is structured as follows. In the next section we show the project background. Then we outline the technical implementation and present results from the evaluation. Finally, we give a conclusion and sketch future work.

Project Background

The Trauma Network North-West is a union of 43 hospitals in north-western Germany and the Netherlands. Its main goal is to improve trauma care. In the TEAM project, emergency physicians are equipped with mobile devices to get a quick overview of the time needed by an ambulance to the nearest trauma centers. Furthermore, they are able to request a rescue helicopter, and see, if it is on the way and when it will arrive. Thus, they are able to decide which transport would be best for the injured. After selecting a hospital, his decision will be shown to an agent at the next PSAP who is able to accept or decline this suggestion [5].

The described procedure works well for one or two injured people, but in a case of a mass casualty incident, the emergency physician does not know all the circumstances to properly decide which transport would be best considering the whole situation. In such a case, only the agents at the PSAP are able to decide properly about transfers and destination hospitals. However, they do not have much time to decide on dispatching plans. Since a fast transport to hospitals can sig-

nificantly increase survival rates [6], agents need the means to work out plans without much delay or effort.

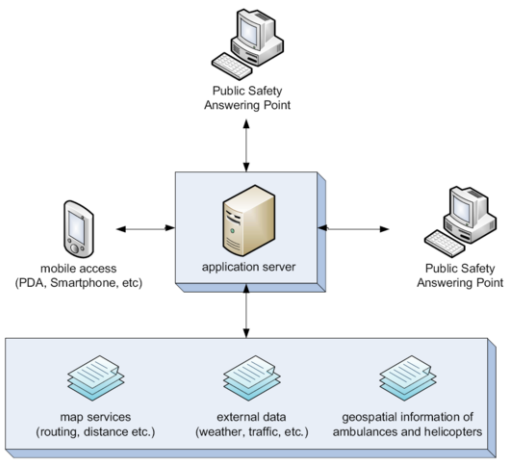

Figure 1- The technical architecture of the system.

Implementation Details

Technical Details

The software used on the server is written in Java and deployed to a central Tomcat application server. It is platform-independent and flexible [7]. Furthermore, the business rule system Drools [8] is included to provide the rule-based decision functionality. The rules can be edited with Guvnor, a web based rule editing tool [9]. The whole system is accessible online using a standard web browser. No proprietary software is needed on the client device.

External services are included in different ways. For example the "Rescue Track", a system to get geospatial information from rescue helicopters, is included as a XML-web-service (see Figure 2). In addition to its current location, its status is transferred via two-way radio [10]. The dispatchment system is able to recognize if the helicopter is available for another mission or if it currently carries a patient. Additionally, the estimated time for the helicopter to be available again can be provided by the system.

Also the mapping service which provides the geospatial information is included externally. It is possible to reconfigure the system to use a local installation easily [11].

In general, one of the advantages of external web services is their exchangeability. If a service is broken or discontinued, it is possible to get the needed data from another provider. This change can be done automatically in case of a failure or manually if it becomes clear that another service is able to provide more actual or detailed data. For that purpose multiple sources of external services can be provided in the system.

In addition to using the clients at the PSAP, it is possible to get access to the system with mobile devices such as PDAs or notebooks. This is useful to get a fast overview in a mass casualty incident at the accident site.

Rule Management

As outlined before, rules are edited by a special editing tool. (see Figure 3). The rules are written in a DSL (domain-specific language [12]) which is leaned against usual language and may include technical terms of the considered domain. A benefit value is allocated to every transportation possibility. This value is made up of the hospital's care level, the characteristics of the ambulance or rescue helicopter and the duration of the transportation. The rules are used to manipulate this value.

The screenshot in Figure 3 shows a rule that recommends an ambulance with special baby equipment for a patient with an age below two years. This rule causes ambulances with this equipment to be rated higher. Therefore, such an ambulance is rated higher if it is available. It however would less likely be assigned to an injured that is older than two years. The system tries to keep special equipment available if the medical conditions of patients that currently need help allow it. This means that it prefers available ambulances without special equipment that can transport an injured as fast as the one with the (not required) equipment could.

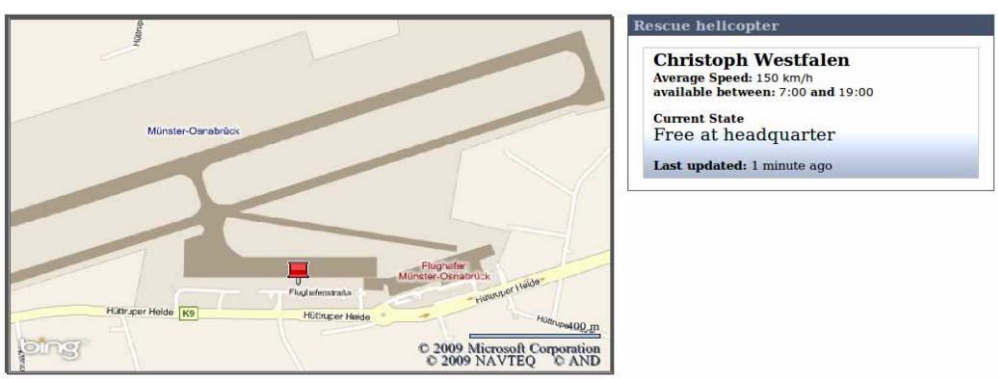

Figure 2- The rescue helicopter at its base.

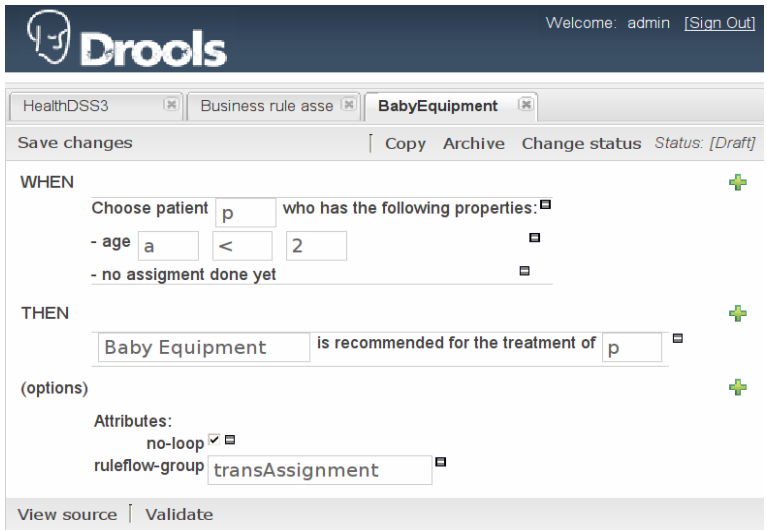

Figure 3- An example rule to assign an ambulance with special baby equipment.

In case of conflicting rules, the first rule that fits to the given situation is fired. Thus, there is no possibility of a deadlock situation. If no specialized rule fires, general rules will apply to ensure transportation for all patients.

Using this technique simplifies the creation and maintaining of rule sets to a level at which no knowledge in programming is needed. Furthermore, every user is able to validate them and to see how they work. The understanding of the rules is very important to create trust in the system. The rules can of course not be changed arbitrarily; we however suggest that a system that can be changed by authorized personnel in order to cope with new situation is suited for the complexity and criticality of disaster management operations.

New rules or entire rule sets are activated and deactivated with one mouse click in case of a mass casualty incident or disaster situation. This ensures that the dispatchment in these cases follows special rules, e.g. that vehicles for non emergency patient transfers are used as ambulances to deal with many injured.

Evaluation

To evaluate the execution time of the dispatchment program, two different rule sets have been run on a 1,6GHz Intel Core2Duo processor with 1GB of DDR2 RAM. Even with sophisticated rule sets the dispatcher gets an optimized result within about one second.

As shown in figure 4 using hard-coded rule preparation may increase performance significantly. But even without them calculation time grows only linear with the number of transportation possibilities. By using high performance hardware it is possible to decrease the calculation time to an acceptable minimum. Also the parallel execution of several calculations could be realized in a future version of the program.

Other factors for the execution time are external web services. If they are, for instance, used to calculate the time required by every transport possibility, they are called hundreds of times for one calculation and may slow down the dispatchment to an unacceptable rate. Therefore, the most important web services such as distance and routing calculation should be provided locally.

At all stages of the development, test runs were made by medically skilled personnel to verify the system. The results are promising and show that the dispatching system presented is able to enhance the dispatching system currently used.

Nevertheless, the presented system is in prototype stage. Further evaluation is needed before installation in time- or life-critical environments.

Conclusion

We presented a system for the dispatchment of casualties. By using a business rule management system it is possible to dispatch nearly every mission from an accident with only one injured to a mass casualty incident. The PSAP operators are able to get an optimized dispatching plan within seconds after a new emergency call is answered.

While the evaluation of the system is very promising, the system can be extended. For future purposes it is planned to include live GPS data from every vehicle involved in emergency services. This would allow even more precise routing and a better assignment of vehicles and injured.

To increase the performance of distance calculation between two positions it is possible to set up and run a local routing server. It is also conceivable to use the linear distance for the first optimization and then the real routing and traffic information for the few realistic transport possibilities only.

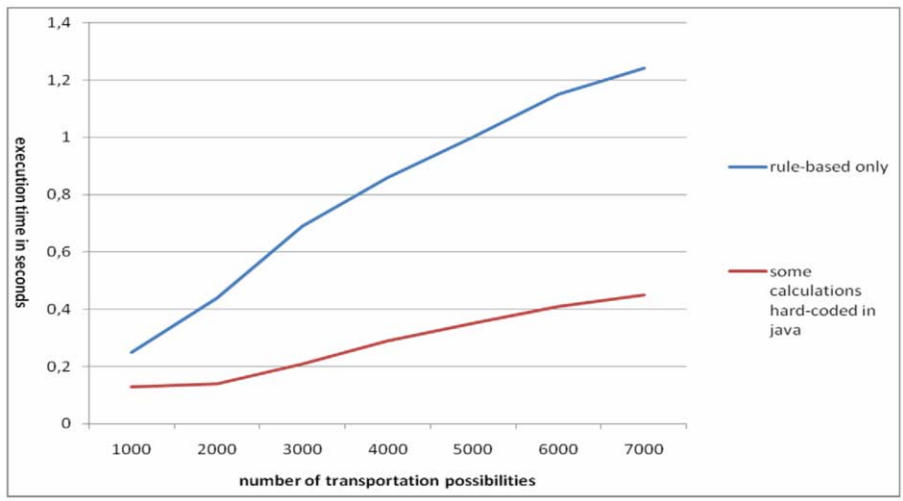

Figure 4- A partial hard-coded rule set may decrease execution time.

This would speed up calculation without losing precision. Furthermore, the local mapping web service can be extended to provide an intelligent visualization and a more sophisticated routing mechanism which includes the current traffic situation [13, 14].

In the next development step, the system will be included into the dispatching system of the Trauma Network North-West. In that project an emergency physician is able to suggest a destination hospital on a mobile device. Afterwards the PSAP agent receiving his request has to accept or decline it. The new dispatching system will assist the PSAP agent to rate these suggestions according to several characteristics like the current load of rescue vehicles and emergency physicians.

If the emergency physicians are equipped with mobile terminals in case of a mass casualty incident, they may be used for other purposes like an electronically health card [15]. Eventually, medical personnel could be equipped with multi-purpose mobile devices that allow for an even better treatment of injured.

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Measuring the effectiveness of hospital-acquired infection prevention

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Abstract

This article deals with data on nosocomial infections acquired in the Geneva University Hospitals. Goal of the work is to derive a model from a hospital-acquired infection (HAI) prevalence survey of year Y and apply them to a prevalence survey of years Y+1, Y+2. This analysis permits to evaluate the effectiveness of preventive measures taken after the prevalence survey in year Y. It also analyzes the robustness of the SVM algorithm on time-variable attributes. The model build on the dataset of year Y gives better results than in a previous study. The application of the model on the Y+1 and Y+2 prevalence surveys shows simultaneously improvements and deteriorations of 5 performance measures. This highlights the effectiveness of prevention and reduces the risk of HAI after the prevalence survey of year Y. We introduce a new method to detect redundancy in a dataset with the SVM algorithm.

Keywords:

Hospital infections, Program evaluations, Machine learning.

Introduction

A hospital is a facility providing medical care to sick people. Independent of the reason for admission, a patient may acquire new infections inside a hospital due to the presence of microorganisms. These hospital-acquired infections (HAI) usually appear 48 hours after the patient admission. The infectious agents can be transmitted from other patients or by health care workers during medical procedures. In Switzerland, 70'000 hospitalized patients per year are infected and 2'000 deaths per year are caused by HAI. Many prevention and surveillance programs are carried out to prevent and/or reduce the risk of HAI. A prevention program, for example, includes hygiene measures permitting to isolate or eliminate infectious agents such as washing hand before any contact with patients, the use of gloves, use of masks, disinfection, sterilization, etc. A surveillance program aims at detecting infections. *French et al.* proved that a repeated prevalence surveys is a valid and realistic approach for infection control and surveillance [1]. The prevalence of infection is the number of infected patients divided by the total number of hospitalized patients at the time of the study [2]. The infection prevalence rate can also be used as an indicator of the quality of patient care.

However, the HAIs are not always documented in the electronic health record (EHR) of the patients and the infection control practitioners have to carry out a survey to obtain the prevalence rate. For this purpose, the EHR of all hospitalized patients admitted for more than 48 hours are analyzed. If necessary, additional information is obtained by interviews with nurses or physicians in charge of the patient. This survey is performed during one to three months on a yearly basis at the University and Hospitals of Geneva since 1994. This survey is labor intensive and it cannot be carried out all year long.

In a previous study, we extracted the most important features of a HAI database allowing the prediction of an HAI infection [3]. Fisher's linear discriminant was used to evaluate the predictive power of these features and it provided good results. However, maximum margin classifiers such as support vector machine (SVM) are more appealing with respect to generalization performance from a theoretical viewpoint. A maximum margin classifier looks for an optimal hyperplane separating the training dataset so that the distance of training points to the optimal hyperplane is maximized. This supposes that the training data are separable. Finding the optimal hyperplane is equivalent to resolving the following optimization problem:

$$\min\left(w^T w\right) \textit{ subject to } y_i\left(w^T x_i + b\right) \geq 1 \qquad (1)$$

In the relation (1), w is a vector perpendicular to the hyperplane, b is a scalar value, $\left\{x_i \in \mathbf{R}^d, y_i \in \{-1,1\}\right\}_{i=1}^{N}$ are the training points, N the number of examples and d the number of variables. If certain conditions hold and using the Lagrangian formulation, the previous problem is equivalent to its dual (2), which is a quadratic optimization problem and which can be solved using several techniques.

A SVM is a maximum margin classifier using only points on both sides of the margin or support vectors (points x_i for which the Lagrangian multipliers $\alpha_i > 0$) to build a model.

$$\max_{\alpha \geq 0} \sum_i \alpha_i - \frac{1}{2}\sum_i \sum_j \alpha_i \alpha_j y_i y_j x_i^T x_j \quad st \sum_i \alpha_i y_i = 0 \qquad (2)$$

For non-separable training datasets, penalty variables ξ_i are introduced to soften the constraints of the maximum margin formulation (1). The penalty variables are drawn as follows: $0 < \xi_i \leq 1$ if the points are on the correct side of the hyperplane and $\xi > 1$ if the point is on the wrong side. A cost variable *C* is also introduced to control the trade-off between the width of the margin and the points within the margin. The goal of the SVM classifier is then to maximize the margin while minimizing the total sum of the penalties and thus the equation (1) becomes:

$$\min\left(w^T w\right) + C\sum_i \xi_i^p \; st \; y_i\left(w^T x_i + b\right) \geq 1 - \xi_i, \xi_i \geq 0 \qquad (3)$$

However, the dual problem is often solved because the duality theory provides a convenient way to deal with constraints. The dual optimization problem can also be written in terms of dot products permitting the use of the kernel functions. The kernel trick allows applying the maximum margin algorithm to a transformed version of a non-separable dataset (feature space) via a mapping function ϕ. The related dual problem can be expressed as:

$$\max_{\alpha} 2\alpha^T e - \alpha^T\left(G(K) + \frac{1}{C} I_n\right) \quad st\, \alpha \geq 0, \alpha^T y = 0 \qquad (4)$$

In the previous relation, e is the n-vector of ones, $\alpha \in \mathbf{R}^N$, *G(K)* the Gram matrix and defined by $G_{ij}(K) = [K]_{ij} y_i y_j = k(x_i, x_j) y_i y_j$, I_n is a diagonal matrix of 1 and $\alpha \geq 0$ means $\alpha_i \geq 0$ for all i=1,…,n. The transformation function ϕ is integrated in the definition of the kernel matrix *K*. One kind of such kernel is the Gaussian kernel or RBF kernel expressed as $K(x_i, x_j) = \phi(x_i)^T \phi(x_j) = e^{-\|x_i - x_j\|^2 / 2\sigma^2}$. For such a kernel, the misclassification cost *C* and the kernel parameter σ need to be optimized.

Many researchers consider SVM as one of the best classification algorithm due to its theoretical foundation based on structural risk minimization implying a better generalization performance [4]. However, SVM can provide bad results used with wrong parameters. The usual way to find the parameters of SVM is to scan a range of possible values of the parameters, evaluate the classifier with a data splitting methods such as cross-validation or bootstraping and then select those providing the best performance. A better method is to evaluate the SVM with the leave-one-out procedure during grid search. This process is expensive with respect to computation time and a more efficient way to choose the SVM parameters is to take advantage of the underlying theory especially the bound of the leave-one-out error.

For the SVM with an RBF kernel and in the case of non-separable training data, *Vapnik* showed that the leave-one-out error is upper bounded by $4R^2\|w\|^2$ (the radius margin bound) [4]. *R* is the radius of the smallest sphere containing all $\phi(x_i)$ and is a solution to the following optimization problem:

$$\max_{\beta} 1 - \beta^T K \beta \quad st\, \beta_i \geq 0, e^T \beta = 1$$

This bound of the leave-one-out error can be used to estimate the parameter σ of the RBF kernel and the soft margin parameter *C*. The reader is referred to [5] for a survey of SVM error bound estimation. To obtain the radius margin bound for non-separable training data, we perform the following change:

$\tilde{w} = \begin{bmatrix} w \\ \sqrt{C}\xi \end{bmatrix}$ and $\tilde{\phi}(x_i) = \begin{bmatrix} \phi(x_i) \\ y_i e_i / \sqrt{C} \end{bmatrix}$ as the i-th training data. The kernel function becomes:

$\tilde{K}(x_i, x_j) = K(x_i, x_j) + \delta_{ij}/C$, where δ_{ij} is the Kronecker symbol. The new radius margin bound is $\tilde{R}^2\|\tilde{w}\|^2$ where $\tilde{R}^2$ is the objective value of:

$$\max_{\beta} 1 + \frac{1}{C} - \beta^T\left(K + \frac{1}{C}\right)\beta \quad st\, \beta \geq 0, e^T \beta = 1 \qquad (4)$$

The relation (4) can be solved using optimization techniques such as the gradient descent algorithms [6]. The use of the radius margin bound to estimate the parameters of the SVM is attractive thanks to the speed of its resolution.

Even if preventive measures are taken along the year to reduce and/or prevent the risk of HAI, many signs and symptoms and/or risk factors remain reliable to diagnose an infection (e.g. antibiotics treatment, fever, use of devices such as catheter or urinary tract, etc.). The goal of this paper is to evaluate the robustness of the SVM with respect to generalization performance i.e. its capacity to predict future unseen prevalence surveys. For this purpose, we predict the presence of an HAI on patient enrolled in the 2007 and 2008 prevalence survey from a model build on the 2006 data. This evaluation can also provide an insight of the effectiveness of the preventive measures taken between two prevalence surveys. A longer-term objective is to build an automated prevalence survey tool using information within the hospital data warehouse.

Materials and Methods

Datasets and software

As introduced in the previous section, we use a 2006 prevalence survey to build the HAI model and the 2007 and 2008 prevalence surveys for evaluation. We use three versions of these datasets as did in a previous study [3]. The first dataset, called S, contains all features from the prevalence database: demographic information; admission diagnostic according to the McCabe score and the Charlson index classification; patient information at the study date (ward type and name, status of Methicillin-Resistant Staphylococcus Aureus portage, etc); and information at the study date and the six days before (clinical data, central venous catheter carriage, workload, infection status, etc). After a first data cleaning and binarization, this dataset contains 60 features and 1384 cases including 166 positive ones (11.99%). The second dataset, called S1, contains 20 features obtained after application of 2 feature selection

methods (information gain [7] and SVM RFE [8]). The third dataset S2 is obtained from S1 but without the fever and workload features as the values of these features are not systematically gathered in clinical practice. We also highlighted in our previous study the redundancy or the negative interaction of these two features with the others making the learning with the dataset S and S1 challenging. The 2007 (resp. 2008) prevalence survey contains 1528 (1467) unique cases including 153 (156) positive cases. The ratio of positive cases turns around 10% and 12% for the 3 years.

We use libsvm with L2 implementation (i.e. $p=2$ in relation (3)) and having a radius margin bound resolution implementation using gradient descent algorithm [9]. The software is executed on a linux machine having quad-processor of 2.33GHz frequency and 3Gb of memory.

Model selection and evaluation

We implement the same strategy as in our previous study: 105 random training and testing splits are created for S, S1 and S2. The number of splits is taken arbitrarily. The SVM parameters are obtained on 5 random training sets. The gradient descent algorithm is applied to each of the five training sets using 4 initialization points. For each of the initialization point, 3x5 cross-validations are performed and provide 60 couples of the SVM parameters. As the datasets present imbalance ratio on positive and negative cases, we arbitrarily correct the imbalance by taking equal numbers of positive and negative cases before performing cross-validations. The radius margin optimization may converge to the final SVM solution from each initialization point but we take the results having less absolute value of covariance on the 2 parameters.

The evaluation of the model on 2006 data is done on the 100 remaining training/testing splits i.e. 100 models are created with the best parameters and are evaluated on the corresponding test set. The mean of f-measure, precision, recall or sensitivity, specificity and accuracy over the 100 test sets is used as performance metric. The 2007 and 2008 prevalence data are also evaluated with the 100 models. The prediction of a case is the mean prediction over 100 models using a majority vote.

Results

Four initialization points are considered for model selection: $init1 = (e,1)$, $init2 = (e^2, e^2)$, $init3 = (e, e^{2^{-10}})$ and $init4 = (e^5, e^5)$ where e denotes the exponential function. The 60 SVM parameters of the dataset S (respectively S1 and S2) are obtained in 81 (respectively 56 and 53) seconds. Table 1 provides a summary of the obtained parameters with respect to their mean, median and standard deviation. The last line of Table 1 provides the absolute value of the covariance of the SVM parameters. All initialization points converge to the same value of C and $Sigma$ but the initialization point *init4* (respectively *init3* and *init4*) provides less covariance of the SVM parameters for the dataset S (respectively S1 and S2).

These best parameters are used to build 100 models on the 2006 prevalence dataset; the results are depicted in Figure 1 and more details can be found in table 2. The horizontal bar on the top of figure 1 indicates if the results obtained with S, S1 and S2 are not significantly different based on the Mann-Wilcoxon mean test. This is the case for precision, specificity and accuracy of S and S1 and the Sensitivity of S1 and S2.

The evaluation of these models on the 2006, 2007 and 2008 data based on the features used is summarized in table 2. The mean of the f-measure, precision, sensitivity, specificity and accuracy of the models are reported. Confusion matrices are also reported for an intuitive reading of the results (A1, A2, A3, B1, B2, B3, C1, C2, C3). The numbers in the confusion matrix is the rounded mean of true positive, true negative, false positive and true negative obtained over the 100 models.

Discussion

As we have seen in the previous section, the use of the radius margin bound is attractive for SVM model selection with respect to its computational efficiency. A cross-validation procedure can take days if the step of the variables is thin. The computational efficiency of the radius margin bound allows us to carry out more experiments with several values of the ratio between the positive and negative examples.

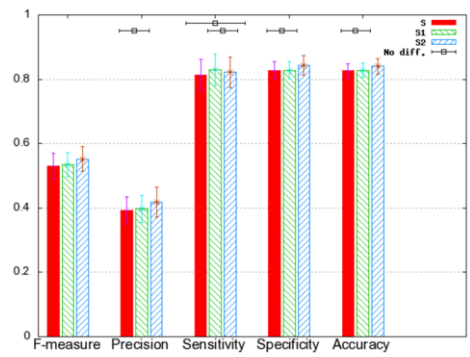

Figure 1 – Performance metrics of the models on the 2006 prevalence survey data.

For the 2006 dataset, the down-sampling methodology penalized the precision at the expense of recall. The obtained results are better than those from a previous study especially with the dataset S [3]. We have seen in the relations (1), (2), (3) and (4) that the SVM formulations are independent of the features present in the dataset. This was illustrated by the equivalence of the precision, sensitivity and accuracy between the datasets S and S1. The sensitivity of the three datasets S, S1 and S2 are equivalent and the other performance metrics of S2 are improved. From these results, we propose a new method to detect redundancy in a dataset using the SVM algorithm: if the removal of a subset of features keeps the recall unchanged while the other performance measures are improved then the subset of features has a negative interaction with the others. Many experiments are needed to confirm this proposal.

Table 1 - Best parameters C and Sigma according to the datasets and the initialization points on the dataset S, S1 and S2

		Dataset S				Dataset S1				Dataset S2			
		Init 1	**Init 2**	**Init 3**	**Init 4**	**Init 1**	**Init 2**	**Init 3**	**Init 4**	**Init 1**	**Init 2**	**Init 3**	**Init 4**
C	**Mean**	3.395	0.678	1.152	0.577	0.406	0.408	0.392	0.400	1.273	0.363	0.362	0.358
	Median	0.555	0.556	0.561	**0.549**	0.389	0.388	**0.391**	0.397	0.356	0.350	0.349	**0.348**
	Std dev	21.529	0.445	4.173	0.128	0.085	0.077	0.051	0.060	7.914	0.065	0.081	0.061
Sigma	**Mean**	0.069	0.067	0.068	0.065	0.199	0.199	0.198	0.197	0.232	0.230	0.230	0.227
	Median	0.066	0.065	0.071	**0.064**	0.189	0.194	**0.193**	0.193	0.205	0.201	0.204	**0.199**
	Std dev	0.041	0.038	0.040	0.029	0.086	0.085	0.076	0.082	0.128	0.124	0.115	0.108
Abs(Covariance (C,Sigma))		0.1906	0.005	0.035	**0.002**	0.0001	0.002	**0.000**	0.000	0.2123	0.001	0.002	**0.002**

Table 2 - Results obtained when applying the best parameters on the prevalence datasets of the year 2006, 2007 and 2008 according to the number of features in datasets S, S1, and S2

	2006			2007			2008		
Dataset S	**A1**	L+	L-	**A2**	L+	L-	**A3**	L+	L-
	P+	54	84	P+	69	35	P+	57	35
	P-	12	404	P-	84	1340	P-	99	1276
	F-MEASURE		0.5297	F-MEASURE		0.6008	F-MEASURE		0.6270
	PRECISION		39.29%	PRECISION		66.35%	PRECISION		61.96%
	SENSITIVITY		81.29%	SENSITIVITY		54.90%	SENSITIVITY		63.46%
	SPECIFICITY		82.78%	SPECIFICITY		97.45%	SPECIFICITY		97.33%
	ACCURACY		82.60%	ACCURACY		92.21%	ACCURACY		90.87%
Dataset S1	**B1**	L+	L-	**B2**	L+	L-	**B3**	L+	L-
	P+	55	84	P+	60	37	P+	56	40
	P-	11	404	P-	93	1338	P-	100	1271
	F-MEASURE		0.5377	F-MEASURE		0.6132	F-MEASURE		0.6108
	PRECISION		39.79%	PRECISION		61.86%	PRECISION		58.33%
	SENSITIVITY		82.88%	SENSITIVITY		60.78%	SENSITIVITY		64.10%
	SPECIFICITY		82.79%	SPECIFICITY		97.31%	SPECIFICITY		96.95%
	ACCURACY		82.80%	ACCURACY		91.49%	ACCURACY		90.46%
Dataset S2	**C1**	L+	L-	**C2**	L+	L-	**C3**	L+	L-
	P+	54	77	P+	65	41	P+	62	44
	P-	12	411	P-	88	1334	P-	94	1267
	F-MEASURE		0.5547	F-MEASURE		0.5936	F-MEASURE		0.5936
	PRECISION		41.87%	PRECISION		61.32%	PRECISION		58.49%
	SENSITIVITY		82.13%	SENSITIVITY		57.52%	SENSITIVITY		60.26%
	SPECIFICITY		84.27%	SPECIFICITY		97.02%	SPECIFICITY		96.64%
	ACCURACY		84.02%	ACCURACY		91.56%	ACCURACY		90.59%

With respect to our longer-term objective and with the features existing in S2 we can expect to have 41.87% true positive cases, which represent 82.13% of all infected patients when we build the model with the 2006 data. When the models were applied to datasets from 2007 and 2008, the "profile" of the performance changed: the sensitivity goes down considerably while the other performance measures increase. For the 2007 data, with the features in S2 we retrieved 61.32% true positive cases representing only 57.52% of infected patients. This drastic change of the performance measures can be explained as a consequence of the effectiveness of the prevention measures of the hospital. In other words, the prevention measures did not reduce the prevalence rate (around 10% from 2006 to 2008) but changed the signs and symptoms importance in our datasets and/or the risks of contracting the infections. A quick measure of the information gain followed by a chi-square filtering on the 3 datasets, as in [3] while we created the dataset S1, highlights a change in the order of the attributes and the appearance of new important ones. In machine learning this phenomenon is called "concept drift" [10]. Usually, the concept drift makes the model built on old data inconsistent with new data. If we want to use SVM to achieve our long-term objective, we need to take into account concept drift and implement, for example, an incremental method proposed in [11] i.e. exploiting the models build on previous prevalence survey datasets to predict actual cases.

Another important point in the analysis of the data warehouse data to support an automated prevalence system is the number of features to be extracted from the data warehouse, which was the topic of our previous study. A McNemar test (with Bonferoni's adjustment) was carried out in order to compare the performance obtained on the datasets S, S1 and S2 of years 2007 and 2008. This test indicates that the features present in S provide the best performance followed by S2. This indicates that if all the information of S can not be acquired for a new patient we have to use only those present in the dataset S2 (and not S1).

Conclusion

This study allows evaluating the robustness of SVM in a situation where the distribution of the features is changing over time. The sensitivity decreases and the other metrics increase when we apply a model build from datasets of the year Y on datasets of the year Y+1 and Y+2. This situation allows highlighting the effectiveness of the preventive measures taken after the prevalence survey in year Y. The use of the radius margin bound to select the SVM parameters was effective and allows us to carry out more experiments with respect to the manipulation of the ratio of positive and negative cases. We propose a new method to find redundant subsets of features in a dataset. We also found that the features present in S or S2 are necessary to build models. However it would be better to investigate the performance obtained using a dataset S3 including only common features obtained after the application of the information gain followed by a chi-square filtering on the prevalence datasets from the year 2006, 2007 and 2008. In the future, we plan to create models focusing on precision rather than the recall by using an asymmetrical misclassification cost. The main challenge is the adaptation of the radius margin bound for asymmetrical misclassification cost.

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Evaluating the relevance of disability weights for adjusting disease-cost and comorbidity calculations at the Kigali University Teaching Hospital

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Abstract

Evaluating the burden of diseases treated in hospitals in terms of (co)morbidity and financial impact is a long standing problem. Proposed solutions often rely on very sophisticated medical registration systems that are less suitable for developing countries. The authors have developed a simple prototype method for calculating financial impact and comorbidity of clinical conditions treated in a Sub-Saharan hospital environment (CALCO method) using disability weights. The developed method has been tested for 4 major clinical entities (tuberculosis, nutritional deficiencies, perinatal complications and malaria) on a dataset of 8.309 electronically registered admissions between Februari 1st 2009 and September 1st 2009 at the Kigali University Teaching Hospital. Results suggest that the method consists an acceptable instrument for estimating the financial burden of diseases treated in the hospital and that the proposed algorithms provide a useful formal method for quantifying hospital-bound comorbidity. The CALCO method might find its use in future implementations of Performance Based Financing (PBF) programs in Africa.

Keywords:

Cost of Illness, Comorbidity, Financing, International Classification of Diseases

Introduction

In 2009, the Kigali Health Informatics Research Institute (KHIRI), a department of the Kigali University Teaching Hospital (CHUK), began working out a set of pathology grouping codes in an attempt to enable efficient evaluation of clinical activity in a typical sub-Saharan hospital. This collection of grouping codes [1] was called the KHIRI Pathology Grouping Set (KPGS) and is a bi-classified grouping system, based on ICD-10 [2,4] and ICPC-2 [3] classification standards, completed with a clinical thesaurus [6]. The code structure has been derived from ICD-10 chapters. KPGS is somehow similar to the well known concept of Diagnosis Related Groups (DRG), which has proven to be useful for health management mainly in the Western world. However, the usability of these sophisticated, expensive and complex systems in developing countries with different cultural, demographic and health environments [5], is at least questionable. The KPGS classification can therefore be considered a simplified African implementation of DRG's, addressing clinical conditions that better match local African health management requirements. [1,5,6]

The CHUK is using today the KPGS classification of clinical conditions for documenting a number of important health facility management parameters: length of stay, episode of care based co-morbidity, care delivery costs related to specificic clinical conditions etc. The Kigali University Teaching Hospital is a national reference hospital; a large number of patients are being admitted at the health facility with complex health conditions involving multiple diseases or clinical concepts. At present, no formal structured registration has been put in place to qualify the actual burden of different clinical conditions linked to one and the same episode of care. Therefore, every documented clinical condition for an episode of care is being considered of equal severity by the actual hospital information system. This means that if the hospital management wants to calculate disease related costs based on care deliveries linked to a specific episode of care, the only method being available today is to distribute costs equally over all diseases linked to the considered episode of care. Such an approach appears of doubtful use in approximating the real financial burden of disease and can therefore not be used for practical (disease related) management needs (e.g. predicting cost/income evolution related to major changes in incidence of specific diseases and modulating human resources assignment to hospital departments based on the typical disease profiles of the patients treated in those departements)

Being able to quantify the average (financial) burden of diseases would greatly improve the way care delivery costs can be distributed over different diagnoses that have been associated to one and the same episode of care. In that approach, severe diseases would get more admission days, care delivery costs (drugs, consumables, clinical acts) and overhead costs attributed to than mild or even insignificant diseases, reflecting much better the real cost distribution in complex multi-pathology clinical situations.

Materials and Methods

Purpose of the study

The purpose of this study was to:

1. Assign weight-scores to clinical conditions reflecting their importance in terms of financial burden and comorbidty.
2. Evaluate the usability of the assigned weight-scores for quantifying comorbidity related to clinical conditions
3. Evaluate the usability of the assigned weigt-scores for enabling realistic distribution of care delivery costs over associated diagnoses for hospital admissions

Study concept

This is a comparative retrospective study in which disease related cost of care information is studied including episode of care identification, length of stay (LOS), cost of provided care deliveries and diagnostic codes under ICD-10, ICPC-2 and KPGS classifications.

Materials

Since the 3th quarter of 2008, discharge diagnoses and detailed information about provided care deliveries are being systematically encoded for every in-patient in the CHUK hospital information management system (OpenClinic®). For the purpose of this study, we will use a dataset extracted from the hospital information system covering all hospital admissions between February 1st 2009 and September 1st 2009 (n = 8.309).

Methods

Step 1: Elaborate a method for attributing weight scores to all 167 KPGS codes in use at the hospital site. A weight score should ideally reflect the (financial) burden of a particular disease or clinical condition

Step 2: Develop a method for distributing care delivery costs/income proportionally over all clinical conditions linked to an episode of care based on corresponding weight scores (estimation of direct disease-related costs)

Step 3: Develop a method for distributing overhead costs proportionally over all clinical conditions linked to an episode of care based on corresponding weight scores (estimation of indirect disease costs)

Step 4: Develop a method for calculating the (financial) burden of diseases treated at the health facilty in a defined period of time

Step 5: Compare the results of financial burden of disease calculations based on a sufficiently large dataset using 3 different methods (evaluation of the developed method)

1. The method of equal distribution of care delivery costs over all clinical conditions linked to an episode of care
2. The newly developed CALCO method of weight score based care delivery cost distribution
3. The method of manually distributing care delivery costs over all clinical conditions linked to an episode of care. This is done by a clinician and is referred to as the 'golden standard'.

Results

Step1: development of a weight-scoring method

This method has been based on elements of the work of Murray and Lopez on the concept of Disability Adjusted Life Years (DALY's). The DALY is a metric that is used to quantify the burden of diseases, injuries and health risk factors in a single measure. It is based on years of life lost from premature death and years of life lived in less than full health:

$$DALY_x = YLL_x + YLD_x \quad (1)$$

Where:

$DALY_x$ = DALY for clinical condition x

YLL_x = Years of Life Lost due to premature death caused by clinical condition x

YLD_x = Years Lived with Disability caused by clinical condition x

= [Incidence$_x$] x [Average disability duration$_x$] x [weight$_x$]

The weight reflects the seriousness of the clinical condition on a scale from 0 (perfect health) to 1 (death) and therefore has been considered an excellent candidate for weight-scoring KPGS clinical conditions. The concept has been introduced by Murray and Lopez for the purpose of their Global Burden of Disease (GBD) study in 1990 and was reused in the WHO GBD study in 2004 [7] assigning a score to a total of 107 GBD-clinical conditions (diseases and injuries). For every concerned GBD-clinical condition, a link has been made to corresponding ICD10 codes, enabling mapping on KPGS-clinical conditions used at the Kigali University Teaching Hospital:

- 76 of the 167 KPGS codes could be directly mapped onto a GBD clinical condition. In these cases, the GBD weight-score was transferred to the corresponding KPGS code.
- 21 KPGS codes cover symptoms or circumstances influencing health and have not been assigned a weight-score
- The remaining 70 KPGS clinical conditions had no equivalent in the GBD study. They have been assigned weight scores by clinicians referring to a table of sample-scores as shown in Table 1.

Table 1 – Sample scores table

Score	Sample clinical conditions
0,00	Mild anemia, mild hearing loss
0,05	Upper respiratory infection, migraine, skin diseases
0,10	Sleeping disorders, moderate hearing loss, low back pain
0,20	Serious hearing loss, reumatoid arthritis
0,30	Tuberculosis
0,40	Neuropsychiatric disorders
0,50	HIV, mental retardation
0,60	Meningitis
0,70	Major depression, metastatic cancer
0,80	Terminal cancer, major neurologic handicap
0,90	Complicated CVA

Step 2: develop a method for distributing care delivery costs

The purpose of this method is to distribute care delivery costs/income proportionally over all clinical conditions linked to an episode of care based on corresponding weight scores. In order to do so, we have first developed the concept of *Comorbidity Index of a diagnosis d* (I_d). The index I_d expresses the importance of a diagnosis within the context of an episode of care and is calculated as follows:

$$I_d = \Sigma W / W_d \quad (2)$$

Where:

- I_d = Comorbidity index of clinical condition *d* for an episode of care.
- ΣW = Sum of all weight scores of all clinical conditions associated to the episode of care
- W_d = Weight score for clinical condition *d*

As a consequence, the value of I_d is at least equal to 1 (e.g. when diagnosis *d* is the sole diagnosis linked to the episode of care), greater values indicating a lower weight of the diagnosis within the global clinical picture of the admission.

Care delivery costs can then be assigned to particular diagnoses using the following formula:

$$C_d = \Sigma C / I_d \quad (3)$$

Where:

- C_d = Care delivery costs/income associated to a clinical condition *d* for an episode of care
- ΣC = Sum of all care delivery costs/income for the episode of care
- I_d = Comorbidity index of clinical condition *d* for the episode of care.

Step 3: develop a method for distributing overhead costs

The purpose of this method is to distribute overhead costs proportionally over all clinical conditions linked to an episode of care based on corresponding weight scores:

$$O_d = \frac{\Sigma O}{\Sigma \delta} \times \frac{\delta}{I_d} \quad (4)$$

Where:

- O_d = overhead costs associated to a clinical condition *d* for an episode of care
- ΣO = the total overhead costs of the health facility for the studied period of time
- $\Sigma \delta$ = the total number of admission days at the health facility in the studied period of time
- δ = duration in days of the episode of care
- I_d = Comorbidity index of clinical condition *d* for the episode of care.

Step 4: calculating the (financial) burden of disease treated at the health facilty in a defined period of time

The total financial burden of a diagnosis *d* at a health facility can then be described by the sum of direct disease-related costs (care deliveries) and indirect disease costs (overhead):

$$F_d = \Sigma C_d + \Sigma O_d \quad (5)$$

Where:

- F_d = the total financial burden of disease for diagnosis *d* over the studied period
- ΣC_d = direct disease-related costs, represented by the sum of all care delivery costs/income associated to a clinical condition *d* for all episodes of care in the studied period
- ΣO_d = indirect disease costs, represented by the sum of all overhead costs associated to a clinical condition *d* for all episodes of care in the studied period

The average financial burden per episode of care for a diagnosis *d* at a health facility would then be:

$$F_{da} = F_d / n_d \quad (6)$$

Where:

- F_{da} = the average financial burden of disease for diagnosis *d* per episode of care over the studied period
- F_d = the total financial burden of disease for diagnosis *d* over the studied period
- n_d = the total number of episodes of care with diagnosis *d* in the study period

Then we also calculate the average comorbidity index for a diagnosis *d* (I_{da}):

$$I_{da} = \Sigma I_d / n_d \quad (7)$$

Where:

I_{da} = the average comorbidity index for diagnosis *d* per episode of care over the studied period

ΣI_d = the sum of all comorbidity indexes for all diagnosis *d*-related episodes of care over the study period

n_d = the total number of episodes of care related to diagnosis *d* in the study period

Step 5: evaluation of the methods developed in steps 1 to 4

The main objective of this evaluation step was to compare the results obtained with the newly developed CALCO method to:

1. A 'golden standard' provided by manual analysis of the same dataset by a hospital physician, calculating F_d and F_{da} based on clinical analysis of every episode of care by manual assignment of care deliveries to individual diagnoses
2. The actual method of equal distribution of care delivery costs over all diagnoses linked to an episode of care (equal weight-score for all diagnoses)

Because no reliable data on care delivery costs was registered in the hospital database, only care delivery income has been taken into account for the evaluation. The comparison was performed for all cases of 4 major clinical conditions treated at the hospital in the period between February 1st and May 1st 2009. The results are shown in Table 2.

Table 2 shows that the total care delivery cost F_d and the average cost per episode of care F_{da} related to 4 important clinical conditions could be estimated by the CALCO method within an acceptable margin of error. The deviations from the results obtained by the 'golden standard' method vary from -8,7% to +8,4%. This certainly presents an important improvement compared to the method of equal distribution of costs over all episode of care-related clinical conditions where deviations vary between -22,1% and +78,4%. However, the improvement seems to be minimal for 'KPGS code 160: Perinatal complications'. This is primarily due to the fact that in the large majority of the related episodes of care, 'Perinatal complications' represented the sole diagnosed clinical condition. This fact is also documented by the low I_{da} score for the 'Equal distribution method', where I_{da} equals to the average number of diagnoses per episode of care related to 'Perinatal complications'.

In a second stage, we have calculated F_d and F_{da} for all clinical conditions treated at the CHUK in the period from February 1st and September 1st 2009 (8.309 episodes of care). Table 3 shows the top 10 of clinical conditions responsible for the highest accumulated costs in the study period (F_d). Table 4 ranks the top 10 clinical conditions according to the average cost of an episode of care (F_{da}).

Table 2 – F_d, F_{da} and I_{da} calculation method comparison

Method	F_d	F_{da}	I_{da}	deviation
KPGS code 01B: Tuberculosis (n=31)				
GS	$4.349,87	$140,32	-	-
CALCO	$4.214,60	$135,95	1,340	-3,1%
ED	$3.461,89	$111,67	1,730	-20,4%
KPGS code 01V: Malaria (n=42)				
GS	$3.338,90	$79,50	-	-
CALCO	$3.046,79	$72,54	1,250	-8,7%
ED	$2.601,26	$61,93	1,610	-22,1%
KPGS code 04D: Nutritional deficiencies (n=29)				
GS	$1.088,97	$37,55	-	-
CALCO	$1.180,11	$40,69	7,860	+8,4%
ED	$1.942,79	$66,99	2,220	+78,4%
KPGS code 160: Perinatal complications (n=93)				
GS	$9.922,18	$106,69	-	-
CALCO	$10.268,56	$110,41	1,360	+3,5%
ED	$10.377,26	$111,58	1,250	+4,6%

GS = Golden standard

ED = Equal distribution of care delivery costs over all diagnoses linked to an episode of care

Table 3 – Top 10 clinical conditions sorted by F_d

Clinical condition	F_d	F_{da}
15B: Pregnancy complications	**$86.819,06**	$122,97
19A: Fractures	**$66.431,48**	$254,53
140: Genito-urinary diseases	**$39.581,10**	$122,54
190: Other trauma / intoxication	**$31.439,31**	$236,39
160: Perinatal complications	**$23.213,62**	$87,93
02F: Benign neoplasms	**$20.403,62**	$153,41
02A: Malignant neoplasms	**$19.835,44**	$146,93
11G: Peritoneal diseases	**$19.553,61**	$376,03
04B: Diabetes mellitus	**$16.470,61**	$249,55
10C: Pneumonia	**$14.635,57**	$114,34

Table 4 – Top 10 clinical conditions sorted by F_{da}

Clinical condition	F_d	F_{da}
19B: Burns and corrosions	$14.035,99	**$467,87**
11G: Peritoneal diseases	$19.553,61	**$376,03**
19A: Soft tissue disorders	$1.879,72	**$375,94**
07D: Diseases of iris & cil bord	$363,82	**$363,82**
06H: Polyneuropathia	$2035,94	**$339,32**
11P: Intussusception	$5.244,12	**$308,48**
09L: Intracranial haemorrhage	$4.220,70	**$281,38**
13C: Spine disorders	$1.117,67	**$279,42**
11G: Appendix diseases	$5.021,61	**$278,98**
11R: Hepatic failure	$1.319,05	**$263,81**

Discussion

The study provides evidence that the CALCO method enables calculation within acceptable margins of error of the financial burden of diseases in a hospital environment in Sub-Saharan Africa. CALCO has been completely integrated in the OpenClinic® hospital information system used at the CHUK health facility. All necessary calculations can be performed based on information registered in daily routine procedures and require no extra data-entry from hospital staff.

The method documents the distribution of hospital-bound income and costs over 167 clinical entities covering all ICD10 codes. This information can be used for multiple purposes:

- Detecting the clinical conditions that weigh most on the health facility budget. The actual study taught us that the top 3 clinical conditions in Table 3 account for more than 10% of the total hospital income.
- Estimating income/cost evolution related to disease incidence changes
- Comparing episode of care based costs for specific clinical conditions between health facilities
- Monitoring episode of care based costs for specific clinical conditions over time within a health facility

In the near future, the CALCO algorithms will be reused in a number of PBF implementations in Rwanda, notably for the health district of the City of Kigali. However, the actual CALCO method makes no use of international coding standards for procedures and care deliveries, limiting to some extent comparability of health facilities. Future developments will have to focus on this aspect.

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Analysis of data captured by barcode medication administration system using a PDA; aiming at reducing medication errors at point of care in Japanese Red Cross Kochi Hospital

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Abstract

Preventing medication errors by using a barcode administration system has become prevalent in patient safety. Analyses of data captured by bar code systems provide opportunities to understand the actual situation at the point of care. Our study aims at understanding issues of medication safety as well as investigating measures taken to prevent medication accidents, by analyzing data captured by a bar code system and a personal digital assistant (PDA),. The barcode administration system named Point-of-Act-System implemented in Japanese Red Cross Kochi Hospital was designed to capture every activity at the bedside. Complete activity data captured by the system, which included injections, treatment and other nursing activity, as well as injection warning data, were used for our analyses. We describe the data and analyze them statistically to find potentially times of risk and to ascertain the relation between busyness and error. The injection warning rate as a whole was 6.1% on average. The results showed there was a negative correlation between the number of injections given and the injection warning rate (-0.48, $p<0.05$). The warning rate was low during the hours when a large number of injections were administered. The data also showed that a variation in activities being performed has a negative effect on medication safety. A bar code administration system is quite an effective way not only to prevent medication error at point of care, but also to improve patient safety through analyses of data captured by such a system.

Keywords:

Point of Care System, Medication Errors, Administration and Organization, Handheld Computer, Patient Safety

Introduction

It is widely believed that patient safety is an important issue for health care systems. Many organizations and hospitals have been accumulating information on patient safety and medication errors to improve patient safety based on the data collected. These data is accumulated to provide information on threats to patient safety. Such data are quite useful in understanding the threats and actual situations related to medication errors in hospitals. However, most of this evidence is basically information on medical accidents and incidents, compiled from voluntary reports submitted by medical workers. This information is not detailed enough to enable the discovery of underlying general principles, because accidents and errors are part of the reality in a hospital setting. A complete picture of the situation in hospitals, including details of medical accidents and incidents, is essential to identifying general causes and frequencies of medical errors. However, it is extremely costly to obtain by observational research sufficient data to enable an understanding of all the activities conducted in a hospital, and furthermore, the accuracy of data collected by observation is sometimes defective. Information technologies such as electronic medical records and barcode administration systems at the point of care have the potential to provide new opportunities for us to understand the overall picture of medical activities by digital capturing data on daily medications and patient care in hospital settings. By using information systems for all patients in all wards, data captured by the systems become useful resources to understanding various phenomena in medical situations and investigating research questions. In terms of medication accidents, the point of care is a potentially risky area in medical activities [1-3]. Therefore, data captured at the point of care is quite effective in understanding medication accidents. One potential candidate system for this is a barcode administration system for safe injections and medication. Barcode medication administration systems prevent medication errors by authenticating the "5 Rights" of medication: right patient, right drug, right dose, right time, right route. Performed at the bedside, the system offers an excellent opportunity to gather data on medications [4-7]. In addition to their contribution to the authentication of the 5 Rights, data captured by barcode administration systems have the potential to provide sources of research to improve patient safety in terms of actual injections and medication data.

Our study aims to use and analyze complete data on medical activities captured at the point of care by the system to understand all the activities and issues related to medical safety, and to investigate preventive measures for medical accidents to manage healthcare situations. We focused on injections, which

a major cause of medical accidents, and investigated the relation between mistakes and the context of medical activities including how busy staffs were, and shift work.

Materials and Methods

Settings and items to be addressed

Japanese Red Cross Kochi Hospital has 482 registered beds and approximately 290,000 out-patients and 9,355 in-patients per year. The hospital implemented a hospital information system called "Point of Act System," or POAS, in 2004. POAS is a real time bar-code capturing health information system designed to prevent medication errors by capturing the barcodes of patients, workers and drugs, and then authenticating the 5 Rights of each medical action [10-12]. Figure 1 shows a Personal Digital Assistant (PDA) for barcode capturing, nursing work management, and risk management for injections and intravenous drips (IV). When nurses scan the barcodes of drugs or IV bags for patients, the system checks the correctness of the injections and IVs against real-time accurate information in a computerized order entry system and electronic health record within 2 seconds.

At the same time, POAS captures complete data on each medical action including 6W1H information (When, Where What, Why, for What, to Whom and How) conducted in the hospital. The units of data recorded by the system are: Who—the implementer (the person who initiated the order, or the person who carried it out), to Whom—the patient, How—medical activities and changes in them, What—materials used (pharmaceuticals, medical materials and others), How much—amount of materials used and number of applications, for What—name of patient receiving medical services, When—date the order was placed, implemented and discontinued and the activities that were implemented, and Where—place of implementation (department, hospital, ward, etc.). The principal characteristics of data captured by this system are (1) complete data at a specific place including every action recorded in real time and accurately and (2) process data-based process management that enables POAS to ensure the correct process of medication and assures it captures complete data. The collection of complete data including 6W1H information is an innovative source in understanding actual situations directly without estimation or bias, and enables the investigation of solutions to prevent errors.

Data

Data captured at the sites of the injection process were used for our analyses of medication administration. In this study, data on injections means both injections and IVs. 6W1H information was captured at each point of the injection process: Order to give injection, Drug selection, Drug audit, Drug mixing, and Injection. Although the first objective of a bar code administration system is to ensure patient safety by verifying the 5 Rights of medication, another objective is to record the activities of nurses to support nurses' request of drugs and devices consumed, and enforce medication for patients.

At the point of care, nurses uses PDAs to scan the barcodes of ampoules or vials containing the medication to be injected or scan the barcodes of activities to enter information on their actions such as treatment, care, observations, counseling and emergency. This information is primary used for the documentation of nursing activities. However, this information can also be used not only for hospital management—by understanding the workloads of nurses and the actual costs of administering medications—but also for patient safety by understanding the prevailing situations when mistakes are made. In addition to these data entered by nurses, we also used warning data demonstrating mistakes that can be made in scanning the barcodes on drug vials. Warning data do not directly mean data on medication errors, because the system prevents error by alerting staff before a mistake is made. However, warning data are useful sources of information in analyzing the causes of medication errors, because a warning means a potential medication error without a barcode administration system. Therefore, high warning rates at specific times, places, situations and workers mean risky times, places, situations and workers in terms of patient safety. Basic types of warning are basically: a wrong or expired vial scanned by a nurse for a patient; wrong patient; and mixing error meaning incorrect mixing of drugs. Data collected from January 2005 to June 2008 were used for the analyses. The total numbers of activities represented by the data are 14,824,046 individual acts, and the number of injections and IVs administered were 604,847. The data covered almost 100% of the injections and 99% of the activities by nurses in the hospital according to internal research.

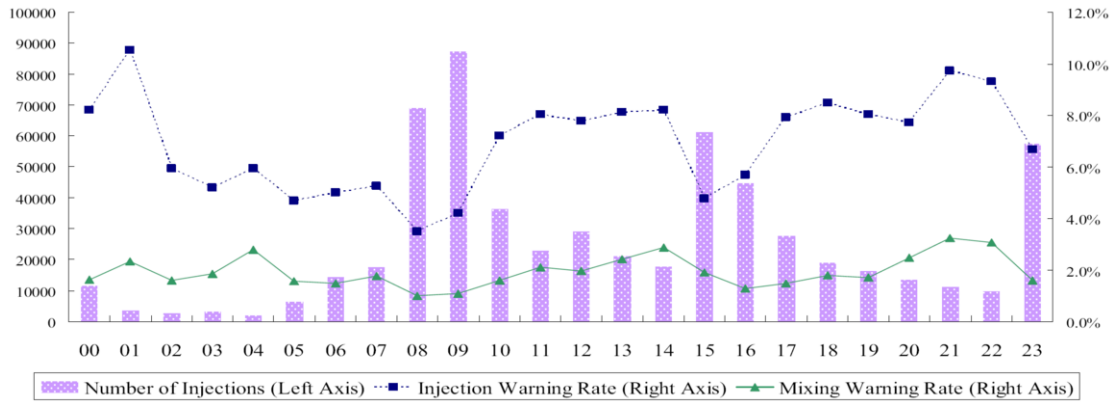

Figure 1 - Number of injections per hour and warning rate

Data Analysis

We accumulated data for each hour (for 24 hours a day) to identify times of high risk so as to understand the big picture of medical activities and medical errors in hospital wards. Warning rates were computed for each hour. These rates were treated as indicators to show risky times and situations.

We described these data, and analyzed them statistically to investigate correlations between situations and warning rates. Total number of injections per hour, total number of activities, total number of injections per PDA by hour, and total number of activities per PDA by hour were used as indicators for a nurse's workload at the time. The fraction out of total activities spent giving injections was used as an indicator for variation in hours. We calculated the proportion of the number of injections among total activities at that time. We employed Pearson Correlation Analysis to investigate relations and the significant level was 5%.

Results

Total number of activities was 14,824,046 including 69,276 injections (0.4%), 535,571 IV starts (3.6%), 483,770 IV finishes (3.3%), 1,979,804 care giving (13.3%), 10,437,250 observations (70.4%), 14,713 counseling (0.1%), 824,743 treatments (5.6%) and 478,919 emergencies (3.2%). The number for observations is extremely high. The total number of injections including IVs was 604,847, and the total warnings for injections were 37,046 (6.1%). The injection warning rate during early periods of implementation was around 9%, but has decreased to around 6 %.

Figure 1 shows the trend in warning rate and activities by the hour. The bar graph shows the number of injections by hour. There is a variability in the number of injections by hour, with three peeks for injections administrated: 9:00, 15:00 and 23:00**.** Most injections were administrated around these three peaks. The two line graphs show injection warning rates and mixing warning rates by the hour. Minimum and maximum of injection warning rates were 4.2% and 10.5%, while the minimum and maximum mixing warning rates were 1.0% and 3.2%. These figures vary quite a bit over the hours.

This graph shows the warning rate was lower when nurses where administrating a large number of injections. For example, the warning rates between 8:00 and 10:00 are lowest, although the numbers of injections are highest. The warning rates between 15:00 and 17:00 are also lower compared with the warning rates around the time.

In this hospital, the nurses work three shifts: Day shift (8:00-16:40), Evening shift (16:00-0:40), and Night shift (0:00-8:40). The warning rates per shift were 5.5% Day shift, 7.3% Evening shift, and 6.0% Night shift. Some researchers have reported that warning rates during nighttime are higher than during daytime [5]. However, there is no clear evidence to support the statement in our analyses. The trends in injection warnings and mixing warnings have basically the same tendency, although the tendency can be recognized more clearly in the injection warning rates. Especially during Day shifts, this tendency was demonstrated quite clearly.

We ran some statistical analyses to investigate the relation between warning rate and other variables. According to the results of a correlation analysis between variables, there was a negative correlation between the number of injections and injection warning rates. Figure 2 is a scatter plot of the number of injections per nurse and injection warning rate. The correlation coefficients between the number of injections and injection warning rates was -0.48 ($p<0.05$), and that between the number of injections per PDA and injection warning rates was -0.34 ($p<0.05$). Both results were statistically significant at the 95% level. This results show there is a tendency that more injections means safer injections at specific times as described above.

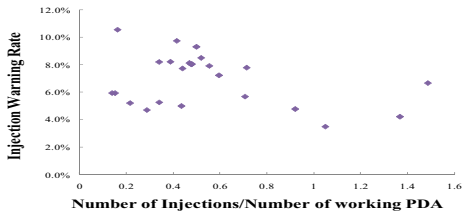

Figure 2 - Number of injections per nurse and warning rate

Variation in activities had a negative effect on the injection warning rate according to other correlation analyses. Figure 3 is scatter plot showing the relation between the injection fraction of total activities computed by the number of injections divided by the total number of activities and injection warning rates. The correlation coefficient between the treatment fraction of total activities and injection warning rates was 0.35 ($p<0.05$) and statistically significant. This indicator implied a high fraction of treatment, meaning nurses should administrate injections along with other treatments for patients and discourage nurses from concentrating on injections.

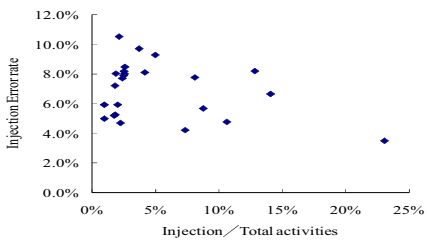

Figure 3 - Number of injections and warning rate

Discussion

There are some differences between our study and previously published literature. In past literature on patient safety, many studies had said workloads and busyness are the principal cause of medication errors, based on observatory studies of nursing practice [13-14]. These studies implied that it was acceptable that healthcare workers were so busy that they had to rush tasks, which caused a lack of due care and attention to be given to the administration of medications, and sometimes resulted in the certification processes being skipped. However, this study shows an opposite tendency in the medication errors rate. This study implies that people made mistakes not because they were doing too many things, but because they were doing too many different kinds of things. During a high frequency time for injections, nurses can concentrate on administrating injections to patients. Literature on human factor engineering indicate the same kinds of conclusions to ensure quality of activities [15-16]. It basically says that doing too many kinds of things is not a good way to ensure quality and reduce costs of activities, and that specialization is essential to redesigning workflow to improve management.

There is also another difference in our results compared with previously published literature. Injection warning rates in this study were relatively high compared to other studies on administration errors in injections [1-3, 13-14]. Many researchers have assumed injection error rates by observation of daily work, and their results gave a figure of around 4% for injection error rates as opposed to the 6.1% found in our study. Of course, there is a possibility that the difference in the injection warning rate came from environmental or other factors. However, the accuracy of data used in the analyses and detection of mixing errors could be regarded as the cause of the difference in results. Data captured by observational study has a bias in that people administrate more carefully when being observed. Therefore, the data captured by observational studies might be better than in reality. Other reason for the difference stem from the fact that other studies could not detect incorrect mixing of drugs. To identify incorrect mixing, drugs need to be managed not by a drug name ID but by a serialized ID [11]. A serialized ID on each product makes it possible to distinguish mixed and unmixed vials by recording the mixing for each drug and injection.

Clarification by time is an aspect of related factors for medication processes. Multivariate analyses with risk adjustment are needed to investigate more precisely reasons for medication errors. It is possible to accumulate data by place and people to identify a risky situation more precisely and in more depth, instead of clarifying by time. Figure 4 shows an example of another type of analysis, a scatter plot for the number of injections and injection warning rates per ward. The numbers of injections administered are totally different, but the injection warning rates are similar.

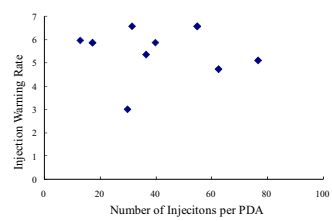

Figure 4 - Number of injections and warning rate per ward

We can identify one outlier whose warning rate is lower than for the other wards. To investigate the reason for this result, we need more in-depth analyses based on multiple variables and qualitative analyses.

One limitation to our research is in treating injections and other activities as the same workload activities, though actually there are quantitative and qualitative differences between these activities. It is necessary to assign weighs to each activity based on a time study or some methodology so as to capture more deeply and accurately the workloads of nurse for subsequent analysis. Another issue to be developed in this kind of analysis is privacy protection. In this analysis, data accumulated by hour and ward was utilized. The results did not contain personal data such as health care workers performance or data on patients. All patients and healthcare workers have unique identification numbers in this hospital. Therefore it is possible to analyze data using the identification numbers—including patient identification and worker

including patient identification and worker identification. To utilize digital data from electronic health records and other hospital information systems, discussions on the utilization of data and privacy protection is essential for the development of methodologies for data utilization and protection, as well as for frameworks supporting and sometimes restricting the use of data.

Conclusion

This study showed general trends in medication mistakes in practice using data captured by the hospital information system "Point-of-Act System" in real time and accurately. The results suggested that a high variation in activities performed might have negative effects on patient safety, and that busyness could not be regarded as the main causes of errors. Our study also implied the possible effects of bar code administration systems. According to the results, the injection warning rate was about 6%, and these warnings prevented nurses from committing errors and accidents. The lack of accidents with respect to injections in the hospital provides the system's ability. In conclusion, the bar code administration system might be quite an effective way not only to prevent medication errors at point of care, but also to improve patient safety through the analyses of data captured by them, if a system were designed correctly. Further research is needed to make progress in digital data usage and the utilization of healthcare IT.

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A Business case for HIT Adoption: effects of "meaningful use" EHR financial incentives on clinic revenue

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Abstract

The goal of this study is to describe a framework that allows decision makers to efficiently evaluate factors that affect Electronic Health Record (EHR) adoption and test suitable interventions; specifically financial incentives. The United States healthcare delivery system is experiencing a transformation to improve population health. There is strong agreement that "meaningful use" of Health Information Technology (HIT) is a major enabler in this effort. However it's also understood that the high cost of implementing an EHR is an obstacle for adoption. To help understand these complexities we developed a simulation model designed to capture the dynamic nature of policy interventions that affect the adoption of EHR. We found that "Effective" use of HIT approaches break-even-point and larger clinic revenue many times faster that "average" or "poor" use of HIT. This study uses a systems perspective to the evaluate EHR adoption process through the "meaningful use" redesign as proposed in the American Reinvestment and Recovery Act 2009 in the United States healthcare industry by utilizing the System Dynamics methodology and Scenario Analysis.

Keywords:

Electronic health record, Health information technology, EHR, HIT, System dynamics, Care management plus, Meaningful use, Adoption, Diffusion, Financial incentives, Revenue, Scenario analysis, Physicians, Care managers, Policy, National healthcare

Introduction

In order to introduce significant and measurable improvements in populations health in the United States, various government and private entities seek to transform the healthcare delivery system by enabling providers with real-time access to medical information and tools to help increase quality and safety of care [1]. Performance improvement priorities have focused on patient engagement, reduction of racial disparities, improved safety, increased efficiency, coordination of care, and improved population health [1]. Using these priorities the Health Information Technology (HIT) Policy Committee, a Federal Advisory Committee (FACA) to the U.S. Department of Health and Human Services (HHS), has initiated the "meaningful use" agenda for adoption of Electronic Health Records (EHR).

Fueled by the $19 billion investment available through the American Recovery and Reinvestment Act of 2009 (Recovery Act), efforts are in full swing to accelerate the national adoption and implementation of health information technology (HIT) [2]. The Recovery act authorizes the Centers for Medicare & Medicaid Services (CMS) to provide payments to eligible physicians and hospitals who succeed in becoming "meaningful users" of an electronic health record (EHR). Incentive payments begin in 2011 and phase out; by 2015, non-adopting providers will be subject to financial penalties under Medicare [1].

Medicare is a social insurance program administered by the United States government providing health insurance to people aged 65 and over, or individuals with disabilities. Similarly Medicaid provides insurance for low income families [3].

CMS will work closely with the Office of the National Coordinator and other parts of HHS to continue defining incentive programs for meaningful use. The Healthcare Information and Management Systems Society (HIMSS) recommend that a mature definition for "meaningful use of certified EHR technology" includes at least four attributes [4]:

1. A functional EHR certified by the Certification Commission for Healthcare Information Technology (CCHIT);

2. Electronic exchange of standardized patient data with clinical and administrative stakeholders using the Healthcare Information Technology Standards Panel's (HITSP) interoperability specifications and Integrating the Healthcare Enterprise's (IHE) frameworks;

3. Clinical decision support providing clinicians with clinical knowledge and intelligently-filtered patient information to enhance patient care; and

4. Capabilities to support process and care measurement that drive improvements in patient safety, quality outcomes and cost reductions.

While existence of such mentioned programs is a motivation to consider using an EHR, historically adoption has been slow and troublesome [5]. One often cited obstacle is the high cost of implementing Electronic Health Records. Since usually incentives for adoption often go to the insurer recouping the

cost are difficult for providers [6-8]. Other challenges existing in the United States healthcare system include variations in practices and proportion of income realized from adoption [9,10].

Hence in this paper we propose that having a complimentary and value-adding care model next to the EHR will facilitate more meaningful use of HIT. One such product is the Care Management Plus (CMP) program developed at Oregon Health & Science University (OHSU)[11]. CMP is a validated and disseminated model of care coordination, information technology, and quality improvement in primary care for older adults and patients with complex, chronic diseases [12].

CMP couples an ambulatory care team with health information technology (HIT). For seniors with complex needs, CMP demonstrated a 20% reduction in mortality, a 24% reduction in hospitalizations and a 15-25% reduction in complications from diabetes [13, 14]. CMP facilitates use of HIT to establish and track care plans and specific patient goals, to teach and encourage self-management, to measure and improve quality, and to manage the complex and interleaving tasks as patients and teams prioritize needs.

Background

The Care Management Plus (CMP) model for primary care, developed by researchers at Intermountain Healthcare through funding from the John A. Hartford Foundation, uses specially trained care managers and tracking software to help clinics better care for patients with complex chronic illness. The model helps the clinical team prioritize health care needs and prevent complications through structured protocols, and it provides tools to assist patients and caregivers to self-manage chronic diseases. Specialized information technology includes the care manager tracking database patient summary sheet and messaging systems to help clinician's access care plans, receive reminders about best practices, and facilitate communication between the health care team.

CMP focuses on two primary areas: well-trained care managers embedded in the clinic and IT technology to help them manage patients with chronic illnesses. Figure 1, describes the primary aspects of the CMP program. Physicians refer patients with complex needs (about 3-5% of the population in primary care clinics) into the program. The care manager then co-creates a care plan with the patient, acts as a guide to help the patient and family meet their goals, and facilitates access to necessary resources when the patient or family needs navigation [15].

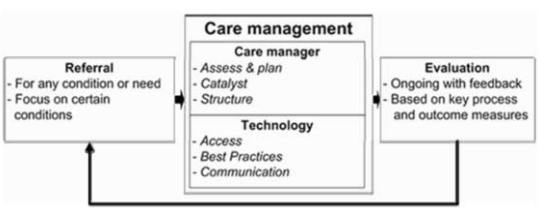

Figure 1- Care Management Plus

Figure2 shows a systems view of the Care Management Plus Program and its interaction with the EHR and various stakeholders. Integrated Care Coordination Information Systems (ICCIS) is the new revision of the Information Technology component of the CMP model. Physicians, Nurse Care Mangers, Patient and Patient family are able to interact and manage the patient's continuous care through the ICCIS web-0based interface. Additionally the ICCIS database is integrated with the EHR database for two way communication and reduced redundancy.

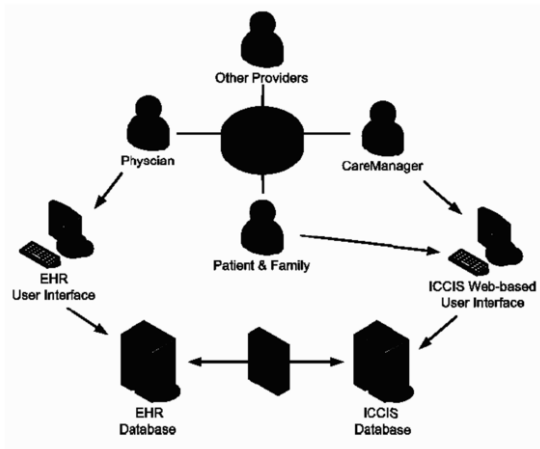

Figure 2- Medinfo 2010 paper submissions

Methodology

The goal of this study is to evaluate a framework that allows decision makers to efficiently evaluate factors that affect EHR adoption and test suitable interventions.

To this end we have develop a comprehensive simulation model designed to capture the dynamic nature of policy interventions that affect the adoption of EHR. We have aimed to capture interactions in the adoption of EHR for hospitals, physicians and Nurse Care Managers.

We have developed scenarios for clinic types based on the representative demographic that have already adopted the Care Management Plus Program which are listed in the results section. Then we have built a model of the adoption process and life cycle using the System Dynamics methodology. System Dynamics was introduced by Jay W. Forrester in the early 1960s to study complex systems such as the urban dynamics problem is used to build our simulation model [16].

To perform the simulation we have ran the System Dynamics model for each of the scenarios and the results are discussed in the next sections.

The model captures the dynamic characteristics of policy interventions and can be used to test different policies that might influence the adoption of EHR while providing insights.

For our model, we chose the following policy interventions, which can affect adoption First, *physician productivity*, which

includes for example activities that would stream line the physician workflow. Second, *financial incentives*, such as government reimbursement for use of HIT. And third, *cost*, for example the resources necessary to implement an EHR. Figure 3 shows a high-level view of the system dynamics based simulation model.

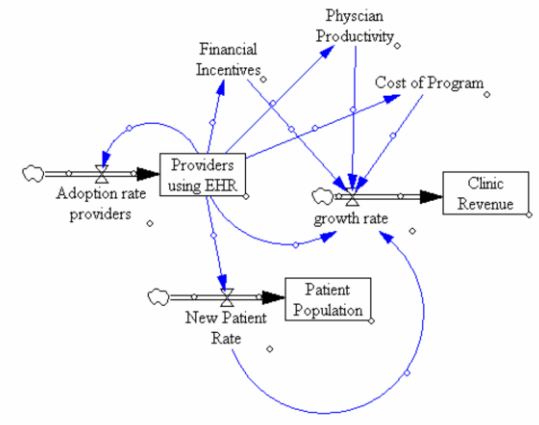

Figure 3- System Boundary

As stated previously it's this experiments goal to evaluate how policy interventions effect the adoption of EHR with meaningful use criteria while using the Care Management Plus program. To assess adoption of EHR, we propose the following set of dynamic conditions:

- *The more a Physician or a Nurse Care Manager is aware of EHR benefits, the higher the likelihood of adoption.*
- *The level and quality of "meaningful use" implemented by the clinic; low, medium or high will affect likelihood of successful adoption.*
- *Presence of Financial incentives will positively influence the adoption rate of EHR in hospitals and physicians offices.*

These hypotheses were examined using the system dynamics model created.

Results

In order to run the simulation three scenarios that were representative of existing CMP adopter clinic types were created and are shown in Table-1[15]. Small and medium sized private practices and a Safety Net Clinic are most common fit profiles of typical CMP users. Statistics of interest in the model included Number of physicians, number of Nurse Care managers in the practice as well as their patient panel size. The last column in Table1 lists the source of financial incentives for each clinic type, these numbers are average numbers based on available data [15]. Government incentive refers to Medicare and Medicaid reimbursements through the various programs available across the United States. Private incentive sources are mainly commercial sources and may include private insurance, employer-based funds or self-funding.

Amongst the listed scenarios a Small Rural Private Practice receives 53% of its total incentives from the government. Of that amount 50% is from Medicaid and 50% from Medicare. A Medium Private Practice in our second scenario receives 20% of it incentive from the government which 100% comes from Medicare. The Safety Net Clinic in our scenario receives 80% of its incentives from the government, with 75% from Medicaid and 25% Medicare. Health care safety net clinics are community-based providers who offer health services to low-income people, including those without insurance [17].

Table 1 - Clinic Type Scenarios

Clinic Type	**# of Physicians** **# of CareManagers** **# of Patients**	**Incentives**
Small Rural Private Practice	2 1 4600	Government: 53% Private: 47%
Medium Private Practice	5 1 11,500	Government: 20% Private: 80%
Safety Net Clinic	5 1 11,500	Government: 80% Private: 20%

In order to exercise the model we define three levels of HIT use with CMP:

- *Effective:* 40 patient referrals/month to CMP– meets meaningful use measures
- *Average:* 20 patient referrals/month to CMP– meets meaningful use measures
- *Poor:* 20 patient referrals/month to CMP– does not meet meaningful use measures

We run the simulation for each clinic for 3 years and the results are shown in Table 2. The new clinic revenue due to implementing CMP with EHR is listed in the second column of this table. New revenue is roughly calculated based on the formula below:

Revenue = (Patient Population Growth + Physician Productivity) - Implementation & Cost

The third column of the table shows the societal cost saving for each scenario. Average societal cost savings is estimated at $10,548 per hospitalization [12]. Societal savings were based on $640-$1,650 per patient per year savings.

Table 2 - Scenario Results after 3 years

Clinic Type	New Clinic Revenue	Societal Savings ($)
Small Rural Private Practice	-$76,776	$163,200 – $420,750
Medium Private Practice	$267,004	$409,600 – $1,056,000
Safety Net Clinic	$178,712	$409,600 – $1,056,000

Discussion

Figure 4 trends the clinic revenue due to implementing CMP with an EHR over roughly three years. The trends show that an initial investment in HIT affects the revenue of clinic adversely, which is expected. The three scenarios trended are with effective HIT use, Average and low as described in earlier sections. Effective use of HIT approaches breakeven point for adoption in 1 year. Average HIT with meaningful use break even at two years and poor usage of HIT almost breaks even in three years.

Therefore suggesting that better use of IT means the clinic recoups the cost earlier. However another interesting point is that effective and average use of HIT will lead to almost 5 times the revenue in three years compared to poor IT use. This is probably due to internal dynamics of the clinic workflow.

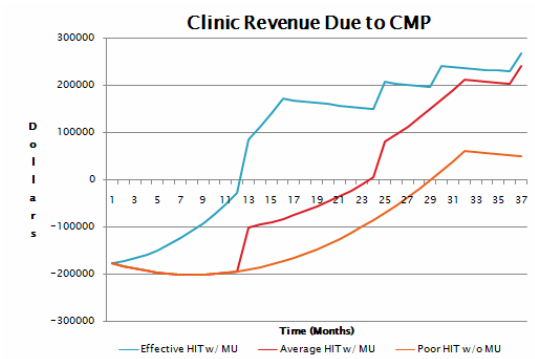

Figure 4 - Clinic Revenue Trend

Figure 5 takes a closer look at the complex system and reveals a positive feedback loop in the system. The more people are referred to Care Management, the more CM patient encounters and therefore larger financial incentives from government and private sources. There will be more revenue for the program which can lead to increased total clinic profit, which requires hiring new care mangers to handle the load. This positive feedback should generate financial incentives that continue to entice the providers to use HIT in a meaningful way.

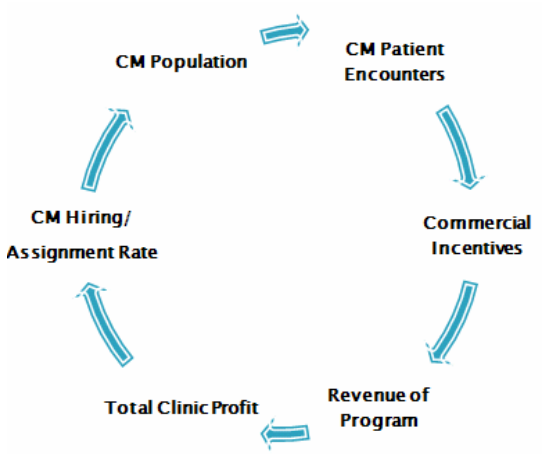

Figure 5- Incentive Positive Feedback Loop

Conclusion

This study uses a systems perspective to the evaluate EHR adoption process through "meaningful use" redesign in the United States healthcare industry by utilizing the System Dynamics methodology with Scenario Analysis. The model provides insights to understanding the factors influencing the adoption process and their interactions.

In this study, we investigated the often troublesome process of EHR adoption among hospitals, physicians, and patients. This study highlights the need for financial incentives with effective HIT meaningful usage for promoting EHR adoption.

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More information regarding CMP is available through the Care Management Plus website at:

http://www.caremanagementplus.org

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Why is it so difficult to measure the effects of interruptions in healthcare?

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Abstract

Interruptions are a complex phenomenon where multiple variables including the characteristics of primary tasks, the interruptions themselves, and the environment may influence patient safety and workflow outcomes. Observational studies present significant challenges for recording many of the process variables that influence the effects of interruptions. Controlled experiments provide an opportunity to examine the specific effects of variables on errors and efficiency. Computational models can be used to identify the situations in which interruptions to clinical tasks could be disruptive and to investigate the aggregate effects of interruptions.

Keywords:

Interruption, Medical error, Safety, Efficiency, Evaluation studies, Observation, Computer simulation.

Introduction

Interruptions seem to be inherent in the way work is undertaken in many clinical settings [1, 2]. Numerous studies have characterised this phenomenon over the last decade, and examined the extent to which doctors and nurses are interrupted in undertaking routine clinical tasks. Hospital doctors and nurses are interrupted anywhere between once every two hours, up to 23 times every hour in emergency, intensive care and surgery [3]. Interruptions may be a risk to patient safety in certain types of clinical tasks [4].

While there is solid evidence from psychology on the disruptive effects of interruption on human cognition [5], there is little evidence to date about the domain specific consequences of interruptions on clinical work. Interruptions have been reported as a contributing factor in IT-related medication incidents. Examination of 7029 CPOE-related medication incidents in the United States Pharmacopeia Medmarx database found that distractions were a significant contributing factor in eight out of ten errors [6]. In a UK study, interruptions and distractions were reported as a factor in up to 11% of errors in dispensing medications [7]. Interruptions also have a time cost. In one study clinical staff in an emergency department spent 24% of their time in dealing with interruptions [8].

A recent review of clinical interruption studies found that most studies were observational, describing the frequency, duration and types of interruptions [3]. Only one controlled experimental study examined the effect of interruptions on programming an infusion pump [9]. The review concluded that it is currently not possible to be certain about the causal links between interruptions and errors in healthcare. Yet interruptions have been well studied in other domains such as psychology, human-computer interaction [10] and aviation [11]. In most instances interruptions have been found to be disruptive, increasing time spent on a task and leading to errors in completing tasks. Studies also identify some of the characteristics that make interruptions disruptive such as the interruption complexity [12], similarity of an interrupting task to the primary task [13] and the availability of retrieval cues in the primary task [14]. While this literature provides a useful starting point for examining interruptions in healthcare, the disparity in tasks and environmental context make it necessary to investigate the specific consequences of interruptions to clinical work and their impact on patient safety.

In this paper we seek to examine the problem of studying interruptions in healthcare. We argue that the complexity in studying interruptions and measuring their impact on clinical work is one reason why little is still known about the clinical consequences of interruptions and this may require different research methods to those currently used in interruption research.

Methods

This study draws upon general literature about interruptions in non-health domains; experimental studies of the impact of interruption on electronic prescribing [15] and error behaviour [16]; and a series of observational studies in emergency and intensive care [8, 17, 18]. We firstly bring together a range of process and outcome measures to describe the complexity and consequences of interruptions. This is followed by a discussion of how observational studies, controlled experiments and computer simulations can be used to study interruptions and their impact on the safety and efficiency of clinical tasks.

Results

Table 1 lists primary task and interruption variables that may contribute to the outcomes of interruptions.

Task and interruption variables

1) Task type: Primary tasks and interruptions can be described in terms of their phenotype or their genotype. The *phenotype* is used to refer to the surface characteristics of a clinical task. In an observational study we found that doctors attended to a

range of task phenotypes that included prescribing medications, answering their pagers, phone calls, conversations with patients and colleagues on the ward, consulting medical records and reviewing investigation results [19].

The study of interruptions also requires description of underlying task characteristics or *genotype* such as task complexity and working memory load requirements, which have been shown to influence the disruptiveness of an interruption [20, 21]. Few clinical tasks fit neatly under the broad heuristic classes of procedural or problem solving traditionally used in interruption studies to describe task phenotype. A more sophisticated approach may be Wood's definition based on acts and information cues allowing task complexity to be quantified and compared [22, 23]. Models such as GOMS (Goals, Operators, Methods, and Selection rules), a well-recognised cognitive engineering method, also allow differentiation of the relative complexity of computer-based tasks by working memory load requirements. We have applied this method to analyse electronic prescribing tasks [19].

Table 1- Variables associated with effects of interruptions.

Task and interruption variables (process measures)
1. Task type (primary and interrupting task)
2. Point of interruption
3. Duration of interruption
4. Similarity of interruptive task to primary task
5. Modality of interruption
6. Environmental cues
7. Interruption handling strategy
Impact on task performance (outcome measures)
8. Safety: task errors
9. Efficiency: time on task, interruption lag, resumption lag

2) Point of interruption: Interruptions at the beginning of a task appear less disruptive than those in the middle of a task [24]. Interruptions at the end of a task may also be particularly disruptive, especially when the main goal is accomplished and a small sub-task remains. For example, a nurse who administers a medication may fail to complete documentation relating to that medication when interrupted. Such errors are known as post-completion errors [16, 25].

***3) Duration of interruption*:** The longer an interruption, the longer it takes to re-orient and restart the primary task afterwards, indicating that the disruptiveness of an interruption is directly related to its duration [26].

***4) Similarity of interruptive task to primary task*:** In computer-based tasks, interruptions have been found to be less disruptive when they are dissimilar to the primary task [27].

***5) Modality of interruption*:** A range of modalities like heat, smell, sound, vibration, and light can influence interruption effect [28]. For example, a doctor interrupting a nurse who is administering medications, to discuss the care of a patient, is a different experience to a device mediated interruption such as a phone, pager or an alarm, which could be turned off.

***6) Environmental cues*:** The availability of information cues in the primary task, such as an x-ray, should help return to it after interruption. Studies have shown blatant cues are highly effective, but the availability of subtle cues is the same as having no cues at all [29]. While the clinical environment is full of cues, some may be less obvious than others. A doctor who is interrupted when reviewing an x-ray is cued to resume and complete her primary task by the image display. The absence of cues when an interruption dislocates a clinician from her primary task may be particularly relevant in hospital settings where some roles require staff to be highly mobile. For example, when a pharmacist reviewing a chart is called away to a different unit, is not cued by the new environment to return to the primary task.

7) Interruption handling strategy: Clinical workers may use different strategies to handle interruptions, which may influence the extent of disruption to primary tasks. Consider the case of a doctor prescribing a number of medications who is interrupted by a mobile phone call:

a. *Attend to interruption*: The doctor may choose to take the call immediately or, with a momentary delay to rehearse the name of the next medication to be prescribed. The availability of an *interruption lag,* the time taken to attend to an interruption, may allow encoding of the next action. This can be effective in reducing interruption disruptiveness. After attending to the interruption the doctor may either *switch* to the interrupting task (i.e. suspend prescribing) or *multi-task* (i.e. prescribe while on the phone).

b. *Delay interruption*: The doctor may choose to switch off the phone and check for a message after finishing the primary prescribing task.

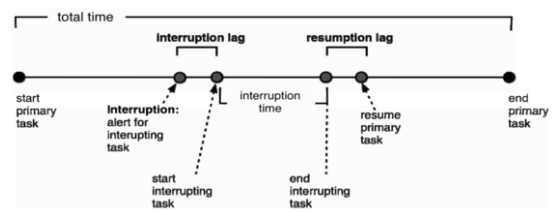

Figure 1- Time-course of an interruption (adapted from [30]).

Effects of interruptions on task completion

Interruption effects are typically quantified by examining errors [11, 16] and time penalties [5, 10].

Errors

An error is a "failure to carry out a planned action as intended, or application of an incorrect plan" [31]. Similar to task type, errors can be described in terms of their phenotype or genotype. We will use the example of electronic prescribing using a computerised physician order entry (CPOE) system to distinguish error phenotypes and genotypes.

Error phenotype: This is the observable property of an error. Or, the clinical manifestation of the error depending on the type of task. For example, a range of prescribing error types can be identified, such as wrong patient; missed allergy status; incorrect medication name dose, route or formulation; admini-

stration time; frequency; missing instructions to administer medications; and failure to prescribe or cease medications [15].

Error genotype: Is used to describe the underlying causes of an error or the ways of making the error.

a. *Errors of commission: are manifest by doing the wrong thing " [31].*

b. *Errors of omission:* are failures to do the right thing [31].

Errors can also be distinguished into slips and mistakes based upon knowledge about the intentions of an actor. A *mistake* is an "action that may conform exactly to the plan, but the plan is inadequate to achieve its intended outcome" [31]. Mistakes are associated with lack of knowledge about a task. A *slip* is an error of action, defined as "an unintended error or execution of a correctly intended action" [31]. Slips are associated with human fallibility in executing routine procedures despite having the correct how-to knowledge.

As with any other risk to patient safety measuring the frequency of errors due to interruption along with identification of potential causes is needed to facilitate investigation of corrective and preventative strategies. For example, in electronic prescribing identifying user interface features (i.e. dropdown menus, text entry) and actions associated with specific errors provides a basis to improve design of the CPOE system.

Measuring task errors: As clinical tasks often provide multiple opportunities to make an error, a normalised error rate, which takes into account the number of opportunities, can be calculated to compare the impact of interruptions across tasks (Equation 1) [16, 25].

$$Error\_rate = \frac{E_j}{E_n} \quad (1)$$

where, E_j=no. of errors and E_n=no. of error opportunities.

Error rate can be aggregated by phenotype. For example, error rates can be calculated for each prescribing error type or an overall error rate can be computed by aggregating all error types. As some errors may pose a greater risk to patient safety than others, another way is to calculate a weighted score. For example, errors can be weighted with a value of 1 (low risk), 2 (moderate risk), 3 (serious risk) to calculate an error score.

Task efficiency

The impact of interruptions on efficiency is examined in terms of the resumption lag and time-on-task (TOT).

Resumption lag: The time taken to re-orient and then restart the primary task after an interruption is generally regarded as a measure to examine the time cost of interruption (Figure 1) [26, 30].

TOT: The time taken to complete a primary task is used to examine any residual effects of an interruption (Equation 2). Studies have shown that for simple office tasks participants tended compensate by speeding up post-interruption [20, 21]. This measure may be highly relevant in a hospital context where clinicians are time pressed with a finite amount of time to complete tasks.

$$TOT = T_{total} - T_i - t_{inlag} - t_{rlag} \quad (2)$$

where, T_{total} = Time taken to complete the primary task including any interrupting tasks;
T_i = Time taken to complete the interrupting task;
t_{inlag} =interruption lag; and t_{rlag} = resumption lag.

Discussion: Challenges in measuring the effects of interruptions

As we have shown, interruptions are a complex phenomenon where multiple variables including characteristics of primary tasks, different dimensions of the interruptions and the environment may influence outcomes. In this section we discuss some of the challenges in using observational studies, controlled experiments and computer simulations to measure the effects of interruptions in healthcare.

Identifying situations where interruptions are problematic

Observational studies have been successfully used to identify *types* and *frequency of primary and interrupting tasks; sources of interruption;* and *time on tasks*. A range of highly resource intensive methods and tools have been used to examine interruptions including audio (e.g. COM [8]), video recordings (e.g. computer screen-capture [32], eye-trackers) and direct observations of work patterns (e.g. PDAs) in clinical settings.

The time cost of interruptions is not easily measured in observational studies. Whilst it is possible to examine time on task, observational studies may only provide rough estimates of resumption lag, which is typically measured in the order of a few seconds. For example, it is possible to only broadly compare resumption times for a medication administration task with a documentation task that may require a nurse to spend some time gathering his thoughts prior to resuming.

The effect of interruptions on errors is less clear-cut. Errors often result from the interplay of multiple events over time, and the error contributed to by an interruption may only occur after a researcher has stopped observation. Whilst slips may be observable in tasks with well-defined structure (for example, a nurse does not check the name of a patient before administering medications) mistakes are less identifiable because the intention of the actor is not always clear to the observer. Further, error identification is complicated in tasks with less rigid task structures, i.e. when there are many ways of achieving a goal.

Given that multiple variables affect the outcome of an interruption, interruptions are likely to be problematic only in certain situations e.g. poor cue availability. While observational studies may be useful to identify particular situations in which interruptions are disruptive, they present significant challenges for recording many of the process variables that influence the effects of interruptions. These variables include the *point at which primary tasks are interrupted, the modality, length* and *similarity of the interruption to the primary task, environmental cues* and *interruption handling strategies* (Table 1).

Quantifying effects in the laboratory

Controlled experiments provide an opportunity to examine the effects of specific *task* and *interruption variables* on task completion (*errors* and *efficiency*) and have been effectively used to examine the effects of interruptions in other disciplines. In healthcare, controlled studies provide an opportunity to exam-

ine the impact of interruptions in a range of task environments from low fidelity laboratory tasks (e.g. use of a CPOE [15], programming of an infusion pump [9]) to high fidelity simulation environments (e.g. surgery [33], medication administration on a ward). However, within a laboratory setting there is a trade-off between obtaining causal relationships among controlled variables and ensuring ecological validity.

One of the challenges is to design tasks and interruptions that are representative of typical tasks undertaken by the intended participants. For example, to examine the impact of interruptions to electronic prescribing using a CPOE by junior doctors, tasks could be based on hypothetical clinical scenarios representing typical prescribing tasks undertaken by doctors working on a medical ward. Interruptions in such a setting will often be initiated by a phone or pager (*modality of interruption*) and require the doctor to walk away from her primary task.

Another challenge is to effectively control for all independent variables. For example, if several different clinical scenarios are used to examine interruptions in electronic prescribing all scenarios must be of similar task complexity. Interruption variables such as the *length of the interruption*, *similarity of the interruption to the primary task* and *cues available in the task environment* require meticulous consideration when designing the experiment. The experimental procedure for such interruptions requires careful coordination by investigators, especially to control for variables such as the *point at which primary tasks are interrupted*, and *interruption handling strategies*.

A third challenge relates to the measurement of outcomes. In particular, error rates as a measurement may not be sensitive enough to detect the disruptive effect of interruptions compared to measures such as resumption lag, which can be reliably measured in laboratory studies. Baseline error rates in clinical tasks are fairly low – for example, baseline error rates in electronic prescribing using a CPOE ranged from 0.5% to 15.6% [15]. Thus, designing an experiment that is adequately powered to detect a small effect size is a challenge (Table 2). While the sample size may be adequate to detect a difference in resumption lag, the study may not be adequately powered to examine the smaller differences in prescribing errors.

Table 2 - Sample size required to detect error rate with interruptions using a paired samples t-test [34]

Effect size (d)	**Small** 0.2	0.3	**Medium** 0.5
Sample size* (n)	156	71	27

α=0.05, 1-β=0.8

In comparison, time on task and resumption lag are highly sensitive measures, which can be accurately captured. For example, screen capture software (e.g. TechSmith Morae®) can be used to record and analyse computer-based tasks and eye-tracking systems can be used for mobile task environments.

Examining impact on patient safety and task efficiency

The impact of interruptions on specific clinical tasks ought to ultimately be examined within the wider clinical workflow within which tasks are typically undertaken. Inbuilt error checking and redundancy within workflow plays a significant role in minimising the effects of errors. By investigating the aggregate effects of interruptions over a large group of clinicians, we may better establish links between errors caused by interruptions and the adverse events that occur relatively infrequently. In addition, we can describe situations in which an individual's interruption time-cost does not necessarily correspond to an overall negative cost in efficiency for the group.

We know that very few errors lead to an adverse event (in one study, 1.4% of the total led to adverse events compared to a 60% error rate [35]). However, when we aggregate the effect of all errors across a hospital, the result is that 10% of admissions are associated with an adverse event [36]. This implies that the aggregate effect of errors on patient safety, whilst low in probability, is considerable and measurable. Since we also know that a considerable proportion of errors are associated interruptions, it follows that large numbers of interruptions contribute to errors that are associated with small but significant numbers of adverse events.

When extending beyond the individual to larger groups of cooperating clinicians, there may be a nonlinear trade-off between efficiency and interruptions. Intuitively, some interruptions are necessary and can improve the net task efficiency of the group (e.g. less need for idle waiting and asynchronous communication). However, given the relationship between interruptions and the potential for medical error, it follows that an increase in some types of interruptions may increase the overall potential for adverse events. This suggests an optimal level of interruptions that minimises error and maximises efficiency. Another limit occurs when the net time-cost of interruptions is negative – the aggregate time-cost to individuals caused by interruption outweighs the aggregate time-savings associated with reductions in idle time and asynchronous communication. There may be a non-intuitive optimal level of interruptions unique to each group and environment.

Computational modelling of interruptions

There is a strong precedent for using computational models in healthcare [37], and computational models have a role in the study of interruptions. They permit the explicit modelling of interactions between individuals and groups beyond what is typically done in a laboratory, assist in the development of hypotheses for controlled studies, and present one way to conduct first-phase validation of interventions prior to controlled studies [38]. Computational models provide an efficient way of examining the effects of different combinations of variables and can be used to identify the situations in which interruptions have the potential to be disruptive. Models of this type may help describe patterns of variability in interruption effects on groups and therefore locate problematic interruptions (problematic to overall efficiency and safety rather than just to the individual's efficiency and error rate).

Conclusion

Interruptions are a complex phenomenon with multiple variables that affect task performance. Disruption to clinical tasks can be understood by firstly using observational studies and computational models to identify the situations in which interruptions are particularly problematic. Secondly, using controlled experiments to measure the extent to which interruptions generate errors and impose a time cost. Computational

models can be used to examine overall impact on patient safety and task efficiency.

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Chapter 11.

Decision Support

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Optimizing Medication Reminders Using a Decision-Theoretic Framework

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Abstract

We discuss a new approach to patients' adherence to enhance to their medication-taking regimen by developing a context-aware alerting system that would optimize the expected utility of alerts. Each patient's instantaneous context is assessed using a real-time sensor network deploying a variety of sensors. The alerts are generated to optimize the expected value to the patient. This paper is focused on the initial assessment of the utility of alerts, including the tradeoff between effectiveness and annoyance.

Keywords:

Medication adherence, Artificial intelligence, Machine learning, Home monitoring, Reminders

Introduction

Medication adherence, defined as adherence to a plan mutually agreed upon between a patient and his or her primary clinician, is key in therapy as well as in clinical trials of new drugs. Insufficient adherence to the planned medication regimen can obviously have a significant impact on the efficacy of care. Population-based studies of medication taking in aging patients and in those with chronic diseases have shown that medication non-adherence leads to increased hospitalization and mortality [1-4]. One population-based study found that drug-related visits accounted for 12.6% of all emergency room visits, with 19% of these visits being directly related to medication non-adherence [5]. Non-adherence is of particular concern in clinical drug trials, where good adherence is essential to accurately assessing the safety and efficacy of the drug [6, 7].

Since more than 3 billion prescriptions worth $203 billion are dispensed annually in the USA [8], strategies to improve medication adherence have the potential to both reduce health care costs, and to significantly improve health outcomes. In a meta-analysis of intervention studies to improve medication adherence, McDonald and colleagues found that most studies had only a modest effect, and the most successful studies involved a variety of interventions including information, self-monitoring, counseling, and reminders. These interventions included behavioral, cognitive, and social aspects, and no single characteristic of the interventions led to improved adherence or outcomes [9]. Kripalani and colleagues also found that although 54% of interventions led to some improvement in adherence, only very small improvements, if any, were seen in clinical outcomes[10]. Thus, while it is clear that strategies to improve adherence are needed, it is still not obvious which strategies are most effective.

Prior research studying patients' adherence to medication taking regimens has been plagued by technical limitations. Even the measurement of adherence has been a difficult problem because of the researchers' frequent reliance on subjective reports of the patients' behaviors [11, 12] or on pill counts [11, 13, 14]. These reports are often unreliable because of patients' memory lapses and sometimes because of their unwillingness to admit missing medications. These problems are exacerbated in older populations because of the combination of typically complex medication-taking regimens and a frequent decline in cognitive abilities, such as memory and executive functions [15, 16].

Two problems must be solved in order to improve patients' adherence to their medication plans. The first one concerns our ability to assess objectively any individual's adherence to their plan. The second problem involves the development of effective and acceptable alerting and reminding systems.

We and other researchers have demonstrated the feasibility of automatically assessing medication taking behaviors [13, 17]. This assessment is generally based on various technological solutions whereby sensors detect the opening and closing of medication containers. The differentiating feature of the technology investigated in our prior study is that the medication dispenser is wirelessly connected to a local area network and permits medication-taking behaviors to be monitored in real time. As described below, this feature is important in order to make the alerting system aware of the patients' medication-taking behaviors. We note that this type of assessment techniques is limited to sense only patients' interactions with the medication dispenser. Although opening the dispenser does

not guarantee medication taking, this technique is more reliable than the approaches based on self-reports or pill counts.

With very few exceptions [18], most of the existing reminding and alerting systems generate alerts at fixed time points prescribed by the medication taking regimen. Although these have been shown to be useful, they frequently fail to achieve adherence for a variety of reasons, mostly associated with the patients' context and concurrent activities. For example, if the patient is involved in various concurrent activities such as sleeping, telephoning or is not near the medication dispenser when the alert is generated, he may not respond to the alert. In addition, if the alerting system is not aware whether or not the patient took the medication, it cannot generate follow up alerts.

To mitigate these problems, we have recently prototyped and investigated a context aware system and compared it to a time based approach [19-21]. The investigated system used a variety of sensors situated in the patients' homes and interconnected by a real-time sensor network designed to assess their state, and used a rule-based approach to infer the patients' state and to generate context aware alerts. The results of this rather limited study suggested the potential of context-based reminding, but the study was limited by the choice of the type and intensity of alerts.

The key challenge for this work is to develop techniques and supporting technology that would remind the patient at times when the patient could act on the reminder, and that the reminder would be most effective and minimally annoying. It would not be hard to generate alerts that would be effective in forcing the medication-taking behavior. For example, one could theoretically install extreme alerts such as a siren used in emergency vehicles that would be very difficult to ignore. The problem is that most patients would not tolerate such annoying devices and would turn them off. The selection of the most effective alerts is, therefore, a compromise between the benefits of the intensity of alerts and their annoyance.

Since the medication-taking behavior is a stochastic process, this optimization can be conveniently cast in a decision-theoretic framework. This paper describes a decision-theoretic framework to implement such a system based on a state representation of the activities of the patient, the prompting actions and the patient's responses. The state of the patient is inferred from a variety of sensors that represent indirect measurements of his or her activities. Therefore, a framework appropriate for optimization should be based on a partially observable, possibly Markov, decision process (POMDP) [22]. However, for the sake of simplicity we illustrate the approach using a simpler, one step maximizing utility approach. The main focus of this paper is to describe the general approach, the theoretical framework and its feasibility, with a particular focus on utility assessment. The ability to assess the utility of the alerts is a key problem in making this approach feasible.

Utility-Based Medication Adherence Framework

Metrics of Adherence

There are numerous ways to describe the degree of adherence. For example, the most frequent metric for adherence is the probability of taking medications within and interval ± 90 minutes of the prescribed time. Another, more sensitive metric is the average deviation from the nominal time. The metrics should also include deviations in the type of medication or the dose, i.e., taking the wrong amount or wrong drug. For the purpose of this paper, we focus on the temporal deviations.

Context and State Assessment

One of the key components of a principled, expected utility-based approach involves a representation of the patient's activity that would in turn enable one to estimate the probability that he will take the medication. For the sake of computational simplicity, i.e., computability, we assume that a patient's activities can be categorized into a small number of discrete states, q. The state of a patient is inferred from a set of contextual measurements implemented as sensors located in the patient's home. The set of sensors may include a variety of devices ranging from passive motion sensors, contact switches, to range measuring systems. The contextual measurements are then used in combination with an appropriate model to infer the state of the patient and ultimately the likelihood of taking a medication.

Explicit Costs and Benefits

As described in the introduction, one of the most important knowledge acquisition and representation tasks in designing a medication reminding system has to do with the explicit incorporation of the costs and benefits associated with all actions that the reminding system might perform. For example, simply detecting that a patient in the home has probably forgotten to take an evening dose of a particular drug does not necessarily imply that a loud alarm should ring. Factors to consider in designing a protocol for reminding include:

- Reminder Intensity - Reminders can be delivered via various media at various stimulus intensities and modalities (text / light display on medication caddy → text / soft beep → louder beep on watch → text message on cell phone → phone message → phone call). Each of these approaches to reminding is associated with a different level of annoyance to the user and different probability of being noticed and attended to.
- Length of time since target time – Reminding too early or too late has a higher cost that reminding on time. However, reminding prior to when the user was going to take the medication anyways has a fairly high annoyance cost.
- Importance of the specific medication – It is more important to remind a user of a critical drug (e.g., anticoagulant) as compared with a noncritical pill (e.g., vitamin). Higher annoyance factors will be tolerated for more critical medications. In addition, for some medications, the

timing is more critical (e.g., 4 times / day) versus others that could be taken any time of day.

- Context for the user – Reminders that account for a user's location and availability to take the medication will be far more successful than a strictly time-based reminder. For example, there is a high utility for reminding when the user is near the medication caddy and when they are occupied with conflicting activities (e.g., sleeping, visiting with others, in the middle of a meal).

Our approach to medication reminding is cast in an expected utility framework for determining when and with what type or "media" and intensity or "strength" to remind a user to take a medication. More formally, the general expression for the expected utility has the form

$$\bar{U}[A,C] = \sum_{q=1}^{M} p(q \mid A,C) u_q(A,C), \qquad (1)$$

where $\bar{U}$ is the expected utility of an alerting action $A(t)$ when the patient is in state q and context $C(t)$. $A(t)$ is one of possible actions generated by the alerting system and may include visual and auditory modalities as well as different alert intensities. We note that one of the possible actions is $A = \varnothing$ or "do nothing." The context $C(t)$ is a vector that represents all available measurements including motion sensors, for all times $t' \le t$. In general, the state of a patient is related to the instantaneous activity, such as sleeping, but in may also be an abstract representation of sensor data.

The probability that the patient is in state q given an action and contextual measurements is denoted by p. This embodies the two levels of uncertainty: (1) uncertainty due to the indirect measurements of the patient's state and (2) the uncertainty of taking the medication, given the state. Within the expected utility framework in Equation (1), the latter uncertainty is incorporated in the utility $u_q(A,C)$.

To illustrate the approach, we assume that the patient is in one of two states: $q = 0$ and $q = 1$ representing the failure and success in taking the medication, respectively. When the patient is in state 1, the time T when he takes the medication is a random variable with a probability distribution $F_1(T)$. Assuming that the only available sensor is the medication dispenser, that indicates that a medication was not taken by time t, it is possible to compute the probability that the patient is in the "forgetting" state by

$$\Pr\{q = 0 \mid T > t\} = \frac{p_0}{1 + (1 - p_0)[1 - F_1(t)]}, \qquad (2)$$

demonstrating that as time increases and medication is not taken, the probability that the patient will forget increases and consequently, the expected utility of an alert increases. With information from additional sensors, it is possible to increase the number of possible states and improve the accuracy of this assessment.

Estimation of Time Probability Distribution

As shown in Equation (2), an essential component of the maximum utility calculation is the probability distribution of times that the medication is taken without prompting. In order to implement this approach, it was necessary to estimate this distribution by monitoring individuals taking medications without any alerts. Such estimates were obtained in a baseline condition of a prior study [19, 20]. Because of the cyclic nature of time, i.e., daily periodicity, we developed a novel approach to the density estimation process. For the purpose of the present discussion, however, we performed a maximum likelihood fit using beta distributions.

Empirical Estimation of Alert Utilities

The goal of this laboratory study is to estimate the utility of alerts and prompts. The utility assessments includes the benefits (positive utility) representing the effectiveness of reminding the patient to take his or her medication, as well the cost (negative utility) associated with the alert annoyance and failure to achieve the desired result. Our current study was designed to investigate several modalities, device form-factors and signal intensities of the prompting systems. The main dependent measures were subjective judgments in response to the various system reminders. In addition to the demonstrated prompts, subjects were asked to rate a number of other prompting devices

Methodology

In order to approximate real-life distractions, we introduced new methodology based on dual task. The dual task consisted of a background continuous activity (watching a comedy show) which was occasionally interrupted by the primary task. The computer generated the video as well as the signals that triggered the alerts.

When an alert was generated, the participants' task was to notice the alert and to respond to the alert by walking over to a medication dispenser and opening a specific compartment. The medication dispenser was designed to record both the time of the interaction and the specific compartment that was opened. The collected information comprised quantitative as well as qualitative data. In addition to the objective data (time duration and the identity of the medication tracker compartment that was opened), the participants were asked to judge the annoyance of the alerts generated by the devices included in the experimental part of the study. In addition, following the active experiment, they were asked to rate several devices that were not part of the experiment. The different devices were presented as much as possible in random order for different subjects.

Prompting Devices

The prompting devices used in this experiment were selected to cover a wide range of form factors and modalities. We used a combination of commercially available devices and our enhanced alerting devices. The following is a list of these devices and the corresponding modality:

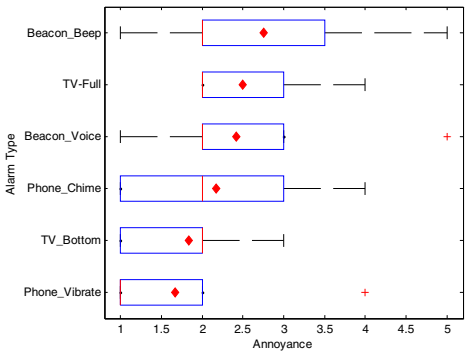

Figure 1- A box plot of the annoyance ratings of different device for 10 subjects.

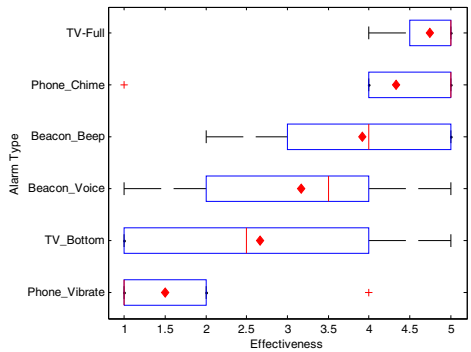

Figure 2- A box plot of the effectiveness ratings of different devices.

1. Vibrating modality, e.g., watch
    a. Adult version of a watch
    b. Pediatric version of a watch
    c. Vibrating Pendant
    d. Vibrating mobile telephone
2. Auditory alert watch with informational display indicating the action to be performed as a part of the secondary task.
3. Medication dispenser with audio-visual alert mechanism
    a. Visual alerts only
    b. Sounds only
4. PDA with auditory and visual (text) alerts and messages
5. Cell phone with voice and/or text messages
6. Office phone alerts
7. Television set (captioned message or full screen)

Procedure

The participants were recruited from a pool of elderly subjects participating in other, ongoing experiments. They were introduced to the study using a brief video in which an experimenter described the purpose, the task, and the procedure. During the video introduction, the participants were asked to adjust the level of the audio to a comfortable level – this was also used to assess their hearing. During the introduction, the participants also learned to use the remote control that enabled them to start and stop the television show. Following this introduction, the participants were consented.

The experiment was initiated by the participants using the remote control that started the television show. The participants were presented the alerts, namely the alert modality and type of signal in a pseudo-random order to reduce the potential of sequential effects. Following the experimental procedure described in the Methodology section above, the participants were asked to rate the devices in several ways including rank-ordering, as well as using a Lickert scale. In particular, they were asked to rate the effectiveness of each alert and its annoyance. In order to ascertain that the participants paid attention to the television show, they were also asked to answer a number of questions about selected details of the show.

Results

In this section we first analyze the data from the empirical utility assessment study and then combine them with the data from our prior study [19, 20]. The results of the annoyance ratings, combined across subjects are shown in Figure 1. Similarly, Figure 2 represents the summary of the effectiveness ratings that appeared to be consistent with subjects' behaviors during the study. Although there appears to be some agreement, there is clearly significant inter-subject variability. A large component of this variability was due to the differences in individual preferences as ascertained by their comments and responses to questionnaires. Using the estimates of the utility and probability distributions from our pilot studies, we simulated a variety of alerting situations in order to determine important details of a potential implementation. An example of such an issue is the notion of a *refractory period*. In particular, after the system issues an alert, the instantaneous annoyance due to potential repetition of the same alert is significantly higher. The actual value of this increase and its temporal course of the refractory period needs to be investigated in a spate study.

Conclusion

We have developed a new decision-theoretic framework and approach to optimize reminding and alerting using contextual information. Our data from several pilot experimental studies, in combination with this theoretical framework, suggest that an optimal, utility-based approach is possible and may improve medication-taking adherence. Additional improvement could be gained by including aspects such as the refractory period and the utility of interruption [23]. However, this study offers evidence to show the feasibility of integrating home monitoring data to infer patient context for reminding systems and also demonstrates the importance of incorporating patient preferences for alerts and reminders. Future directions for work in this area include linking medication adherence data

with personal health records and electronic medical records for broader health management use.

Acknowledgments

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Factors Affecting Physicians Compliance with Enrollment Suggestions into a Clinical Reminders Intervention

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Abstract

Clinical reminders can promote adherence with evidence-based clinical guidelines, but they may also have unintended consequences such as alert fatigue, false alarms and increased workload, which cause clinicians to ignore them. The described clinical reminder system identifies patients eligible for primary prevention of cardiovascular diseases and lets the physician to choose which patients will be included in the reminders intervention. We analyzed data of 87,165 visits of 35,699 patients and evaluated factors which may affect clinicians' decision to enroll patients to the intervention. The physicians included most of the patients suggested for inclusion (85.7%). Yet, they skipped the enrollment suggestion in 62.6% of the visits. Patients with a cardiovascular disease, dyslipidemia, diabetes, or hypertension were more likely to be included in the intervention, while older patients were less likely to be included. Insights regarding the usability of clinical reminders are discussed.

Keywords:

Guideline adherence, Clinical decision support systems, Reminder systems, User-computer interface.

Introduction

Although risk factors contributing to the development of Coronary Artery Disease (CAD) are well known and effective interventions exist, the majority of patients are sub-optimally treated [1]. Clinical reminders (CR) have become a major component in many clinical interventions to promote adherence with evidence-based clinical guidelines [2]. These systems generate patient-tailored reminders for physicians at the point-of-care. The effects of such systems were extensively described in some reviews [3-6]. Many studies showed positive effects on clinical performance [4, 7-9], while others found limited and variable usage [9-13]. Computerized decision-support systems may have unintended consequences, such as alert fatigue, increased workload, workflow issues, communication flaws, and dependence on the technology [14, 15], as well as negative emotions among physicians [16]. Although clinical reminders may provide clinicians with important information, many clinicians may perceive them as a burden and ignore them even when they are critical. We sought to evaluate the extent to which physicians follow a reminder system's suggestions to enroll eligible patients to the prevention program, and the factors effecting this decision.

Method

Setting

The "Computerized Community Cardiovascular Control" (4C) is a nationwide intervention, aimed to promote prevention of clinical atherosclerosis. It is operative since 2007 by "Clalit Health Services", a nationwide HMO serving more than 3.7 million patients in Israel.

Workflow

The system identifies patients at high risk for cardiovascular events (such as cardiovascular disease, dyslipidemia, diabetes, hypertension, smoking, high SCORE [17] or Framingham [18] risk). Once such a patient visits the primary care physician, the system evaluates available clinical information and decides if the patient should be included in the intervention according to the guidelines. If so, it presents an enrollment screen to the physician (Figure 1). The physician can now choose: (1) to include the patient in the intervention, (2) to include the patient, but to postpone the follow-up for one year, or (3) to exclude the patient from the intervention. The physician can also "escape" from the screen by clicking the [X] (in the upper right corner of the screen), which will close the enrollment screen and will end the process without including or excluding the patient. If the patient was excluded from the intervention, the system will ask for the exclusion reason, and will re-suggest inclusion after 6 months. Once a patient was included in the intervention, the system will periodically suggest the physician about therapeutic actions, such as further screenings, pharmacotherapy and expert consultations. After a patient was included in the intervention, the physician can postpone the follow-up or exclude the patient from the intervention at any time.

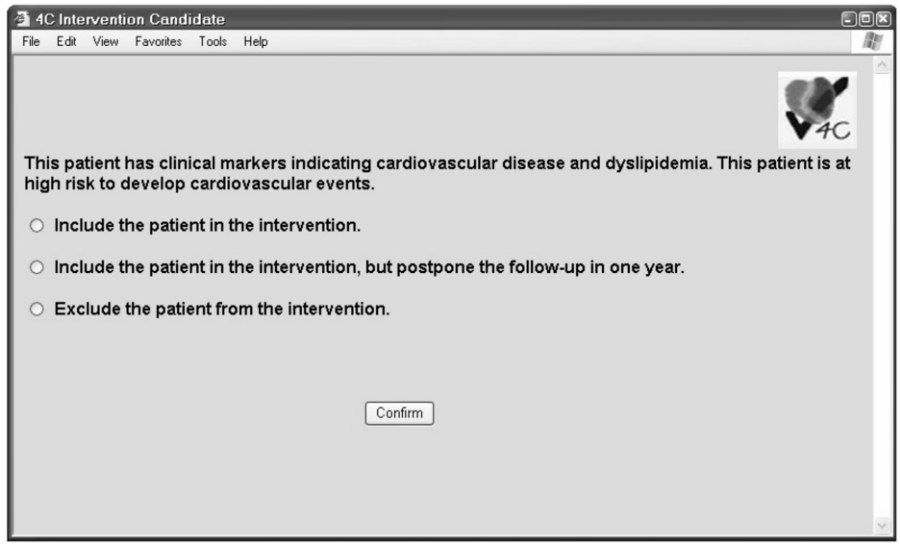

Figure 1 - Enrollment screen

Sample

The data include 87,165 visits in 50 primary care clinics of 35,699 patients (average 2.4 visits per patient), treated by 379 physicians, between 16/10/2007 and 14/12/2008.

Analysis

We analyzed log files collected by the 4C system. We calculated the probabilities to eventually include or exclude patients in the intervention. We analyzed only cases in which the system suggested to enroll the patient to the intervention. We used a logistic regression model with backward elimination for model selection with the binary outcome variable (patient included or not) and patient characteristics of age, gender, and markers of hypertension, diabetes, dyslipidemia, diagnosis of cardiovascular disease, and smoking status as predictors.

Results

Descriptive statistics

Most patients identified for inclusion by the system were male, with an average age of 60 years, diagnosed with hypertension, diabetes, and dyslipidemia. Only about one third of the patients were already diagnosed with cardiovascular disease (due to the primary prevention nature of the project) and about a fifth of them were smokers (Table 1).

Enrollment rates

The system evaluated that patients should not be included in the intervention in 75.4% of the total 355,371 visits analyzed, and hence the enrollment screen was not presented to the physician. The physicians did not make any choices regarding these cases. In the remaining 87,165 visits in which the enrollment screen was presented, the physicians chose to include patients in 30,999 visits (35.6%, with 0.5% postponed inclusions), exited the enrollment screen without explicitly excluding the patient in the intervention in 54,554 visits (62.6%) and excluded patients from the intervention in 1612 visits (1.8%) (see Figure 2). Yet, 85.7% of the 35,669 patients suggested by the system for inclusion were eventually included, 0.2% were literally excluded, and for the rest 14.1% (4,989 patients), the physicians kept ignoring the enrollment suggestion. Apparently, the physicians enrolled the most of the patients (85.7%) in the 35.6% of the visits, and mostly escaped the enrollment screen in the rest of the visits.

Table 1 - Predictors' descriptive statistics

Predictor	Descriptive
Age (Mean±Sd)	60.7±9.6
Gender (% female)	44.2%
Hypertension (% patients)	58.9%
Diabetes (% patients)	56.8%
Dyslipidemia (% patients)	69.6%
Cardiovascular disease (% patients)	32.1%
Smoker (% patients)	24.6%

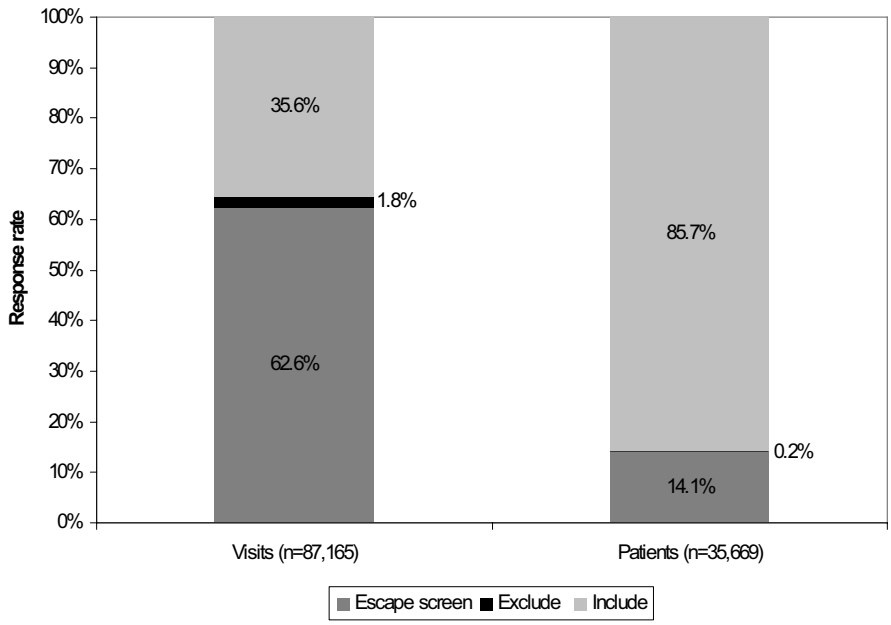

Figure 2 - Inclusion, exclusion and escape rates

Enrollment prediction

The logistic regression model (after backward elimination iterations) yielded that patients with a cardiovascular disease, dyslipidemia, diabetes or hypertension had a better chance to be included in the intervention (OR=1.880, 1.868, 1.729 and 1.278 respectively). Older patients had lower chance to be included (OR=0.991). Patient's gender and being a smoker did not play a significant role to predict the chance of being included in the intervention. Having a cardiovascular disease, dyslipidemia or diabetes were apparently more prominent factors for inclusion than hypertension (Table 2).

Table 2 – Odds-ratios to include patients in the reminders intervention from the logistic regression model (n= 35,669 patients).

Predictor	OR (95.0% CI)
Age	0.991 (0.988, 0.995)
Hypertension	1.278 (1.198, 1.363)
Diabetes	1.729 (1.616, 1.849)
Dyslipidemia	1.868 (1.753, 1.990)
Cardiovascular disease	1.880 (1.744, 2.027)

Note: This table shows the odds ratio of the estimated regression coefficients of the probability to enroll patients to the intervention with their 95% confidence intervals.

Discussion

CR systems are implemented under the assumption that they will be beneficial for the patient and the physician. The effectiveness of these systems relies almost entirely on physicians' compliance with them, and the patient's compliance with the physician. Physicians may respond to information from such systems in various behavioral responses [19].

The described system provides physicians with information about patients who can benefit from being included in a prevention intervention. Ideally, patients identified by the system as eligible for intervention (according to the evidence-based guidelines) should be included in the intervention. Nevertheless, one cannot expect the physicians to include all suggested patients and to include patients necessarily during their first visit (although this may have advantages). The data show that most patients suggested to be included in the intervention were eventually included (85.7%). However, these patients were included in only about one third of the visits (35.6%), and in the remaining 62.6% of the visits the physicians simply ignored the enrollment suggestion (i.e., escaped the enrollment screen). In other words, the physicians could actually prevent 54,554 interruptive pop-ups (62.6% of the total 87,165 visits) by either including or excluding the patient once the enrollment screen appeared. These 54,554 visits were "wasted", both because the patient was not enrolled in the intervention for the benefit of improved prevention, and because the system kept "nudging" the physicians in subsequent visits. This is a seemingly irrational

behavior of the physicians, and the reasons of such behavior require deeper exploration.

One way to explore this behavior is by looking at patients' characteristics, which may affect the physician's decision to include the patients in the intervention. The data show that patients with a cardiovascular disease, dyslipidemia, diabetes and hypertension had a better chance to be included in the intervention. Older patients had lower chance of being included in the intervention. Older patients' usually have more complex clinical conditions and co-morbidities, and the prevention of cardiovascular disease may be only one of conditions to handle. Patients' gender and being a smoker did not play a significant role for predicting the chance of being included in the intervention.

These data show that physicians apparently weighted these clinical markers when deciding whether a patient should be included to the intervention. The physicians are aware that once a patient will be enrolled, the system will send them treatment reminders and suggestions, which may interrupt future clinical encounters. Hence, they carefully pick the patients that will be included. Although they included the majority of the suggested patients, they did not automatically include all suggested patients, but apparently weighted their clinical markers.

The high "escape" rate can be explained by the nature of the reminders, as being interruptive to the current visit. Inclusion will result in further "interruptions", and when the physician chose to exclude a patient, the system will ask the physician to specify the exclusion reason. These two tasks may be unrelated to the reason for which the patient came to the visit, and may distract the physician from the patient's current complaints. "Escaping" the screen may seem to be an easy and less time-consuming option, since the physician can focus on the patient's complaints. Other reasons can be suggested for the high "escape" rate, such as alert fatigue, increased workload, deviance from traditional workflow, low motivation to use, emotional reasons, low perceived alert validity, usability issues, and system-specific reasons (e.g., physicians may ignore alerts when they sense that the specific guideline is not suitable for the specific patient, overall disagreement with a guideline, patient non-compliance, etc). Moreover, because the system was in an operative pilot at this period, it is possible that the physicians didn't know how to use the system, or were unaware of the benefits of using it, and hence chose to "escape" from the screen. The findings may suggest these as possible reasons, yet further research should explore the various reasons for such behaviors and physicians' motives for choosing them.

This system is unique in the physician's ability to choose which patients will be included in the intervention. CR systems typically generate reminders according to automatic patient identification without giving physicians control over the inclusion of patients. Hence physicians' usage of our system may be different from systems with forced reminders in which the physicians cannot choose upon which patients reminders will be given.

These results raise questions regarding the design of such system. System designers should be aware of such unintended consequences and strive to avoid them, either by using alternative ways to disseminate the information to physicians, improved user interfaces, organizational measures such as incentive systems, etc. Physician involvement in the design process, which is a theme which the MEDINFO conference is trying to highlight, is crucial to ensure competent and valuable systems.

Conclusions

We evaluated factors which may affect clinicians' responses to suggestions to enroll patients to a CR intervention. The majority of the patients suggested for inclusion were eventually included. However, these patients were included in only about one third of the visits, and in the remaining visits the physicians ignored the enrollment suggestion. Patients with a cardiovascular disease, dyslipidemia, diabetes, hypertension or younger age had a better chance to be included in the intervention. System designers should be aware of such usage of reminder systems and regard to human-computer interface design and physicians' expectations and motives for use them. Further research should explore the various reasons for such behaviors, aiming at providing physicians with efficient and useful systems.

Acknowledgments

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Impact of Content-Specific Email Reminders on Provider Participation in an Online Intervention: A Dental PBRN Study

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Abstract

Engaging busy healthcare providers in online continuing education interventions is challenging. In an Internet-delivered intervention for dental providers, we tested a series of email-delivered reminders - cues to action. The intervention included case-based education and downloadable practice tools designed to encourage providers to increase delivery of smoking cessation advice to patients. We compared the impact of email reminders focused on 1) general project announcements, 2) intervention related content (smoking cessation), and 3) unrelated content (oral cancer prevention focused content). We found that email reminders dramatically increased participation. The content of the message had little impact on the participation, but day of the week was important – messages sent at the end of the week had less impact, likely due to absence from clinic on the weekend. Email contact, such as day of week an email is sent and notice of new content posting, is critical to longitudinal engagement. Further research is needed to understand which messages and how frequently, will maximize participation.

Keywords:
Internet, Dentistry, Cues, Marketing.

Introduction

Use of the Internet for continuing education interventions has risen but little is known about what predicts level of participation and engagement by healthcare providers. Health care providers often access the Internet to search for information. In addition, the Internet is also used for continuing education and quality improvement educational interventions. However, there are various barriers to use of the Internet. Little research has been conducted on overcoming these barriers to sustained participation in Internet interventions. In this analysis we monitored continued participation over time, and utilized various email methods to sustain participation in an Internet intervention.

Providers, generally, have a preference for web-based continuing education as compared to local or national meetings [1]. Many fields have begun to offer online continuing education to meet this preference [2]; however, the format used for continuing education can also be an important factor in predicting online continuing education use. Prior literature has shown that providing content in small amounts, such as cases, spaced over time is more effective than one, large posting of content [3,4] or traditional online continuing education lectures.

Once a website has been accessed, not much is known about maintaining website engagement by providers. One method often used to encourage repeat usage is email. Email has shown promise in encouraging participation in an educational intervention with minimal effort on the part of the provider [1]. When an email message is received, the provider can choose when, where, and how to engage in the website. This ease of use greatly enhances a website's adoption by the provider community. Several studies have found high response rates from email, some as high as 50% [1, 5- 7] and have shown that multiple reminders, even though thought to be intrusive by many, can actually increase participation rates [1]. Reaching an audience with multiple time pressures and scheduling difficulties in such an efficient manner bodes well for future Internet interventions.

Engaging health care providers in educational interventions is especially problematic considering the time constraints of the office setting. Internet delivered programs offer greater flexibility to such schedules. Unfortunately, past studies have found that even if a website is accessed, content is only viewed for short amounts of time [8, 9], indicating the need for in-

creased focus on user retention or "stickiness." This study examines use of targeted email reminders (designed as cues to action) to influence participation by dental providers in an Internet delivered intervention for tobacco control.

Materials and Methods

Study Design

The Dental Tobacco Control.net project (DTC) assessed the use of an Internet-delivered intervention designed to encourage dentists, hygienists, and dental assistants to discuss tobacco use with their patients. Prior to randomization, all practices were required to have Internet access in their practice and complete a run-in phase including baseline data collection from patients. General and periodontal dental practices in both urban and rural settings in Alabama, Georgia, Florida, and North Carolina participating in the Dental Practice-based Research Network (www.dpbrn.org) were enrolled. One hundred and ninety were randomized to the two-year trial from 2005-2007. Of the 190 dental practices, 95 were randomized to the DTC.net intervention website and 95 were randomized to a wait-list control. Our prior published results demonstrate that the DTC.net intervention was successful in increasing smoking cessation advice at six-months of follow-up. For this analysis, we followed the cohort of intervention practices. These 95 intervention practices included 118 dentists and 334 hygienists/dental assistants. The study was approved by the University of Alabama at Birmingham Institutional Review Board.

The intervention website consisted of four educational cases, patient education and practice tools, a forum for chatting, an area to ask questions, and updates in the dental tobacco literature. Users decided how much time they wished to spend on the website. All materials were periodically updated and released over time. The educational cases contained questions to allow interactive learning based on user response and were supported by references and literature. Patient Education Materials and Practice Tools, such as brochures and posters, were available for download or could be requested from the investigative team. The discussion forum allowed providers to directly post questions and receive responses from peers. The "Ask a Question" feature allowed providers to directly communicate with the investigative team.

To encourage more-frequent website participation, push technologies such as email reminders were used by the study to drive participants to the website. Emails were sent to providers to announce cases. The interactive cases (tailored according to provider's responses) were spaced over six months. Dentists received online continuing education credits for completing a case. In addition to case advertisements, to encourage participation, three types of email reminders were sent: 1) general project announcements, 2) intervention related content (smoking cessation), and 3) unrelated content (oral cancer prevention focused content). The new content was summarized in the email reminder and then linked to the updated website content or a full-text version of a new research article. Reminders were delivered on a variable basis, with one or more sent per month for 30-months.

Data Collection

Upon log-in, user authentication was required for all providers and each visit was linked to user tracing logs on the intervention server. The user tracing was used to calculate the various measures of participation including tracking the date, time, pages visited (type and volume), and total time of website visit. We narrowed our user tracing to a group of key web-pages (home, main page of each educational case modules, headlines, etc.). We defined accessing these pages as an "audited event." For this analysis we used longitudinal user tracing follow-up data from the cohort of 95 intervention practices.

Analyses

The main dependent variable was provider participation (number of audited events) collected by user tracing on the intervention server. We first assessed the overall impact of email reminders (independent variable) on website participation. We compared days immediately after the email reminders to days when no reminders were sent. Because the messages were sent on different days, we assessed the impact of day of the week on participation. We then modeled the impact of reminders adjusted for day of the week. Subsequently, we compared the impact of the three categories of email reminders (1. general project announcements, 2. intervention related content (smoking cessation), and 3. unrelated content (oral cancer prevention focused content)) on participation. The dependent variable is a count of tracked pages, and could be modeled with Poisson. Because of over-dispersion in the participation data, we used a negative binomial regression to model the association of email reminders with participation.

Results

Practice Characteristics

Ninety-five intervention dental practices were invited to participate in the Internet intervention (Table 1).

Participation in the Intervention Website

Of the 95 intervention practices, at least one provider from 72 practices (76%) accessed the website at least once. Overall, there were 4,797 audited events (accesses to unique traced pages). These audited events occurred during 531 unique visits to the intervention website by 138 dental providers (73 dentists and 65 hygienists/dental assistants). There were 87 dentists and 249 hygienists/dental assistants in these 72 practices. Thus, 84% of the dentists and 26% of the hygienists/dental assistants in these 72 practices logged on to the intervention website.

The mean number of audited events per day was 5 (SD = 12). Of note, activity occurred only on 28% of days in the 30-month tracing period. On days when activity occurred, the mean audited events was 19 (SD = 18). Our user tracing demonstrated that dentists had higher participation (median audited

events (AE) = 32 (95% CI 22-45)) as compared with hygienists/dental assistants (median AE = 17 (95% CI 14-24), median test p = 0.01. The number of visits to the website was also different (dentist median visits = 3, hygienist/dental assistants median visits = 2, p = 0.001). Participation did not vary by the practice characteristics listed in Table 1.

Table 1- Characteristics of Dental Practices (N=95)

	Intervention	
Practice Characteristics	**n/N**	**%**
Solo/Group *		
Solo Dental	73/93	78.5
Group	20/93	21.5
Total Staff (hygienists/assistants)		
0	5/95	5.3
1-2	26/95	27.4
3-4	37/95	39.0
>4	27/95	28.4
Rural/Urban Status		
Urban over 1 million	28/95	29.5
Other metro	48/95	50.5
Non-metro next to urban	10/95	10.5
Non-metro not next to urban	9/95	9.5
State		
Alabama	15/95	15.8
Florida	39/95	41.1
Georgia	27/95	28.4
North Carolina	14/95	14.7
Patient volume		
<=40 patients/week	9/95	9.4
40-100 patients/week	62/95	65.3
>100 patients/week	24/95	25.3

* missing data on 2 practices

Impact of Email Reminders on Provider Participation

Thirty announcements about cases were emailed to the practices. In addition, 28 reminders were emailed to the providers over time. Figure 1 shows the resulting website usage after each email reminder. The email reminders resulted in the largest number of visits on the day the email was sent (E-mail release day). The day after the email also showed an increase in website visits, then returning to baseline.

Unadjusted model: Compared with non-reminder days, in our initial *unadjusted* negative binomial model, the day of email reminder release and Release Day + 1 were more likely to have had higher audited events (Incidence Rate Ratios 6.6 (95% CI 1.9-24.0) and 5.0 (95% CI 1.4-17.9) respectively), but release day + 2 and beyond were similar to non-reminder days. Incidence Rate Ratios (IRR) are a measure of observed over expected counts from negative binomial regression.

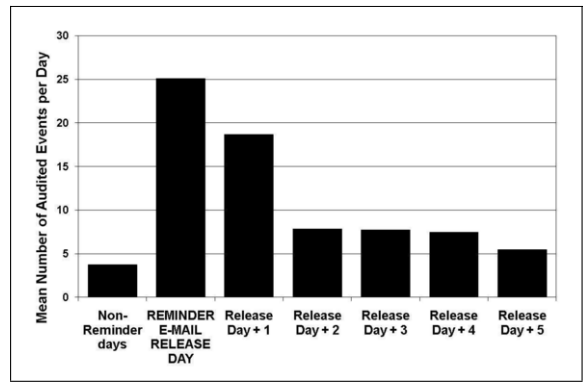

Figure 1- Dentist and staff participation by day of email reminder release

Providers engaged in the website more on weekdays than weekends. As noted in Figure 2, participation peaked on Wednesdays, and began to decline on Thursday, and was quite low on weekends.

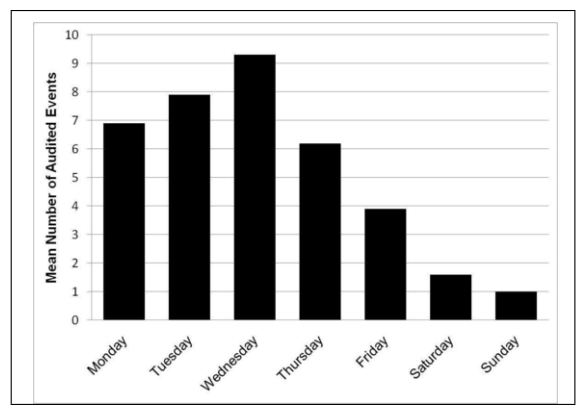

Figure 2- Participation by day of email reminder release

After adjustment for day of the week, when compared to the reference day, the expected count for the number of logons is multiplied by a factor of 5.13 the day the email was sent, and 6.27 on the day after (Table 2). In this multivariable model, adjusting for day of the week, the second day after the email was sent was also significantly greater than the reference.

Of note, six of our messages were sent out on a Thursday or Friday. The negative binomial model provided a better fit than the Poisson model due to over-dispersion of the outcome.

As discussed above, three types of email reminders were sent: five emails were general project announcements (e.g., describing the practices involved, goals, etc.); 13 email reminders were directly related to smoking cessation; and 10 email reminders were about oral cancer prevention, a topic that dental providers in our formative work noted to be of importance to them, a desired area for up-to-date information.

Table 2- Association between email reminders and rate of participation, after adjustment for day of the week and day of education case release

	Adj. IRR*	95% CI	P-value
Reminders Emails			
Non-reminder days	Ref.		
e-Mail release day	5.13	1.53-17.18	0.008
Release day + 1	6.27	1.85-21.31	0.003
Release day + 2	4.79	1.35-16.97	0.015
Release day + 3	2.31	0.67-7.95	0.184
Release day + 4	1.74	0.49-6.23	0.392
Release day + 5	2.25	0 .64-7.93	0.207
Day reminder sent			
Monday	Ref.		
Tuesday	1.21	0.54-2.69	0.641
Wednesday	1.50	0.68-3.30	0.309
Thursday	0.82	0.37-1.83	0.630
Friday	0.71	0.32-1.56	0.392
Saturday	0.25	0.11-0.56	0.001
Sunday	0.15	0.06-0.34	0.000
Case Release Email			
No case release	Ref.		
Case Release Day	3.38	1.09-10.50	0.035

*Adjusted Incidence Rate Ratio (IRR) from a negative binomial model, including 4,797 audited events. IRR adjusted for day of the week, and accounts for release of case emails over time.

The reminders related to smoking cessation resulted in the most audited events (mean 16 per day), followed by oral cancer prevention (10) (Figure 3). Of note, general project announcements that did not include links to new content had less impact. In a subsequent negative binomial model, general project email release days were not significantly greater than non-reminder days.

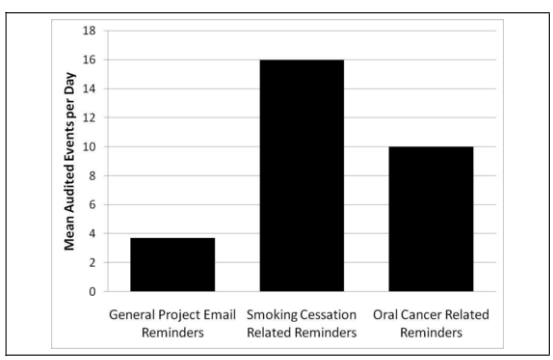

Figure 3- Participation per day for first three days after email release, comparing three types of email reminders

Discussion

In this randomized trial of an Internet-delivered continuing education intervention in dental practices, we were successful in engaging 138 dental providers. We found that email reminders were critical to longitudinal participation in the intervention. On days when no recent reminders had been sent, very little participation occurred. The day after an email was sent, participation had multiplied six-fold, compared with non-reminder days.

As previously published, our randomized trial was successful in increasing rates of smoking cessation advice in these dental practices, compared with control [10]. Intervention dental practices increased rates of smoking cessation advice by 11% from a baseline rate of 44% (OR = 1.55 [95% CI 1.28-1.87]). Control practices did not significantly improve.

The impact of the randomized trial was directly associated with level of participation. Thus, our success in changing provider behavior was dependent on our email reminder system. Without the reminders, level of participation would likely have been too low to have resulted in a change in rates of smoking cessation advice.

Nearly all providers report having access to the Internet [6, 11] but with the growth in new health care knowledge, staying up-to-date can be challenging. Internet use among healthcare providers is at an all-time high and online clinical information seeking and engagement in online education continues to grow. In a study of U.S. physicians of all specialties in active practice, 71.5% of medical providers use the Internet for literature searching and ranked journals as the most important source for clinical information [12]. Updating the content of the website to summarize current news and journal articles and provide training and education in these areas could prove beneficial to the providers and drive website usage.

We have demonstrated the potential improvement in provider website participation and engagement following the introduction of email reminders. Of note, each of our email reminders included an "opt-out" option to no longer receive messages. In all, we sent 28 reminders to 138 dental providers, and received zero opt-out requests despite the nearly 4,000 opt-out opportunities. Future interventions could consider sending email reminders even more frequently.

The email reminders provide a direct cue to engage providers and encourage user retention; however, care should be given to the timing of emails [13] and message content. Provider website visits were higher when the email content was a subject of interest. Our general project announcements had little effect. Only reminders linked to *new content* were effective.

We learned an important lesson – take care to place messages at the beginning of the week, not the end. Because it may take providers two to three days to respond, one must avoid having the time of potential activity overlap with the weekend days. In our multivariable analysis, accounting for day of the week, the association of email reminders and participation was stronger for more days, suggesting reverse confounding by day of the week for Release day + 2.

The results of this analysis are limited to only one intervention. We found that provider characteristics listed in Table 1 were not associated with participation, but other variables may be important predictors. Our analysis did not account for provider variations in interest, time constraints, and computer experience, all of which could influence provider participation in an Internet intervention.

Further research into reasons for participation can enhance website engagement and help researchers learn more about designing effective interventions. Researchers should experiment with varying frequency of email reminders [13], and varying content. In general, additional innovative approaches are needed to engage providers in longitudinal interventions.

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Identifying Best Practices for Clinical Decision Support and Knowledge Management in the Field

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Abstract

To investigate best practices for implementing and managing clinical decision support (CDS) in community hospitals and ambulatory settings, we carried out a series of ethnographic studies to gather information from nine diverse organizations. Using the Rapid Assessment Process methodology, we conducted surveys, interviews, and observations over a period of two years in eight different geographic regions of the U.S.A. We first utilized a template organizing method for an expedited analysis of the data, followed by a deeper and more time consuming interpretive approach. We identified five major categories of best practices that require careful consideration while carrying out the planning, implementation, and knowledge management processes related to CDS. As more health care organizations implement clinical systems such as computerized provider order entry with CDS, descriptions of lessons learned by CDS pioneers can provide valuable guidance so that CDS can have optimal impact on health care quality.

Keywords:

Decision support systems, Clinical, Medical order entry systems, Information management

Introduction

Clinical decision support (CDS) provided through computerized provider order entry is essential to enhancing health care quality [1,2]. We define CDS broadly to include "passive and active referential information as well as computer-based order sets, reminders, alerts, and condition or patient-specific data displays that are accessible at the point of care" [3]. Federally funded incentives are sparking intense interest among most health care organizations to implement clinical information systems that include some CDS over the next few years [4]. At present, only 10 to 20 percent of U.S. hospitals have CPOE available [5,6]. Community hospitals account for 86% of the 5708 hospitals in the U.S. [7] However, only 6.9% of community hospitals report having even a basic level system [6]. Little research about CDS has been conducted in community hospitals, and in fact fully 25% of studies included in Chaudhry's systematic review about the impact of health information technology on quality were from just four academic institutions [8]. In ambulatory settings, although 17% of physicians report that they use clinical information systems, only 4% use systems that include CPOE and CDS [9]. A major criticism of current health information technology (HIT) articulated in a recent report is that HIT fails to provide cognitive support to clinicians when they need to make decisions [10]. In fact, it can produce many unintended adverse consequences [11], especially related to clinical workflow [12]. Because many problems with CDS relate to behavioral, organizational, and cognitive issues [13,14], the Provider Order Entry Team (POET) based at Oregon Health & Science University in Portland, OR, U.S.A. is conducting two multi-site ethnographic studies about these issues, one in community hospitals and the other in ambulatory clinics and vendor environments. The purpose is to identify best practices for CDS implementation and knowledge management. We define best practices broadly to include widely recognized and agreed on procedures and practices that have been shown to improve internal processes.

The following sections summarize foci, methods, and results.

Methods

We adapted a form of ethnography which has been used successfully in international health for the rapid assessment of complex site-based situations, the Rapid Assessment Process (RAP) [15]. By using structured assessment instruments, expert interviews, field surveys, and intensive site visits by a multidisciplinary research team, we minimized the need for lengthy periods of time in the field (a characteristic of traditional ethnographic fieldwork). We also held a conference of CDS experts to help us verify what we found in the field.

Sample Selection

Because we aimed to gather information about best practices, we selected clinical sites with reputations for excellence in the use of clinical systems and CDS. Table 1 outlines attributes of our study sites. The hospitals were community hospitals with different commercial systems [16]. The ambulatory sites

Table 1 – Sites and data collected

	Providence Portland Medical Center	El Camino Hospital	Partners HealthCare	Wishard Memorial Hospital Clinics	Roudebush Veterans Health Administration	Mid-Valley IPA	RWJ Medical Group	Zynx	First DataBank
Location	Portland, OR	Mountain View, CA	Boston, MA	Indianapolis, IN	Indianapolis, IN	Salem, OR	New Brunswick, NJ	Los Angeles, CA	San Francisco, CA
Characteristics of setting	Community hospital	Community hospital	Academic and community outpatient	Academic and county clinics	VA outpatient clinics	Community outpatient	Academic outpatient	Content vendor	Content vendor
Type of system	Commercial	Commercial	Locally developed and commercial	Locally developed	Nationally developed	Commercial	Commercial	NA	NA
Date of visit	12/07	2/08	6/08	9/08	9/08	12/08	2/09	7/09	10/09
Hours observing	36	26	37	20	25	33	26	NA	NA
Individuals observed	10	12	17	16	17	27	17	NA	NA
Number of clinics observed	NA	NA	9	6	5	9	6	NA	NA
Number of interviews	15	12	13	9	9	9	12	6	6

were all members of the Clinical Decision Support Consortium [17]. Four different commercial systems and three locally-developed systems are used at our selected clinical sites. During visits to clinical sites with commercial systems, the team realized that we could not gain a complete picture of knowledge management processes unless we could learn more about the companies that provide CDS content made available through commercial electronic medical record (EMR) systems. We selected two companies to visit first because they provide much of the CDS available through popular EMR*systems; other vendor visits are planned.*

We selected as study sites two community hospitals, five ambulatory settings, and two companies that provide CDS content. Providence Portland Medical Center in Portland, OR is an urban community hospital, part of a larger hospital system, using a commercial system. El Camino Hospital in Mountain View, CA is a stand-alone suburban hospital with the oldest CPOE implementation in the world, also using a commercial system. Ambulatory sites included Partners HealthCare in the Boston, MA area, which primarily uses a locally developed system but also includes some sites with commercial EMRs; Wishard Memorial Hospital, a county hospital in Indianapolis, IN, which uses the locally developed Regenstrief Medical Record System; the Roudebush Veterans Affairs Hospital in Indianapolis, IN which uses the VA's nationally developed CPRS system; the Mid-Valley Independent Practice Association (MVIPA) in the Salem, OR area, which uses a commercial system; and the Robert Wood Johnson (RWJ) Medical Group, in New Brunswick, NJ, which also uses a commercial system. The vendor sites were Zynx Health in Los Angeles, CA, which provides evidence-based order sets and interdisciplinary plans of care and First DataBank in South San Francisco, CA, which provides medication information. We received human subjects approval from each investigator's home organization and from each appropriate site.

Within each organization, we selected subjects with the assistance of a local sponsor. For interviews, we purposively selected a broad spectrum of users who ranged from champions to skeptics, individuals who either develop or customize CDS, support staff, administrators, quality officers, and IT staff members. We observed users entering orders in many areas of the hospitals and in a broad spectrum of primary care and specialty clinics. At vendor sites, we interviewed CEOs, individuals who develop content, technical staff who work with EMR vendors to make content available electronically, training and support staff, and marketing managers. Experts for the expert conference were selected based on their experience with community hospital and ambulatory CDS.

Data Collection

Figure 1 shows the progression of data gathering and reporting that occurred between 2007 and 2009, including the focus of our work, activities, study sites, and publications. After several months of preliminary preparation, including development of an inventory of CDS types and knowledge management practices [18] and a demonstration of each system for each site, four to seven researchers spent three to five days at each clinical site. We visited Zynx and First DataBank for less time. The nature of these last two site visits was quite different since the focus was the vendor perspective and the visits did not involve clinical observations.

For the community hospitals and the ambulatory settings, we asked questions and observed individuals and committees at work to learn more about: Policy, governance, control, culture; User issues including usability, training, and impact on workflow; CDS content/knowledge management practices; and Technology and infrastructure issues. While visiting the content vendors, we asked about: The marketplace, their niche and relations with EMR vendors; CDS content/knowledge

management processes; Customers—types, frustrations, feedback, challenges; and Use of the product.

Data Analysis

The nature of the Rapid Assessment Process is such that we needed to analyze the data quickly so that we could provide feedback to the site in the form of a report, receive comments back from subjects as a form of "member checking" [19], and then prepare for the next site based on what we had learned. We did this expedited analysis by dividing into pairs to scan transcripts and field notes to identify user, administrative, and IT perspectives at each site to write sections of each report. As we did this, we noted general themes, which we began to identify during debriefings held twice a day during site visits. We developed a codebook and used a template method [20] to roughly code the data. For each report, we identified best practices (e.g. what they did especially well) and challenges in addition to themes. We requested feedback about the reports from sites as a form of member checking. Once the reports were written, we began using a more classical qualitative research approach that was inductive and interpretive. This involved content analysis using the words and actions of the subjects to identify patterns and themes to modify and augment the already-identified codes. We discussed the best practices identified across sites with our panel of experts and the CDSC research team.

Iterative Methods

Although we had carefully developed a field guide containing a site inventory profile about CDS at the site, interview question guides, observation guides, and even guides to debriefing, we found that we needed to modify each instrument for each site visit [21]. We made major changes when we started visiting outpatient sites and again when we started vendor visits. The three types of settings vary greatly in their approaches to CDS. Below we describe a number of best practices for optimizing the value of CDS that emerged from our analysis.

Results

Best Practices

Five large categories of best practices emerged from our analysis:

Best Practice 1: View CDS broadly. Experts and users have widely differing definitions and understandings of CDS, causing a barrier to optimization of CDS use and value. The users appreciate CDS that helps them get through their day, a kind of CDS we call "inline" because it is integrated with their workflows. Experts usually describe CDS in terms of sophisticated alerts and reminders. The vendors providing content view CDS as a way to foster the practice of evidence based health care. There is a danger in defining CDS too narrowly in terms of sophisticated alerts and reminders that are available only at elite institutions. While it is useful to learn from their experiences because they are on the cutting edge and can provide models of CDS use for the future, they are not typical of the majority of sites that provide health care nationally. By defining CDS broadly so that it includes passive elements such as default values and workflow enhancement features such as templates to assist with data gathering, documentation, and clinical reports, all stakeholders will be continuously reminded that the clinicians who are the recipients of CDS are the ultimate customers who need to accept and use these features.

Best Practice 2: Move forward with simple CDS no matter what your size. If an organization has the wherewithal to implement CPOE, it can also use CDS. There is some "low hanging fruit" among CPOE-delivered types of CDS. All of our study sites worked hard to review and select appropriate order sets so that they were available electronically when CPOE was introduced. Order sets assist workflow because they streamline ordering and at the same time they help decision-making. Well-designed checklists and templates can provide guidance at the moment the clinician needs it.

Best Practice 3: Focus on "inline" CDS. We use this term to refer to CDS that does not interfere with a clinician's workflow. One type to consider is "background CDS" which works behind the scenes to consider data related to an individual patient along with rules for good care and makes recommendations such as what antibiotic to order. Another kind of inline CDS is that which notifies an intermediary such as a nurse or pharmacist rather than a physician. These strategies can be especially effective in community settings where interrupting the physician in private practice can be particularly burdensome.

Best Practice 4: Use what is available from your vendor but plan to customize the CDS. Each hospital and clinic has its own culture and need for CDS. Sites with locally-developed CDS tend to identify a clinical need and then design a CDS intervention to address it. Organizations with commercial systems may not have the staff to do this, but they can sometimes purchase appropriate CDS content through their EMR vendors. EMR vendors usually do not develop their own CDS. Instead, they rely on content development companies to write content and partner with the EMR vendor to provide it electronically. Usually both the content and EMR vendors provide a wide range of potential CDS interventions, leaving it to the customer (the hospitals and purchasing organizations) to filter out those that are not wanted. This is a necessary, but time and resource-consuming step and often more difficult than expected. Customers must have clinical leaders and skilled "analysts" on staff who understand both clinical work and information technology.

Best Practice 5: Plan knowledge management processes early. The sites we studied that had locally-developed systems are struggling to catch up with their knowledge management needs. Each one found itself at a point where so much CDS had been developed and implemented that it was hard to keep track of it for the purpose of updating and maintenance. Organizations that have implemented commercial EMRs with CPOE more recently can take advantage of knowledge management capabilities available through vendors [22]. First, the EMR vendors track changes made at the vendor level so there is an audit trail available. A wise or-

ganization tracks its customized changes as well so that as time passes, a history of modifications is always available. Second, tools are available from content development vendors specifically designed to help with knowledge management. They can assist with the decision-making and consensus development process, notify customers when updates are needed, and keep an audit trailof decisions. Good knowledge management practices depend on three foundations: the availability of skilled information systems staff, the existence of a well-developed consensus development and decision making structure, and robust computer tools.

Discussion

We have seen that organizations can do this right [23] and can serve as models of best practices. Because we talked with representatives of many stakeholder groups interested in CDS, because we observed clinicians using CDS, because our study sites included a wide variety of sizes and types of health care delivery organizations, and because we verified a number of best practices outlined by others [2,24], we believe the five best practices categories described above represent a high level view that can be useful to all types of organizations planning to implement CPOE with CDS. All of these best practices depend on planning ahead, ideally prior to CPOE implementation. Best Practice 2, moving forward regardless of size, might entail numerous clinics organizing into a larger organization for the purpose of purchasing and maintaining an information system. This is a large undertaking, requiring significant planning, but it can possibly deliver other financial advantages beyond information systems implementation. All of the best practices also involve the availability of skilled informatics specialists. Two of our sites outsourced the customization and maintenance functions to their EMR vendors by contracting with their service organizations. Availability of a clinician leader is absolutely necessary, even if some activities are outsourced. Study limitations include restricted fieldwork and as yet incomplete vendor visits.

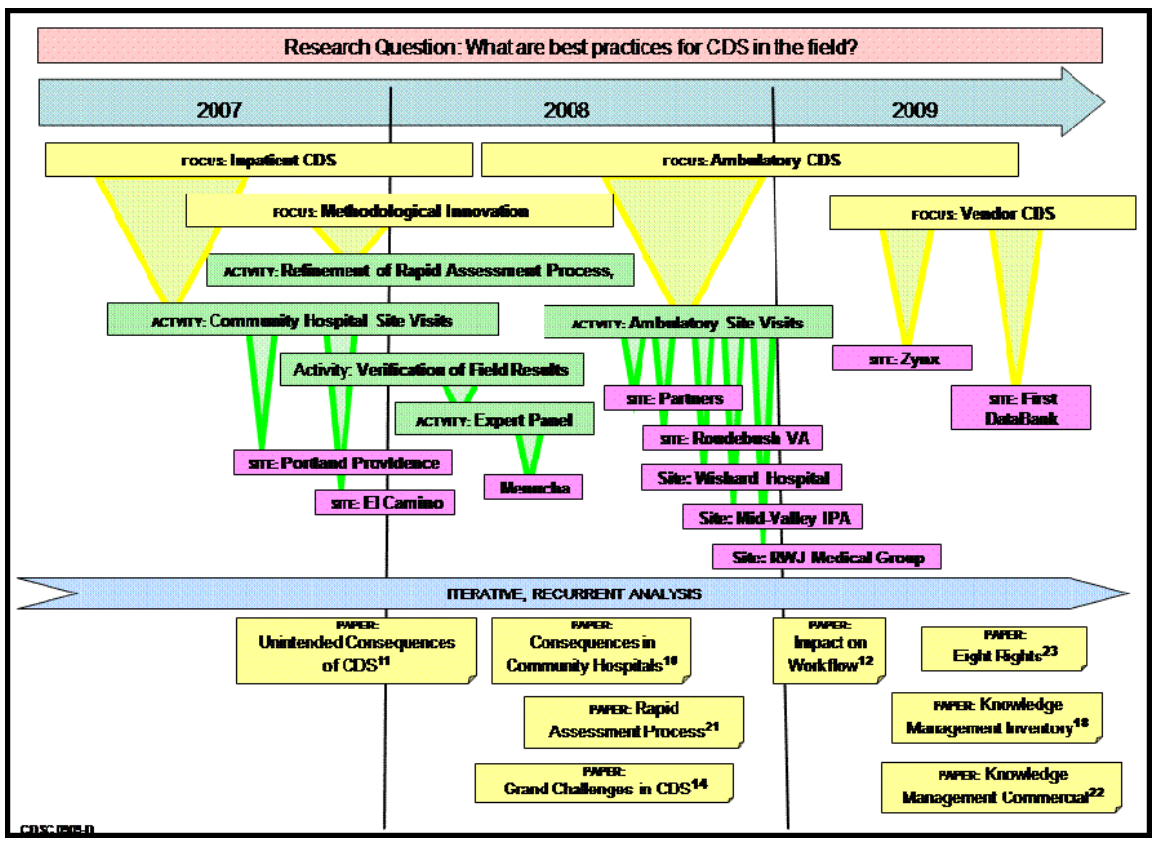

Figure 1- POET research overview 2007-2009
**Foci, activities, and sites as they were approached over time.*

Conclusion

The use of ethnographic techniques to study best practices for CDS and knowledge management in the field allowed us to understand and synthesize a broad range of perspectives. Our study sites included many types of organizations; all of them can be considered pioneers because wide use of CPOE with CDS is still years in the future. Lessons these pioneers teach us now can provide valuable guidance so that CDS can eventually have optimal impact on health care quality worldwide.

Acknowledgments

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Integration of Workflow and Rule Engines for Clinical Decision Support Services

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Abstract

Although recent studies have suggested the feasibility of integrating workflow and rule technology in a Clinical Decision Support System (CDSS), their implementation has not been verified yet. This paper proposes a knowledge engine which integrates workflow and rule engine as a tool for interpretation and execution of computer interpretable clinical guidelines. The objective of this paper is to validate its feasibility in two perspectives: clinical knowledge coverage and execution performance. The two open source engines which were selected and integrated were chosen due to their reliability and consistency. Implementation of workflow and rule engine integration has shown that the integrated knowledge engine (uBrain) is an effective CDSS for the execution of clinical guidelines.

Keywords:

CDSS, Workflow, Rule engine

Introduction

Over the decades, many researchers have tried to develop and implement effective CDSSs. The basic concept of a CDSS is to provide an intelligent tool which can provide clinicians or patients with clinical knowledge and patient-related information to enhance patient care experience. In addition to the revolutionary advances in the field of information technology, recent CDSSs are based on artificial intelligence or knowledge engineering technologies. Furthermore, the architecture of CDSSs has changed from standalone systems to standard-based and service-oriented systems. These advances demonstrate that future research and trends of CDSSs development will aim to maximize the interoperability through separation of their components such as data, rules, processes and services.

Recently, CDSS development basically employs two main components: 1) a clinical knowledge base for what to dispose and 2) an inference engine for how to dispose. The studies on various knowledge bases mainly have focused on computerized and standardized representation of clinical knowledge. One of the most widely used formats is the Computer Interpretable Guidelines (CIGs) which is used as a generic template to facilitate the translation of guidelines from their published formats into computer interpretable algorithms.

The inference engine of a CDSS performs such functions as interpreting and executing the guidelines encoded in the specific representation formats. There are generally two approaches in developing a clinical inference engine. One approach is to develop an engine for a specified clinical guideline format. Well-known guideline formats generally contain their own execution engines [1]. The other approach is to adopt common knowledge tools into clinical decision support. Since the core logic of clinical guidelines consist of complicated rule sets, commercially available rule engines have been adopted on a wide-scale basis. Several researches have reported that commercial rule engines can be an execution engine for clinical knowledge [2].

Although rule engines have been verified as having an alternate core function as an inference engine, they cannot possible provide complete coverage for clinical guidelines. The external part of clinical guidelines consists of triggers, actions and decision-makings. Recent research has focused on reinforcing functions that control the main flow of guidelines, invoking rule execution and interfacing with local applications. The rule invokers were originally embedded in the CDS applications, but as the coverage of clinical guidelines became wider, the necessity to make them independent and to standardize them has increased.

Recent studies have suggested the adoption of the workflow concept into clinical guidelines, particularly in terms of pattern coverage, execution and knowledge representation [3-5]. It is very promising because as the coverage of knowledge bases in CDSS becomes wider spread, so does the original use of workflow as a business process management which can be adequately utilized in clinical processes. The clinical guideline can be effectively separated into the combination of workflow and rule models. Therefore in this paper, we integrate workflow and rule engines as a knowledge engine, and validate its availability.

In this study, a workflow engine is used as an interpreter of the guideline process model, and a rule engine is used as an infer-

ence engine. The workflow definition model represents the logical flow of the guideline model, and the rule model implies unit logics such as clinical concepts, constraint, and criterion. When a service is triggered, the workflow engine invokes the rule engine for execution generating actions according to the results. In this study to increase the integrity in the execution of guidelines, we integrated two open source engines which were verified in a decision supporting system for management information system domain.

The verification of the proposed work is done at two critical points of the CDSS: 1) accuracy of knowledge processing and 2) execution performance. The accuracy of the proposed system can be verified using test cases. The representative clinical guideline models and their test cases can measure the accuracy and reliability of the knowledge engine. Performance was measured as the availability of practical implementation at local institutions. The performance criteria included were service response time, data fetching time, and durability against stress. Acceptable performance and time parameter for a CDSS is two transactions per second [2].

The results of the study show that the elements of the clinical guideline were correctly executed and made within the parameter mentioned above. Additionally, the integrated knowledge engine provided wide coverage and the expression power of the integrated knowledge engine can be extended to other formats for clinical guideline formats. The contribution of this paper is that it verified the availability of an integrated engine using workflow and rule models.

Materials and Methods

Workflow management system and rule engine

A workflow definition model and its management system are widely used in modeling and automation of business processes. A workflow management system employs various tools to support the entire life cycle of workflow from its de-sign to its execution and analysis [6]. The core function of a workflow management system is the enactment service which interprets the workflow definition model step by step, delivers each task to the actual workers and controls and monitors the status of the process. This software component, which acts as the workflow enactment service, is called the workflow engine

Since a workflow model can represent diverse patterns of logical flows such as data, resources, and controls, approaches to workflow for clinical guidelines have been adopted and tried. One of the more significant approaches was the comparison of two concepts in terms of their expression power [4]. These studies systematically analyzed and clustered the process patterns and control structures towards their ability to be automated. The conclusion of these studies showed that CIG modeling languages are remarkably close to traditional workflow languages from the control flow perspective, but cover many fewer workflow patterns. Consequently, workflow management systems may be suitable and applicable for clinical guideline applications [3].

A rule engine is commonly provided as a component of a business rule management system to execute rules. In any IT application, business rules are changed more frequently than the rest of the application code. Rule engines are the pluggable software components that execute business rules that have been externalized from application code. This allows business users to modify the rules frequently without the need of IT intervention and hence allows the applications to be more adaptable with dynamic rules.

Verification of knowledge coverage and performance

In order to apply workflow and rule model into a clinical guideline, the feasibility should be evaluated by measuring the similarity between the two concepts. The verification has two perspectives: 1) knowledge coverage and 2) physical performance. The former is related to the relevance of the proposed method, and the latter is about verifying the applicability for the real clinical field.

Generally speaking, clinical knowledge bases are very complicated and specified to domain experts so it makes it difficult to evaluate and compare with knowledge bases in different domains. One of the significant methods is to compare with generalized models. Recent research concentrates on the similarity of workflow models and CIGs in terms of patterns. The result of the comparison shows that CIG languages such as Abru, EON, GLIF3.5, and PROforma are very similar to process languages of workflow management systems although they do not make use of many of the workflow patterns in such systems [3].

Another dominant point for verification is the physical performance of a knowledge engine, and this may be the biggest benefit for adopting commercial engines. The factors which determine the performance of a knowledge engine are as follows: 1) delivery time of patient data to the engine, 2) response time to make actions when a large number of rule sets are loaded, 3) loading time of rule models. In case of an engine which is a pre-loading type, loading time is negligible [2].

Generally, the operation time of the CDS service is very short; less than a second. Therefore, in case of occurring redundant service requests, the system should endure the stress of multiple accesses to prevent waiting too long a time for the response. Another major bottleneck in service performance is delivery of the data to the engine. In order to minimize the number of round trips between a rule service and an external repository, the rule service should be primed with a large swath of patient data. Consequently, the CDS service system should satisfy not only providing quick response time but also avoid overloading adjacent systems.

Selection of engines

In order to select most suitable workflow and rule engines, the following elements are considered.

- Integrity: In order to achieve fast response and correctness of execution, the two engines should be easily integrated. The ingredients of integrity are the same pro-

gramming language, fully object-oriented design, and simple and extensible interfaces.

- Reliability: The engines are required to contain industrial references in order to assure stable performance against physical stress particularly in practical uses in local institution.
- Extensibility: The framework of engines should be based on a well-known architecture (J2EE etc.) so that its components can be easily added or reconfigured.
- Open source: Because this study was involved from a national perspective, the proposed works should be non-profitable and open to the public.

Consequently, two open source engines; uEngine and BRAIN were selected. uEngine is a workflow engine which has advanced in convenient development of workflow activity types so that it can integrate the other modules with ease. BRAIN is a business rule engine based on an object rule model and <if then> rule expression. Object rule model defines the domain model and interface model. Domain model defines the domain scope and standard value or basis for criterion. Interface model defines the variables to be compared with standards. Various criteria were expressed in if-then statements.

The two engines were fully developed in the Java language platform and based on object-oriented design patterns. These engines were already verified in decision supporting module of management information applications.

Development

The integrated knowledge engine (uBrain) was designed to take a layered approach to partitioning the functions which are provided by the components. Basically, a clinical guideline contains diverse elements which have their own features and functions. The most closed part to users is related to clinical actions such as retrieving patient data, triggering interference, making recommendations or notifications. These kinds of actions can be separated and represented effectively in workflow model. The workflow engine employs basic activity types which have same functions to clinical actions, so a knowledge author can design clinical workflow with them.

The part of clinical guideline for inferences was separated as rule models, and conducted by a rule engine. Logical elements of clinical guidelines such as variables and their values, presence of a status, and composite logics can be interpreted as rule functions in the rule engine. The rule engine reads input data sets at once, executes, and returns the result sets. The role of the workflow engine is activation of rules, delivery of input data sets and the execution results.

The external feature of uBrain was developed as a client-server system which is based on the assumption that there exist many physically distributed clients. Also, standardized clinical guidelines for each disease were defined and registered in the service registry so that a client can find and invoke for the CDS service for a specific type of guideline. Consequently, uBrain defines the business logic of a guideline model, the local EMR provides data, and the associated clinical applications will support the interactions between the users and a guideline implementation system. This architecture is based on service oriented architecture.

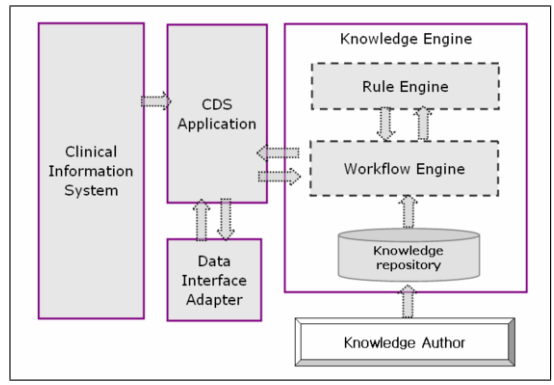

Figure 1- Proposed CDSS architecture

The overall architecture of uBrain is shown in Figure 1. The system architecture was designed to provide flexibility for integration with clinical information system to be taken by a local institution. Clinical guidelines may be stores in a knowledge repository after being encoded by a knowledge author. The engine retrieves the knowledge from the repository according to a request (event) from the CDS application. To load the patient data from the clinical information system to the knowledge engine, the CDS application should fetch the patient data in run time through data interface adapter (DIA).

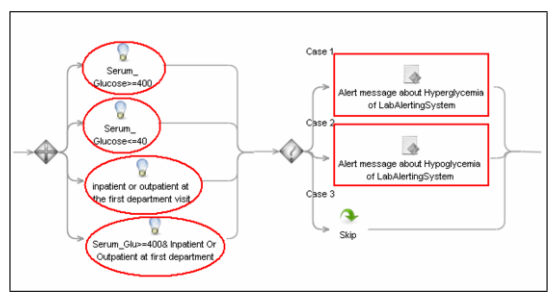

Figure 2- Integration of workflow and rule model

Figure 2 shows the integrated feature of workflow and rule as a guideline model. The rule activity icons (in circles) indicate the invocation points for rule execution, and the result values may be stored at the variables in the process model. At the decision-making points (branching points), the workflow model selects a path to execute based on the rule execution results and activates actions (activity icons in squares), and finishes the process.

Results

Stress test of the integrated engine

To validate the proposed framework, example clinical guidelines were selected. The guidelines are to validate performance, knowledge coverage and extensibility. Lab alerting; a simple type of clinical guideline is first implemented to see the response time of the engine. Lab alerting consists of seven types of sub guidelines which contain one or more rule sets. The stress test is under the assumption that there is a server for guideline service and multiple clients, service requesters. The evaluation points are 1) how the response time decreases according to multiple accesses and 2) how the engine is affordable against overload. The results are shown in Table 1.

Table 1 – Execution results for load test

No. of connections	No. of test cases	Processing time (msec)	
		Average	Std. dev.
1	30	48.3	4.9
2	60	111.3	67.5
3	90	1,368.1	500.9
5	150	4,303.5	562.4
10	300	6,414.3	2,746.6
20	600	14,154.5	7,538.7
30	900	20,823.7	23,638.5

The stress tests were conducted under various conditions. The number of simultaneous requests increased from 1 to 30. In table 1, the average processing time increases proportional to the amount of requests. Standard deviation values increases more sharply than average processing time. This implies that the stressed environment influences the quality of service in both indicators of means and variances. In particular, the largest stress condition makes the variance of processing time much higher so that sometimes users give up waiting for the response.

Performance test in real usage

One of the critical issues in a real environment for CDS uses is the fetching time for the patient data. A DIA was also developed to efficiently retrieve local patient data and make an input data set for the knowledge engine. A test bed which includes a DIA was established based on a clone of the local EMR database which contains real patient data. In all, 323,445 test cases were generated from the database, and the accuracy of uBrain execution results compared to the original lab results was 100%. The performance results for the processing time are shown in Table 2. The results represent that the performance of the system highly depends on the amount of data and rules which should be disposed.

Table 2 – Execution results with test cases

Test name	No. test cases	No. Alerts	Average processing time (msec)		
			DIA	Engine	Total
CBC	39,893	41	137	55	192
Glucose	44,494	229	276	102	378
HCT	62,764	764	457	36	493
Rh typing	10,439	38	787	55	842
WBC	62,612	73	400	32	432
Sodium	51,405	156	446	48	494
Potassium	51,838	349	165	53	218
Total	323,445	1,650	346	52	398

Coverage test

A hypertension guideline was modeled as a case for the complicated knowledge base. It consists of 247 rules and encoded in Sage format. The guideline consists of three recommendation sets; a main guideline which has branches according to existence of diabetes mellitus, and two sub guidelines which make actions for recommendation according to the rule execution results. 201 representative test cases were selected from clinical experts, and the results shows that the integrated engine can cover complicated types of guidelines.

Discussion

The dominant trend in CDSS development is separation of clinical knowledge and reasoning, and their independent disposing. The workflow engine and rule engine were physically integrated in architecture, but independently operated by its own roles. One of the main obstacles which make it hard for CDSSs to spread widely is the hardness to identify or separate the knowledge from other application functionalities and, separation of these components may contribute to increased reliability and maintainability of CDS services.

In the stress test, the engine showed excellent performance and can endure a few simultaneous requests. This will be a factor which needs to be determined to assure the capacity of a CDS server in restricted resources. In run time test, the processing time was found to be divided into three elements: workflow engine processing, rule engine processing, and DIA data fetching. The workflow processing time was almost fixed around 20 micro seconds. The rule processing time was proportional to the number of rule sets. And the data fetching time depends on how many elements should be prepared to execute knowledge engine.

The results of the performance analysis indicate the direction of future works. The number of rule operations is a variable factor to determine the entire processing time so it should be minimized. Some parts of this can be accomplished by caching

for the similar or same conditions. Data fetching operation was still the biggest bottleneck, but this study verifies that the strategy of 'fetching data before execution at a time' is feasible and promising.

Conclusion

The integration of workflow and rule engines is successful in the perspectives of architectural efficiency and availability in clinical domains. The knowledge coverage of the integrated engine was verified by translating and executing Sage based guidelines. Also the engine shows acceptable performance in practical use of CDS services through generation and execution of test cases. Future work is expected utilizing the extensibility and applicability of the proposed methodologies.

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Implementation of a Clinical Decision Support System using a Service Model: Results of a Feasibility Study

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Abstract

Numerous studies have shown that the quality of health care is inadequate, and healthcare organizations are increasingly turning to clinical decision support systems (CDSS) to address this problem. In implementing CDSS, a highly promising architectural approach is the use of decision support services. However, there are few reported examples of successful implementations of operational CDSS using this approach. Here, we describe how Hospital Italiano de Buenos Aires evaluated the feasibility of using the SEBASTIAN clinical decision support Web service to implement a CDSS integrated with its electronic medical record system. The feasibility study consisted of three stages: first, end-user acceptability testing of the proposed CDSS through focus groups; second, the design and implementation of the system through integration of SEBASTIAN and the authoring of new rules; and finally, validation of system performance and accuracy. Through this study, we found that it is feasible to implement CDSS using a service-based approach. The CDSS is now under evaluation in a randomized controlled trial. The processes and lessons learned from this initiative are discussed.

Keywords:

Health information system, Clinical Decision Support System (CDSS), Reminder systems, Computerized medical records systems

Introduction

A significant gap exists between actual clinical practice and optimal patient care. Numerous studies have shown that the quality of health care is variable and often inadequate [1, 2]. To address these deficiencies in care, healthcare organizations are increasingly turning to clinical decision support systems (CDSS) that provide clinicians with patient-specific assessments for recommendations to aid clinical decision making [3, 4]

Wright and Sittig describe four distinct architectural phases for decision support: [5]

1. Standalone decision support systems.
2. Integrated systems.
3. Standards-based systems.
4. Service models.

SEBASTIAN is an example of a clinical decision support technology that supports the latest, service-based architectural approach to CDSS implementation[6]. Developed at Duke University, SEBASTIAN is a clinical decision support Web service whose interface is now the basis of the HL7 Decision Support Service draft standard.[7] SEBASTIAN places a standardized interface in front of clinical decision support knowledge modules and makes only limited demands on how relevant patient data are collected or on how decision support inferences are communicated to end-users. Despite this promising, potentially highly scalable approach to decision support, very little has been published related to experiences using this approach to implementing CDSS.[6, 8]

The Hospital Italiano de Buenos Aires (HIBA) is a non-profit academic medical center founded in 1853, with over 1,500 physicians and 3,500 employees. HIBA has a network of two hospitals with 750 beds (200 for intensive care), 500 home care patients under care, and 23 clinics. It has an insurance plan that covers approximately 150,000 people and also coordinates insurance for another 1,500,000 people who are covered by affiliated insurers. Each year over 38,000 inpatients (pediatric and adult) are admitted to its hospitals that are located in Buenos Aires and its suburbs. HIBA has more than 2,200,000 outpatient visits annually from patients from across Argentina and Latin America.

In 1998, HIBA began to implement a Healthcare Information System (HIS) by integrating clinical information with the administrative applications that were already in use. HIS was completely developed in-house and currently collects and leverages the clinical and administration information related to health care for HIBA. Within HIS, the Electronic Health Record (EHR) is a fully-implemented Web-based, problem-oriented, patient-centred record with customized functionalities depending on the level of care (outpatient, inpatient, emergency care and home care) [9]

This EHR system includes a computerized provider order entry (CPOE) system, available throughout the HIBA network. In the ambulatory setting, CDSS was previously used only for prescriptions, but not for preventive care.

The HIBA information infrastructure includes a terminology server that allows the mapping of local vocabularies to SNOMED CT. This terminology server allows for the structured capture of approximately 80% of diagnoses [10, 11].

Within this existing health information infrastructure, the aim of this study was to evaluate the feasibility of implementing a CDSS for preventive care using a service model. Given our institution's collaborative ties with relevant investigators at Duke University, we chose the SEBASTIAN decision support Web service to conduct this evaluation.

Materials and Methods

Design: A feasibility study was performed to assess the necessary changes in processes and systems for the implementation of a services-based approach to CDSS.

For this test, the study was divided into three phases:

1. System usability evaluation through focus groups

In order to determine the preferences of physicians on how to interact with the CDSS, we conducted focus groups to evaluate the acceptance of different reminders by primary care physicians (PCPs).

Two focus groups were conducted. In each focus group, there were two internists, two family medicine practitioners, and two pediatricians. The group was led by a moderator and a qualitative evaluation expert. Each meeting was recorded and analyzed by the statistical and epidemiology group of HIBA.

2. Integration of SEBASTIAN with Hospital Italiano Health Information System

SEBASTIAN is an acronym for System for Evidence-Based Advice through Simultaneous Transaction with an Intelligent Agent across a Network[6]. It interacts synchronously with client software applications to deliver decision support over the Internet. The framework is implemented as a Java servlet and is hosted by the Apache Tomcat servlet container.

SEBASTIAN uses a patient information model based on the Health Level 7 (HL7) Reference Information Model (RIM), the same reference model used in the HIBA system. Concepts are identified using standard vocabularies like SNOMED-CT, the same reference vocabulary used in HIBA. Patients are modeled as entities described by demographic and "act" data, where an act refers to any act or service constituting health care services, such as an encounter, diagnosis, or procedure.

Medical knowledge in SEBASTIAN is captured in XML documents known as Executable Knowledge Modules (EKMs). Each module specifies the data requirements for assessing a patient, the patient specific conclusions that will be returned by the module, and the logic that will be utilized to generate the conclusions using the specified patient data. EKM results are the primary objects returned to client systems following the evaluation of a patient.

Because SEBASTIAN operates as a Web service, all services can be accessed by sending XML requests over HTTP. The core service offered is a patient evaluation service, in which patient data elements are received as the input and machine-interpretable decision support results are returned as the output.

In this phase of the study, the HIBA team and the Duke team held teleconferences to identify how SEBASTIAN could be used within the HIBA system, and the HIBA team implemented the required system modification work. The initial focus of this study was on the appropriate management of breast cancer screening and prevention.

3. Validation study to evaluate system sensitivity and specificity

After completing the integration of SEBASTIAN with the HIBA system, a study was conducted to validate the operation of the system [12].

The objective of this study was to measure the sensitivity and specificity of SEBASTIAN rules in the detection of mammogram completion, mammogram results (in terms of BIRADS values), patient risk factors, and exclusion criteria. This evaluation also assessed the accuracy of the generated recommendations. The gold standard was the manual review of the medical records. The population reviewed was female members of HIBA's health maintenance organization who were enrolled for at least two years in the health system and were between 49 and 60 years of age. Manual review was done on 210 cases randomly selected from this population.

Results

Figure 1 outlines the timeline in which the three phases of the study were completed.

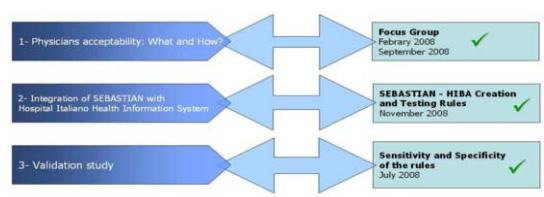

Figure 1- Study phases and completion dates

Usability

The results of the physician focus groups helped to inform the design of the CDSS user interface. Physicians preferred to view the reminders in the following way:

- Reminders displayed in a dedicated frame
- Accessed through main screen or from screen on problems
- No visually intrusive message (i.e., no pop-ups)
- Agile accessibility and handling

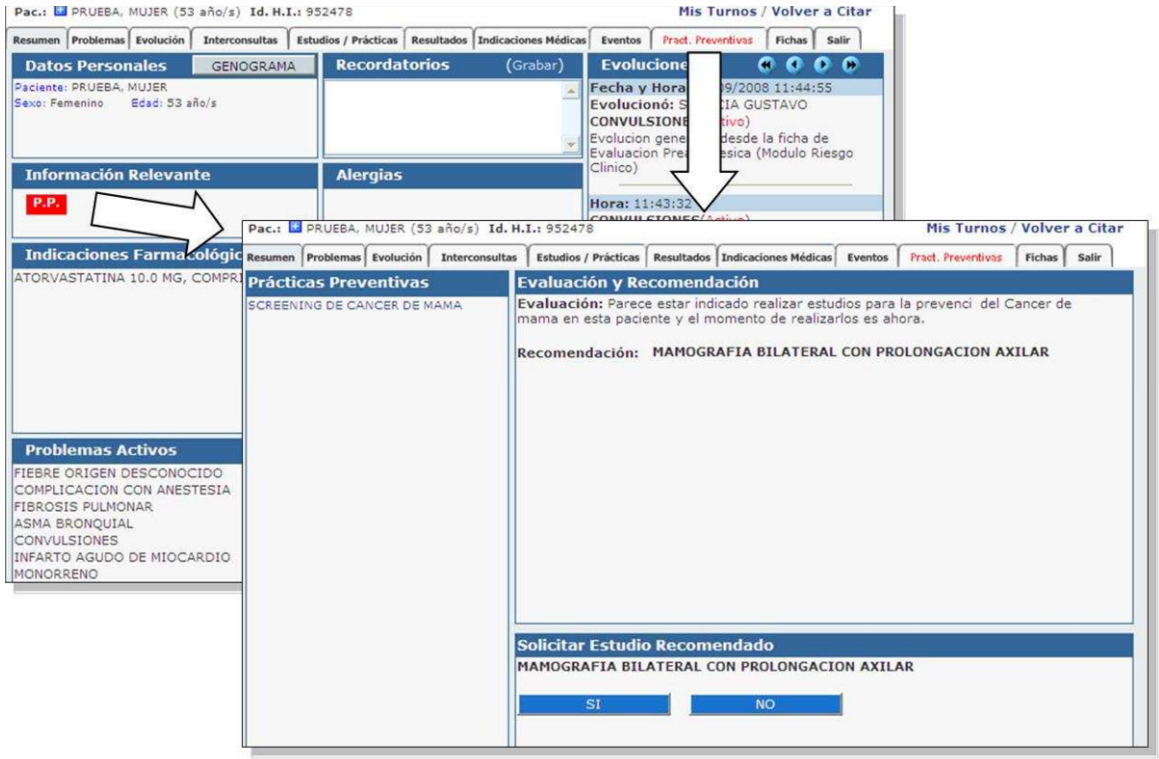

Figure 2 – Sample CDSS Screenshot. Availability of an active reminder for preventive services (breast cancer screening) is indicated by the red "PP" flag in the Important Information section. If the Physician clicks on any red marked section, a recommendation (i.e. order a mammogram) will be shown. If the physician agrees with the recommendation he would order it. In case of non-acceptance the reason should be explained.

- Possibility of personalizing the list of reminders displayed
- Possibility of printing reports as handouts for patients
- Ability to generate a list of patients with pending preventive care needs
- Possibility to graph data trends (for the patient)
- Prioritize patients with unmet care needs for clinic appointments

A screenshot illustrating the availability of one reminder is shown in Figure 2.

Integration of SEBASTIAN with Hospital Italiano Health Information System

To use SEBASTIAN, the developer at HIBA first identified the set of knowledge modules that would best meet application needs. These knowledge modules are captured in XML documents, and they consist of maintenance, library, knowledge, and logic sections [6]. Most module sections are edited using a functionally rich Microsoft InfoPath™ form. This authoring environment was used at HIBA to create and modify rules to enable results-based breast cancer screening.

In addition to developing the SEBASTIAN rules, the HIBA EHR system was configured to send SEBASTIAN the required patient information when an appropriate patient was potentially in need of a breast cancer screening reminder. To enable this data submission, it was necessary to develop a router that understood the demands of the SEBASTIAN rules and collected the required patient data. Also, the EHR system was adapted to parse the patient-specific care recommendations returned by SEBASTIAN for appropriate display in the EHR system. The information flow among the different system components is summarized in Figure 3.

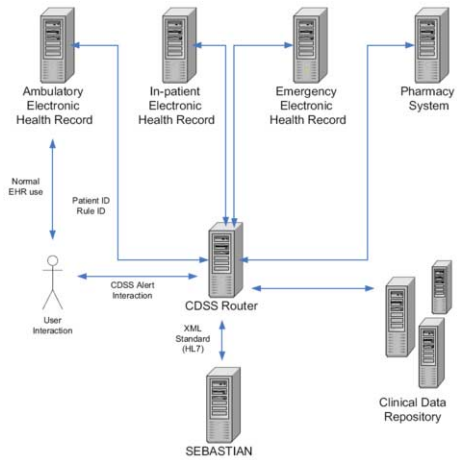

Figure 3 – CDSS System Architecture

Validation study

After implementing the CDSS based on physician feedback, a validation study was conducted to assess the performance characteristics of SEBASTIAN rules. With respect to the detection of an existing mammography report, sensitivity was 94% with a specificity of 91%. For the recommendations generated by the rule for breast caner screening, sensitivity was 97% while the specificity was 72%. For detection of a correct mammography BIRADS score, the sensitivity was 69% and specificity was 70%. Finally, for appropriate detection of exclusion criteria, sensitivity was 100% and specificity was 98%.

The HIBA clinical oversight team considered these values of sensitivity and specificity more than acceptable for production level use of the CDSS. Moreover, in order to further improve CDSS performance, we addressed underlying problems that we identified the testing by incorporating new terminology, implementing new systems for diagnosis and procedure coding, and training pathologists and radiologists to ensure more accurate recoding of the data in the pathology and radiology reports, respectively, that were used by the CDSS.

Discussion

In this paper, we have described the implementation of a Web services approach to clinical decision support that provides effective mechanisms for the transformation of medical knowledge into a machine-interpretable form, and for making that knowledge easily accessible and usable for an external EHR system.

Before the implementation of new technology, it is mandatory to assess with focus groups or other qualitative methods the user's opinion to allow the acceptability and adherence to the use of the this new technology.

One of the strengths of this study is that it demonstrates that it is possible to use the same services-based clinical decision support engine across multiple applications and institutions. Specifically, the SEBASTIAN Web service approach has now been successfully implemented within an academic medical center in the United States[8] and a private teaching hospital in Argentina. Additionally, this study represents only the second published report of an operational implementation of decision support using a system that is the basis for the HL7 Decision Support Service draft standard. Through the implementation described in this paper, we have demonstrated that this system can not only be ported across institutions, but also across international boundaries as well. To accomplish this portability, however, it is essential to have common information models and data standards to exchange and understand the information contained in clinical data repositories.

This report is also significant in that it has shown the ability to use decision support to augment breast cancer screening that traditionally relies only on age and gender, to now also incorporate relevant previous pathologic and radiological findings into breast cancer screening recommendations. The incorporation of these additional data may improve the effectiveness of screening to detect breast cancer. We are currently conducting a randomized clinical trial (RCT) to evaluate the effectiveness of this data-augmented CDSS breast cancer screening resource.

Conclusion

In this study, we have demonstrated that it is feasible to take a services-based approach to clinical decision support and to implement it across institutional and national boundaries. Coupled with usability and system performance testing, we conclude that a clinical decision support service can enable the implementation of CDSS that is accurate and appropriately integrated with existing EHR systems and clinical workflows.

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Evaluation of the use of an "ask-the-expert" e-consultation service for support on health-related requests

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Abstract

E-consultation in health care can be used to respond to an increasing demand for care by offering support on health-related requests. In this study we evaluated the use of an "ask-the-expert" e-consultation service in order to assess whether the service is efficient and useful. A content analysis of e-mail exchange between clients and online health professionals was performed to gain insight in the purposes of use of the service. Our findings show that the e-consultation service was used for health requests on not urgent, minor ailments. Clients asked for health information to increase knowledge on the cause of their injury or disease, its consequences, possible self-care solutions and treatment options. Decision support on assessing the necessity to visit a doctor for a certain health problem was another important reason to use the service. We believe that web-based triage systems could be used to more easily assess whether certain symptoms need to be investigated.

Keywords:

Internet, E-mail, e-consultation, Patient-provider communication, Primary care

Introduction

Due to demographic and socio-economic trends, a substantial increase in the use of health care facilities is expected in the years to come. This poses a huge burden on human resources. The use of e-consultation in health care -online asynchronous patient-provider communication- may be part of the solution of this future problem because these services have the potential to save unnecessary visits to the general practice by offering self-care solutions [1-4]. These services are particularly useful for certain patient groups such as the elderly and patients with a chronic disease because of their greater need for care and their willingness to use e-consultation [5].

These days, a growing number of websites offer "ask-the-expert" e-consultation services where patients can consult health professionals via secured e-mail. These e-consultation services can be used to direct patients to the most appropriate source of care and away from using unnecessary and ultimately more expensive services. Despite these potentials, the use of e-consultation is not yet widespread in primary care. In order to foster the use of e-consultation, we believe that more research is needed on which type of patients actually use e-consultation services, how do they use it and why [5-14].

In this study we evaluated an "ask-the-expert" e-consultation service with so-called type-A interactions; these are encounters in which a pre-existing patient-provider relationship is absent [6,7]. Aim of the study was to assess whether the service is beneficial and efficient for giving support on health-related requests. This paper presents the preliminary results of a content analysis of e-mail exchange between clients and online health professionals. We described the users of the service, the purposes of use, the message content and the efficiency (response time) and usefulness of the service (fulfilment of requests).

Methods

Description of the e-consultation service

Since 2001 Medicinfo (http://www.medicinfo.nl) provides an "ask-the-expert" service for medical advice by telephone. The service is offered free of charge to members and clients of homecare organizations and health care insurers. From 2003 the service also provides the possibility to consult nurses and other health professionals online. Depending on fluctuation in workload during the day and week, the service is staffed by a minimum of two and a maximum of five nurses, handling telephone, e-mail and chat-services according to roster. All personnel are registered nurses who have successfully completed a higher vocational training in nursing. All have prior work experience in various health care jobs and most work part time in their present job. They follow an in company communication training and are subject to regular assessments. At all times a physician is on call for consultation.

Before entering their e-mail request via free-text, users have to create a secured personal account for which they have to provide initials, family name, birth date, gender and e-mail address. After

agreeing with a disclaimer, clients are asked to fill out the purpose of their request on a form:

1. I am looking for: general information about a disease or complaint / a treatment or medical examination / the address of a caregiver or institution;
2. A diagnosis has been established and now I want to know more about the cause / the consequences / the treatment / heredity / possible self care;
3. I want to know if I need to see a doctor for my complaint;
4. My question is about something else.

This classification is based on a content analysis of the "ask-the-expert" service for medical advice by telephone. The incoming e-mail requests are handled by the trained nurses and authorized by a physician. All requests are handled within 2 working days. Some questions are referred to the physician (GP) or to other health professionals. The nurses use standard answer protocols, see Figure 1.

Answer 1 is given for a well-defined health-subject such as "What is a trigger finger". For these "subject" requests general health information is given with links to specific web pages for further information about the subject. If the request is about the specific personal health situation of the client e.g., *"I have these symptoms/complaints; what is wrong with me?"* no advice can be given because a reliable diagnosis can usually not be established online [6]. For these "personal requests" clients are advised to contact their regular physician, see answer 3. In some cases the request embraces two aspects: a personal request of a well-defined subject, for example *"I have psoriasis, what can I do about it? I heard that psoriasis can be treated with injections, could you tell me more about it?"* In these cases answer 2 is given. In case of non-health related requests e.g., questions about the reimbursement of a treatment, answer 4 is given.

Some requests are difficult for nurses to answer, for these requests a GP is consulted. Moreover, specific requests are forward to one out of 25 other health professionals among which are a physiotherapist, psychologist, diabetes nurse, dietician, obstetrician, school doctor, pharmacist, dentist, speech therapist, pedagogue, vaccination expert, and more.

Research instruments

Log files were used to store nurse-client e-mail exchange during the period of September 2008 until September 2009. A content analysis was performed using the taxonomy of Sittig [15] and Eysenbach and Diepgen [16]. We analyzed 222 e-mail requests handled by nurses in the period of September 2008 and December 2008. To assess the type of health-related requests, Units of analysis were a request and reply exchange which formed a pair of emails.

Answer 1: information or advice

We received your message of (date). In this message you ask information / advice about … Please find the information you requested below …

AND/OR

We have found information about this subject on the following website… If you have remaining questions after reading this information we are pleased to answer them. If this is the case, please contact us again via the website or by telephone.

Answer 2: information or advice AND see regular physician

We received your message of (date). In this message you ask information / advice about … We can only answer health-related questions if this can be done safely and reliably. After all it concerns your health! To be able to answer your question properly we need extra information that can only be obtained through personal contact with a physician or other caregiver. Therefore, we recommend contacting your own physician to get an answer for this question. However we did find general information about this subject. Please find it below…

AND/OR

However we did find general information about this subject on the following website…If you have remaining questions after reading this information we are pleased to answer them. If this is the case you can contact us again via the website or by telephone.

Answer 3: no information or advice, see regular physician

We received your message of (date). In this message you ask information / advice about …We can only answer health-related questions if this can be done safely and reliably. After all it concerns your health! To be able to answer your question properly we need extra information that can only be obtained through personal contact with a physician or other caregiver. Therefore, we recommend contacting your own physician to get an answer for this question. If you have remaining questions after reading this information we are pleased to answer them. If this is the case you can contact us again via the website or by telephone.

Answer 4: no information or advice, request not health-related

We received your message of (date). Unfortunately we are not able to answer your question. We only answer questions that are related to diseases, health, wellness and lifestyle. For answers on policy and health insurance related questions we advice you to contact the customer service of your health insurance company.

Figure 1 - Standard answers

Results

Users of the service

Users of the e-consultation service were predominantly women (68%, 151/222). Mean age was 44 years (*SD*=14.1, min. age: 14, max. age: 77, *n*=166). 8% (18/222) of the e-mail requests were submitted for other persons such as children or the partner.

Reasons to use the service

Before submitting their request clients had to fill out the reason for their request. The reasons are presented in Table 1. Acquiring more information after a given diagnosis and decision support on whether it is necessary to visit a physician were the main reasons to use the service. Most requests however were categorized by clients as 'something else' (33.2%). These requests could nevertheless be classified by the researcher in one of the standard categories, see Table 1. These requests were probably categorized

by clients as something else because the request was aimed at getting a personal health advice instead of obtaining general health information.

Table 1 – Reasons of clients to use the service (total mentioned reasons n=247)

	n	%
(1) I am searching for general information about…	**39**	**15.7**
a. a disease or complaint	23	9.3
b. a treatment or medical examination	9	3.6
c. the address of a caregiver or institution	7	2.8
(2) A diagnosis is given and now I want to know more about…	**73**	**29.6**
a. the cause of the ailment	15	6.1
b. the consequences of the ailment	12	4.9
c. the treatment of the ailment	28	11.3
d. heredity of the ailment	3	1.2
e. possible self care	15	6.1
(3) I want to know if I need to see a doctor	**53**	**21.5**
(4) My question is about something else	**82**	**33.2**
1a. a disease or complaint	33	13.4
1b. a treatment or medical examination	7	2.8
1c. the address of a caregiver or institution	2	0.8
2b. the consequences of the ailment	1	0.4
2c. the treatment of the ailment	2	0.8
2e. possible self care	1	0.4
4. not health-related (insurance questions)	36	14.6

Type of e-mail requests

Most e-mail requests submitted to the service (*n*=153) were about physical complaints, diseases or symptoms (see Table 2). Some examples: *"I would like to know how and where I can be treated for definitive depilation of unwanted facial hair"*, *"I'm a woman of X years. My mother has recently been diagnosed with breast cancer for the second time. Her sister has also breast cancer and my grandfather deceased from intestinal cancer. I would like to know whether I should be tested on heredity of (breast) cancer"*.

A substantial amount of questions were about insurance and reimbursement issues. These questions could not be answered, because the service is only meant for health-related questions.

Table 2 - Categorization of e-mail requests (n=222)

Type of requests	*n*	%
Physical complaints, symptoms or diseases	153	68.9
Policy and insurance requests	27	12.2
Medication and treatment	22	9.9
Addresses of physicians or practices	9	4.1
Information on harmfulness of products	5	2.2
Travelers' advice	2	0.9
Lab results	2	0.9
Other	2	0.9

Type of answers and response time

The response time of the nurses was quick; 94% (209/222) of the e-mail requests were handled by the nurses within 24 hours. Table 3 presents the type of answers given by nurses. In most cases (67%, 149/222) general health information or advice was given (Figure 1, answer 1 and 2).

Table 3 - Categorization of answers (n=222)

Type of answers	*n*	%
Answer 1: information or advice	78	35.1
Answer 2: information or advice and see physician	71	31.9
Answer 3: no information or advice, see physician	42	18.9
Answer 4: no information or advice, request not health-related	31	14.1

Health information and advice was provided on:

- *the ailment itself*. For example, Patellofemoral Pain Syndrome, Trigger finger, Tietze Syndrome, "Zurich virus";
- *the cause of the ailment*. For example, the cause of a toe contusion, the cause of Thrombocytosis;
- *the consequences of the ailment* e.g., of Paratyphoid fever, Pfeiffer's disease;
- *the heredity of the ailment*. For example, the heredity of breast cancer;
- *self-care options*. For example, for fatigue, high cholesterol;
- *treatment options*. For example, for snoring, excessive smoking, alcohol problems, excessive growth of hair, sleeping problems, weight problems, premature ejaculation, fungal infection of nails, anus pain, scabies, piles, cysts, retractile testis, ADHD, rheumatic disease, Dupuytren's contracture.

In about 20% of the cases (42/222) no information or advice could be given because lack of adequate information to safely do so. In these cases clients were advised to contact their regular physician (answer 3). Most "answer-3" requests were about physical complaints and symptoms without a prior diagnosis given, for example: *"Lately, I've got itch during the night over my whole body and I am also thirsty. What could this be? Do I need to see my GP?"* In one of these cases the advice to contact the doctor was urgent: *"You are advised to see your regular physician today"*.

Four e-mail requests contained health symptoms that were difficult to evaluate on their seriousness. These requests were judged by a GP on the necessity to see a GP. The results are presented in Figure 2. None of the cases were suitable for e-consultation. These results indicate that clients are really in need for decision support on whether a visit to a regular physician is necessary.

Request 1:

"Recently, I've been using this medication X and I feel really tired and absent-minded because of the medication. The other day, I had a blood test which showed that I've got anemia. It also showed that my liver enzymes are not right. Here is my question: could it be that the medication X is causing this? I stopped using the medication, because I was frightened of the results of the blood test".

The urgency of this health request is unsure. It depends on the degree of anemia and the abnormality of the liver values. Probably, the client already had phone contact with his or her regular physician (to hear the test results). This question has therefore more the character of a second opinion. Advice to call the regular physician today is appropriate in this case.

Request 2:

"I woke up and calmly got out of bed. I fell down in the living room and for the rest I don't know anything about it. I've got a constant pain in my chest and heart. What could this be?"

Could be innocent, but urgency nevertheless high because of insufficient information to prove the opposite. Also the client's age is unknown.

Request 3:

"For weeks I have been dizzy and I have got a headache. Sometimes the dizziness so terrible that I have to go home from work. Everything around me seems to stir. What could this be?"

The request is not urgent, because the health problem is there for several weeks. Nevertheless, the request is not appropriate for e-mail. Client should see doctor for physical exam.

Request 4:

"I found my son of three and a half years old this morning weak and absent-minded in his bed. He reacted very slowly; hardly talked and very softly. He had trouble focusing his eyes. His temperature was 33.6 degrees Celsius (ear thermometer). After giving him dextrose, porridge and lemonade he returned to his normal self after 45 minutes. About one year ago he had the same. Apart from that, he is a healthy boy. I was thinking that this might be caused by a low blood sugar level. Do we have to visit the GP?"

Given the quick recovery the health problem is now not very urgent anymore. Nevertheless, a regular visit to the GP is advised for this problem.

Figure 2 - Assessment of urgency of complaints

Discussion and Conclusion

In this study we evaluated the use of an "ask-the-expert" e-consultation service for advice on health-related requests. We assessed whether the service was efficient and useful for providing health support. This study presented the preliminary results of a content analysis of 222 e-mail messages sent between clients and nurses.

Our results showed that the e-consultation service functioned efficiently; most (94%, 209/222) requests were handled within 24 hours. The service was also a useful means for providing advice on a broad range of health-related requests. The majority (69%, 153/247) of the e-mail messages sent by clients concerned requests about physical symptoms, complaints or diseases and could simply be fulfilled by providing general health advice (68%, 149/222) with the use of standard answer protocols. Another part of the e-mail messages (19%, 42/222) concerned specific personal health requests e.g., *"I have these complaints, what is wrong with me?"*. However, this kind of personal advice on specific physical symptoms could not be provided adequately because of lack of sufficient or reliable information.

We also found that the service was used for decision support on assessing the necessity to visit a doctor (21.5%, 53/247). We believe that web-based triage systems can be a useful addition to the service to assess whether certain health complaints need to be investigated by a regular physician. Triage is the process of assessing an individual's health problem and identifying the level of need for clinical care [17]. We think that adding systems for triage of health complaints could increase both the use and usefulness of the service because it facilitates the gatekeepers' function [18].

This paper presented the first results of a broader research on the use of an "ask-the-expert" e-consultation service for support on health-related requests. Notwithstanding the small number of email requests analyzed which limits the external validity of the study, we believe that our study results contributed to the findings of prior studies on the use of e-consultation in primary care [6,16,13]. Our findings showed that clients made proper use of the e-consultation service by sending e-mails for non-urgent health-related requests on minor ailments. Nurses handled e-mail requests according to the principles for giving Type A (absence of a pre-existing patient-provider relationship) advice on the Internet [6]; no specific diagnoses were given, no medicines were prescribed and no general information was given in the guise of individualized information.

Currently, further research is being performed; a content analysis of the e-mail requests handled by other online health professionals such as a GP, dentist, psychologist, etc. A survey is carried out to assess more detailed user characteristics (demographic and health-related) to get a more thorough understanding of the reasons for use of the service, to determine the level of client satisfaction with the service and to assess the impact of the service on visits to the general practice.

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Analyzing effects of providing performance feedback at ward rounds on guideline adherence – The importance of feedback usage analysis and statistical control charts

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Abstract

Objective: Feedback to clinicians on their past performance is often aimed at increasing adherence to guidelines. We investigate how various analytical approaches influence the interpretation of adherence data. The analytical approaches vary in considering the actual or the intended use of the feedback, and whether outcomes are inspected over time. Material and Methods: At base line, a computerized decision support system was employed at the ICU bedside to increase adherence to a mechanical ventilation strategy. We intervened by providing feedback about adherence to the guideline at the daily ward rounds. The outcome measure was the percentage of ventilation time (V_T) in excess of the guideline's recommendation. Actual usage of the feedback was logged and data analysis was carried out using two approaches: classical statistics, and statistical process control (SPC) that inspect progress of an outcome over time. Design: Prospective, before/after study.
Results: The classical analysis stated that the percentage of ventilation time in excess of the guideline's recommendation decreased significantly due to the feedback (5% reduction, $p<0.001$). When SPC analysis of the outcome was applied, the effect was deemed not significant. When the actual delivery of feedback over time was also included it showed that the experiment does not allow for conclusive results. Conclusions: The concluded effect of providing feedback on adherence to a guideline depends on whether the actual usage pattern of the feedback and the inspection of the outcome over time are considered. Future evaluative studies should report on usage patterns and progression of outcomes over time.

Keywords:

Computerized Decision Support Systems, Provision of performance feedback, Adherence to Guidelines, Evaluative studies, Usage patterns, Statistical Process Control, Mechanical Ventilation, Ward rounds.

Introduction

Mechanical ventilation (MV) is one of the most important life supporting facilities in intensive care units (ICUs) [1]. Several complications, however, have been associated with the use of MV and various guidelines are used to limit the tidal volumes (V_T) applied to patients [2-4]. Such guidelines rely mainly on the predicted body weight (PBW) of the patient, which relies on the patient's height and gender.

Receiving too large V_T, however, is still the norm rather than the exception [5]. Explanations for this include the use of actual bodyweight instead of PBW, reluctance to accept potential hypercarbia and/or perceived increased sedation needs, and lack of knowledge [6-9]. In addition, it can be hypothesized that implementation of lower V_T is hampered by the fact that at times large V_Ts are simply left unrecognized.

Like in other settings, a clinical computerized decision support system (CDSS) can potentially contribute to increasing adherence to this guideline. We have hence implemented a CDSS at the bedside to alert physicians when the patient had a higher V_T than the guideline prescribes. In this paper we consider, aside from the bedside decision support, the effects of adding feedback on adherence at ward rounds, as they form a notable hospital context in which staff members work as a group [10]. In the sequel we refer to this ward round feedback as the "intervention", which itself can also be considered a form of decision support but provided in a new context. The objective of this paper is to contrast the results of three ways to analyze the data on he intervention: (A1) Using the traditional statistical approach, which is very common in the literature, (A2) applying the time-oriented approach of statistical process control (SPC), and (A3) Adding to A2 the patterns on actual usage of the feedback during the intervention period.

Materials and Methods

Study design

We performed a prospective before-after evaluation study on applied V_Ts to examine the impact of providing feedback at ward rounds on adherence (the intervention) to our local MV–protocol. The experiment was conducted during 2 consecutive phases in a 30–bed mixed medical–surgical ICU of a university hospital in the Netherlands.

Patient Data Management System

Since 2002, our ICU uses a commercial Patient Data Management System (PDMS, Metavision, iMDsoft, Sassenheim, The Netherlands). The PDMS is a point–of–care clinical information system, which runs on a Microsoft Windows platform and includes computerized order entry, automatic data collection, clinical documentation, electronic medication administration record, and a data storage repository. Mechanical ventilators are connected to the PDMS and all respiratory parameters are recorded every minute in the PDMS–database. Clinicians can see all fields related to artificial respiration, including applied V_Ts, by clicking on "respiratory tabs" in the PDMS.

Mechanical ventilation

The vast majority of patients are orotracheally intubated or do have a tracheotomy for MV; non–invasive MV is seldom applied. A written MV–protocol is available for all ICU–members, both on the intranet, and in printed form. In short, this protocol advises pressure–controlled (PC)–MV or pressure support (PS)–MV in all patients. There is a clear recommendation on V_T settings, stating that V_Ts have to be as low as 6 ml/kg PBW in all patients, irrespective of the presence of acute lung injury. With pressure–controlled (PC)–MV or pressure-support (PS)–MV, V_Ts are influenced by the applied airway pressures as well as the compliance of the patient's respiratory system. As compliance may change over time, healthcare workers need to continuously adjust the inspiratory pressure [11].

Recommended tidal volume

To calculate the recommended V_T (ml), the PBW (kg) is multiplied by 6. PBW was calculated by the following formula: in men, PBW = 50 + 0.91 * (height in centimeters – 152.4); in women, PBW = 45.5 + 0.91 * (height in centimeters – 152.4).

Ward round

The ward-round team consists of all ICU physicians and residents with possible additional specialists from other hospital wards like microbiologists or surgeons. The ward-round team has a meeting everyday to review patient progress. The PDMS is used to represent the patient conditions, complications and treatment plans. Patients are selected one by one and the related data are displayed by a beamer. The ward-round team discusses and reviews the patient charts, and decides upon the patients' treatment plan.

Intervention

At baseline, before the intervention, when an ICU–physician or ICU–nurse selected the "respiratory page" in the PDMS, the recorded V_T, maximum pressure (Pmax) and PEEP during the previous 60 minutes were queried. The system calculated the percentage of time that V_T was above the guideline recommended V_T. If the pressure support level was at its minimal value, the V_T was rendered "in range V_T". If V_T was above the guideline recommended V_T for more than 25% (15 minutes) of the previous 60 minutes, a pop–up window was shown displaying the guideline, patient's height, gender, PBW, as well as the percentage of time in which V_T was above 6 ml/kg PBW. In order not to disturb the users and to give them time to correct V_T, V_Ts were again queried and checked after at least two hours. The duration of this phase was almost 16 weeks.

In the intervention phase, in addition to showing the CDSS messages at the bedside, the daily ward round was used to display a list of the patients showing per patient the percentage of time in which V_T was above 6 ml/kg PBW. Patients with percentages below 25% were marked in green, percentages between 25-75% in yellow and above 75% in red. The duration of the intervention was also almost 16 weeks.

Usage of feedback

Although the feedback intervention was intended to be provided daily at the ward round, we logged its actual use: whenever the system displayed feedback at the ward round a record was created in the system to indicate this fact.

Outcome measures

The first outcome measure was the percentage of ventilation time in which the V_T was > 6 ml/kg PBW [4]. Mean V_T in excess of 6 ml/kg PBW over time was also measured. We considered all V_T measurements < 6 ml/kg PBW as if they were 6 ml/kg PBW. The third outcome was frequency of V_T measurements ≤ 6 ml/kg PBW. The unit of analysis is the V_T observation (not the patient).

Patients

This study included all ICU–patients who were mechanically ventilated for more than 24 hours in the ICU [5], were not on Adaptive Support Ventilation (which does not allow changes of V_T–settings by healthcare workers) and did not participate in other respiratory trials in which V_T was manipulated. V_Ts < 150 ml or >1500 ml were excluded as these were most likely measurement errors. When pressure support was at the lowest level, the measurement was considered correct (i.e., not in excess of 6 ml/kg PBW) regardless of its value.

Subgroups

We split up the whole ventilation time into spontaneous mode (pressure support ventilation [PSV]) and non–spontaneous mode (pressure control ventilation [PCV]).

Traditional statistical approach

Categorical variables in the before and after intervention groups were compared by X^2 testing, and continuous variables were compared by Student's *t* test or Mann-Whitney testing as appropriate. A *p*–value<0.05 was considered significant.

Statistical Process Control (SPC)

SPC and its primary tool – the control chart - is a branch of statistics that combines rigorous time series analysis methods with graphical data presentation, often yielding insights into the data more quickly and in a more understandable way than other statistical techniques [12-14]. Control charts can distinguish between common and special cause of variation. With common cause variation (noise), the variation is inherent in the process itself and the process is stable and predictable within certain limits. Special cause variation signifies that the

process is no longer stable or predictable and has changed (for better or worse). A control chart includes a plot of the data over time with three additional lines – the center line (usually the mean) and an upper and lower control limits, typically set at ±3 standard deviations (SD) from the mean. When the data points are, without any special pattern, within the control limits then the process is "in control" and stable. There are several rules that indicate when a special cause variation or special pattern has occurred on a control chart. We used the following four common rules [14]: one or more points above or below the control limit; a run of seven or more points on one side of the center line; two out of three consecutive points appearing beyond 2 SD on the same side of the center line; a run of seven or more points all trending up or down.

For analysis we used the X–MR chart (and not the attribute chart) due to the large size of observations per time point and the increased chance of false positive results [14-16]. Our chosen quality indicators (for guideline adherence) were calculated per two weeks, in order to allow for an adequate number of points, and plotted as points on the X–MR chart.

Results

Patients

During the study period 3,434,268 V_T–records (2,243,862 in the pre-intervention period vs. 1,190,406 in the intervention period) of 352 ventilated patients (202 vs. 150) were analyzed. Patient characteristics (age, height, severity of illness etc) before and after the intervention were similar.

Usage

In the first 5 weeks after the intervention the patients' list with the percentage of time in which V_T was above 6 ml/kg PBW was shown (35 times). After the fifth week, the CDSS was triggered only 1-2 times per week in the ward round (10 times in weeks 5-10, and 8 times in weeks 10-16 weeks).

Tidal volumes

Table 1 shows the outcome measures before and after the intervention. Using the traditional statistical approach the percentage of ventilation time with V_T in excess of 6 ml/kg PBW was shown to decrease significantly after intervening (5% reduction, $p < 0.001$). The average volume in excess of 6 ml/kg PBW remained the same after intervention.

Figure 1 shows the distribution of V_T (ml/kg PBW) by 0.25 ml/kg PBW in the two phases. The decrease in the percentage of time with $V_T \leq 6$ ml/kg PBW seems to come at the expense of the percentage of time with V_T between 6-8 ml/kg PBW, which decreased after the intervention.

Table 1 - Outcome measures reported for patients with >24 hours MV.

Mode	Intervention	Before	After	*p*
All	Mean of excessive V_T^{Φ}	1.3±1.7	1.3±1.7	ns**
	% of time > 6ml/kg PBW#	54	51	<.001*
Spontaneous (PSV)	Mean of excessive V_T	1.5±1.8	1.5±1.8	ns
	% of time > 6ml/kg PBW	58	54	<.001
Non-spontaneous (PCV)	Mean of excessive V_T	0.8±1.1	0.8±1.2	ns
	% of time > 6ml/kg PBW	43.5	44	ns

*chi square, **Student's *t* test, $^{\Phi}$Excessive V_T is tidal volume in excess of 6 ml/kg PBW over the whole phase. #To calculate this percentage we tolerated a discrepancy of 10% above the protocol's suggestion (i.e. 6.6 ml/kg PBW) before considering a measurement as being in excess of 6 ml/kg PB

Tidal volumes in (non)spontaneous ventilation mode

Table 1 also shows the outcome measures separately for spontaneous and non-spontaneous ventilation time. Surprisingly the overall effect of the intervention on spontaneous ventilation mode was larger than in the non-spontaneous mode. Results indicate that showing the patients' V_T information in the ward round did not change the percentage of ventilation time in excess of 6 ml/kg PBW during the non-spontaneous ventilation time. On the other hand, during the spontaneous ventilation time, the percentage of ventilation time with V_T in excess of 6 ml/kg PBW decreased after intervention (7% reduction, $p < 0.001$).

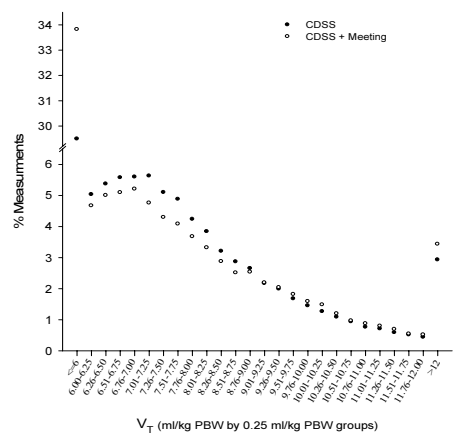

Figure 1 - V_T distribution (PSV mode).

Results based on statistical process control

Figure 2 shows control charts of the main outcome measures, also separately for spontaneous and non-spontaneous ventilation. In contrast to the traditional statistical methods, the control chart showed that the process did not change significantly after the intervention. Also in contrast to classical tests, the reduction pattern after intervention was only shown in the non-spontaneous mode.

Incorporating data on feedback usage

The control charts showed that the percentage of ventilation time with V_T in excess of 6 PBW did decrease steadily during the first 5 weeks but again increased and eventually became stable (The letter "A" in Figure 2 indicates the subgroup of measurements collected in week 5 and week 6). Our data on actual usage of feedback revealed that in these first 5 weeks the feedback delivery was provided daily, as intended. The increase afterwards in the outcome (indicating decrease in adherence to the guideline) is paralleled by the diminished use of feedback during the intervention.

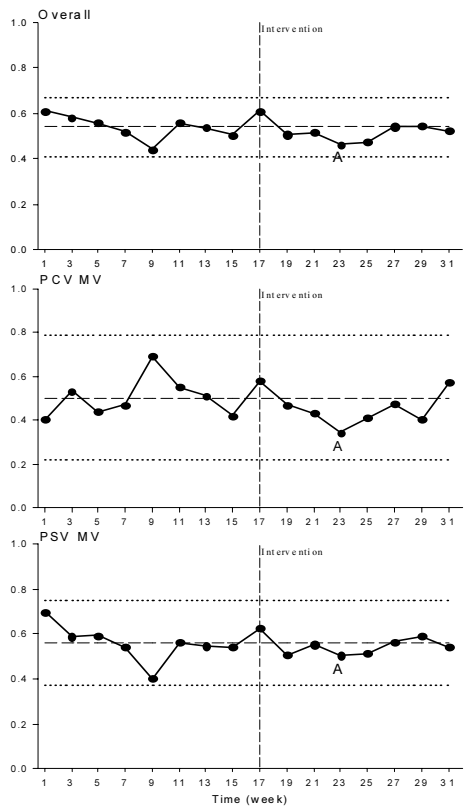

Figure - 2 Control charts of percentage of time > 6ml/kg PBW (overall, during spontaneous (PSV) and non-spontaneous (PCV) mechanical ventilation)

Discussion and Conclusion

Interpreting data pertaining to the effects of providing feedback concerning the performance of clinicians on adherence to a guideline provided three different pictures. In the traditional approach one would have concluded that the effect of our intervention was significant. If one takes into account the progression in the outcome measure over time but disregards the patterns of actual feedback delivery (and hence use) then the conclusion is that the intervention was not effective. If one in addition considers the usage pattern of the feedback then a nuanced picture emerges: as long as the feedback was provided daily, as planned, a decreasing pattern in the main outcome was observable. Once the frequency of feedback delivery has dropped the outcome started increasing again.

To understand the results it is important to point out the ambiguity of the term "intervention". There is the intended intervention (providing feedback daily) and the actual intervention (as was actually provided). Based on our experiments, it would seem too hasty to conclude that there is sufficient evidence (in terms of statistical significance) that our 16 weeks *actual intervention* was effective. An inspection of the SPC charts reveals why it arrived at a different conclusion than classical statistical tests: an apparent initial increase is counterbalanced by an increase in the sequel. Being sensitive to temporal progression, SPC is reluctant to declare statistical significance of this actual intervention (with reduced intensity of the feedback over the weeks). We believe that the SPC's prudent interpretation should prevail. By the same token concluding that the *intended intervention* is not effective is also unfounded. This is because this intended intervention was not implemented. The correct interpretation of the results is that the *intended intervention* does not enjoy enough quantitative support yet (as the usage pattern shows it was not implemented). However, inspecting the patterns of decrease in the first 5 weeks and "bouncing back" afterwards does provide qualitative evidence to the possible effectiveness of this intervention, which should be more properly implemented.

The same logic applies to subgroup analysis. While the control charts showed that the percentage of time > 6ml/kg PBW in the spontaneous mode was stable after the intervention, the traditional approach declared statistical significance.

There are two lessons (serendipitously) learned from our case-study for medical informaticians evaluating effects of IT interventions, such as decision support, on some (quality) indicator. First, measuring the progression over time of an indicator may suggest a different (and better) interpretation of the results than when time is not taken into account. The advantages of this interrupted time-series design is described in [17]. Second, measuring actual usage of an intervention may influence the interpretation of the results. These lessons are important because most of the medical informatics literature reports on results using the traditional approach. The few studies that did apply SPC analysis usually do not consider the possible difference between intended and actual use of the intervention.

Our results stress the importance of reporting or at least reflecting on the possible influence of a time-oriented approach and the CDSS usage on the results. After all, our study could have been reported in three incompatible ways.

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Processing Gradual Information with Fuzzy Arden Syntax

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Abstract

The programming language Arden Syntax is especially adapted to the needs of computer-based clinical decision support. Recently, an extension of Arden Syntax, named Fuzzy Arden Syntax, was proposed by the authors. Fuzzy Arden Syntax is a conservative extension of Arden Syntax and offers special functionality to process gradual information. The background is the observation that in medicine we frequently deal with statements which are neither clearly false nor clearly true but hold to some intermediate degree. In this paper, we demonstrate under which circumstances a Medical Logic Module (a program unit written in Arden Syntax) may show unintended behavior and how the situation can easily be improved by means of the possibilities offered by Fuzzy Arden Syntax. To this end, an example from the domain of nosocomial infection control is discussed in detail.

Keywords:

Clinical Decision Support Systems, Arden syntax, Fuzzy logic, Nosocomial infections.

Introduction

An important aim in medical information sciences is to define standards to represent clinical data in a computer-interpretable form. This task concerns various levels of abstraction and is generally difficult. We may mention, for example, current efforts to establish standards for the structure of an electronic health record, to establish medical terminologies on a symbolic level, or to define computer-interpretable medical procedures.

In healthcare, an issue which becomes the more relevant the more data is available electronically is the automated and intelligent interpretation of facts concerning a patient's course of disease, like symptoms, signs, diagnoses, and treatment. On the lowest technical level, this purpose is supported by a programming language in which general clinical knowledge can be formulated as directly as possible, minimizing the need for the user to get familiar with technical peculiarities.

Arden Syntax

In this latter field, the developers of Arden Syntax have contributed in a specific but valuable way [1]. The programming language Arden Syntax is endowed with an (institution-dependent) interface to a patient database, can be applied to encode methods to interpret the data, and can be used to trigger appropriate reactions in real time. Its syntax has been chosen to make the program flow easily traceable. Arden Syntax was originally developed by the American Society for Testing and Materials in 1992 and is at present maintained by Health Level Seven, Inc. (HL7). The document containing the official specification [1] can be acquired from HL7; (see www.hl7.org.)

Arden Syntax has been developed as a standard of representing general clinical knowledge. This knowledge needs to be present in modular form; an Arden Syntax system is composed of an unstructured set of so-called Medical Logic Modules, or MLMs for short. Each MLM can be designed to react in real time to some specified event, like for instance a certain change in the patient database, in which case a message to the host system is sent or other reactions are induced.

Fuzzy Arden Syntax

The content of an Arden Syntax MLM can be the result of a formalization of information provided in natural language. When mapping information contained in a text to a computer program, even if this text is meant as a precise specification of facts or procedures, we typically encounter the problem that the level of precision is not sufficient to allow the formulation of the program in a unique way. Often then, the original specification needs to be extended in an ad-hoc way. To give a simple example of what we mean, for a clinician it might not be a problem to interpret statements like "the level of aspartate transaminase (AST) is significantly increased" if the normal range of AST is known; in a computer program however sharp limits must be provided.

Conversely, if precise specifications are provided it might sometimes not be desirable to follow them in a purely mechanical way. For example, consider the condition "body temperature $\geq$ 38.0 °C". If the actual body temperature of a patient is, say, 37.9 °C, a clinician might hesitate to simply consider the condition as not fulfilled or might at least argue differently than in the situation when the temperature is 36.9 °C.

If sharp limit points are not specified or even unknown, some extra effort will be needed to deal with this situation in automated decision support. Furthermore, if sharp limit points are

chosen, borderline cases will in general not be apparent in the output: a condition "temperature ≥ 38.0 °C" will be evaluated negative if the communicated temperature is lower than 38 °C, and positive if it is 38 °C or higher, and information about changes of the result under small changes of the input would again require extra effort. It is the idea of Fuzzy Arden Syntax to include into Arden Syntax additional functionality to make the definition of "soft" limit points possible and furthermore to avoid discontinuities in the results.

Fuzzy Arden Syntax was originally proposed by S. Tiffe [2]. It has recently been further elaborated by the authors; we refer to [3] for a complete specification. The new features have been summarized in [4]. The present note shows the effects of these features on the basis of a specific example.

A case study: nosocomial infection control

We will exhibit some features concerning behavior and performance of Arden Syntax with or without the extension provided by Fuzzy Arden Syntax. To this end, we shall consider a typical example of computer-based clinical decision support.

Computer-supported detection of nosocomial infections

For the surveillance of nosocomial infections in ICUs, standards have been defined [5–7]. If the relevant data is available electronically, the possibility exists to have suspicious cases detected automatically. For instance, at the Vienna General Hospital, a system with exactly this purpose has been developed [8]. It is named Moni/Surveillance-ICU and based on HELICS [5] as well as KISS [6, 7] criteria for nosocomial infections.

The following conditions must be fulfilled:

- It is not the case that the patient has fever (≥ 38.0 °C), or urinary urgency, or frequency, or dysuria, or suprapubic tenderness.
- The patient has had
  1. either a positive urine culture ($\geq 10^5$ microorganisms/cm^3 of ≤ 2 species) and an indwelling urinary catheter within 7 days before the culture
  2. or two positive urine cultures (the ≤ 2 species being the same) and no indwelling urinary catheter within 7 days before the culture

Figure 1 - Definition of asymptomatic bacteriuria (UTI-C)

We shall consider the following example which is a specification of a nosocomial infection according to [5] (coded UTI-C there). This criterion is part of the Moni system as well. We note that we have slightly changed the formulation of [5].

As we will see, the implementation of this rule in Arden Syntax is straightforward. Arden Syntax programs are to a certain extent self-explanatory; for this reason also the reader not familiar with Arden Syntax should be able to follow our argumentation. To be sure, we will however include some basic explanations.

An MLM has a predefined structure. The first two parts are the *maintenance category* and the *library category*, which are not important here. Only the third part, the *knowledge category*, contains the executable program. The latter consists in turn of several so-called *slots*. In particular, the *data slot* contains the commands to read the relevant data from the host and possibly additional commands to preprocess this data; in the *logic slot* the decision is made if the *action slot* is executed. A jump to the action slot is caused by the command `conclude true`, whereas `conclude false` terminates execution.

The relevant slots of the knowledge category of an MLM modeling the criterion for asymptomatic bacteriuria could look as follows.

```
data:
   (Patient, Date) := argument;
     /* Input data: patient ID and date of stay */
   Temperature :=
     read {body_temperature,
           Patient, Date};
     /* Body temperature */
   Fever := Temperature >= 38;
   Urgency :=
     read {urinary_urgency, Patient, Date};
     /* Urge to urinate? */
   Micturition :=
     read {micturition, Patient, Date};
     /* Increased frequency of urination? */
   Dysuria :=
     read {dysuria, Patient, Date};
     /* Painful urination? */
   Suprapubic_tenderness :=
     read {suprap_tenderness, Patient, Date};
     /* Suprapubic tenderness? */
   Organisms_in_1_urine_culture :=
     read {organ_1_urcult, Patient, Date};
     /* Number of microorganisms of ≤ 2 species per
     mm^3 */
   One_urine_culture :=
     Organ_in_1_urine_culture >= 1e5;
   if One_urine_culture
     then Urine_culture_time :=
       time of One_urine_culture;
     endif;
   Organisms_in_2_urine_cultures :=
     read {organ_2_urcult, Patient, Date};
     /* Number of microorganisms of ≤ 2 species per
     mm^3 in the last two cultures */
   Two_urine_cultures :=
     Organisms_in_2_urine_cultures >= 1e5;
   if Two_urine_cultures
     then Urine_culture_time :=
       time of One_urine_culture;
     endif;
   Catheter :=
     read {catheter, Patient, Date};
     /* Latest indwelling urinary catheter */
   ;;

logic:
```

```
   if (Fever OR Urgency OR Micturition OR Dy-
       suria OR Suprapubic_tenderness)
     then conclude false;
     endif;
   if (Catheter is present
       AND time of Catheter is at least 7 days
       before Urine_culture_time)
     then if One_urine_culture
       then conclude true; endif;
     else if Two_urine_cultures
       then conclude true; endif;
     endif;
   ;;
action:
   write "The conditions of an
       asymptomatic bacteriuria are met.";
   ;;
```

Behavior in borderline cases

We may say that this MLM reflects the specification UTI-C of asymptomatic bacteriuria one-to-one. However, we may wonder if this is what we want. As a matter of fact, it is easy to construct a case where a clinician familiar with the facts expressed by UTI-C is likely to conclude differently from the MLM. We have in mind the borderline cases; consider the following situations:

- A patient had three positive urine cultures with the same single species and an indwelling urinary catheter until one day before the first positive culture; he has no urgency, frequency, dysuria, or suprapubic tenderness and a temperature of 38.0 °C.
- A patient had a positive urine culture and a urinary catheter until seven and a half days before the culture; he has no fever, urgency, frequency, dysuria, or suprapubic tenderness.
- In the urine culture of a patient $9 \cdot 10^4$ microorganisms/cm^3 were found, the patient had two days earlier an indwelling urinary catheter, and otherwise no fever, urgency, frequency, dysuria, or suprapubic tenderness.

It would be easy to continue this list of cases, which have all in common that an automated detection of an infection fails. However, a clinician will most likely judge in all three cases that the criterion does apply, at least to a certain extent, even if criterion UTI-C is the only source of information.

Fuzzification of formalized clinical criteria

In computer-assisted decision support, one might certainly opt to have information provided only in the clear cases. After all, nobody would expect that no information about a possible disease means that the disease is not present. On the other hand, there are easy means to make the inference of a program like the above MLM more flexible so as to get results also in those cases which are not entirely conclusive on the basis of some given formal rules. Of course then it is essential to exhibit in the output explicitly that the result has restricted value.

These considerations have led to the development of Fuzzy Arden Syntax. Note first that under Fuzzy Arden Syntax, the above MLM would run without change of effect. That is, the same input would lead to the same output. This is why we call the extension "conservative".

However, Fuzzy Arden Syntax offers convenient possibilities to process not fully determinate truth values and to extend the inference coded in a given MLM to borderline cases. In medicine, the situation frequently occurs that facts about a patient do not fit perfectly to the available notions. Indeed, expressions like "having pain" or "being elevated" involve vagueness in the sense that they possess borderline cases in which it is hard or impossible, in any case unreasonable, to tell if they apply or do not.

As the starting point, we borrow from fuzzy logic [9] the simple idea to extend the two-element set of classical truth values to a continuous set of truth values. In classical propositional logic, we use 0 to denote falsity, 1 to denote truth; in fuzzy logic we use in addition any real value between 0 and 1 to express tendencies.

Examples of vague notions are immediate from the criterion UTI-C. Urinary urgency, frequency, dysuria, suprapubic tenderness may in most cases clearly hold or not hold, but there can be unclear situations as well.

The values allowed for yes-no variables in Fuzzy Arden Syntax certainly include the clear "true" or "false" just like in Arden Syntax. In addition, however, also values like 0.8 meaning, say, "rather true" are possible. We note that if continuous values are used for yes-no statements in the input, no changes in the MLM are necessary.

If intermediate truth values are used, it must however be determined in which way the connectives "and", "or", and "not" are to be interpreted. By default, if the variable `Var_1` contains the value $v_1 \in [0, 1]$ and the variable `Var_2` contains the value $v_2 \in [0, 1]$, then

```
Var_1 AND Var_2, Var_1 OR Var_2,
NOT Var_1
```

will be evaluated as $\min\{ v_1 , v_2 \}$, $\max\{ v_1 , v_2 \}$, and $1 - v_1$, respectively. Other interpretations, in particular other t-norms [10] interpreting `AND` are possible.

Let us next describe the method to avoid sharp limit points. Namely, we may replace sharp values by "soft" ones in a straightforward way. Our above-given example can be modified as follows:

```
data:
   [...]
   Fever :=
     Temperature >= 38 fuzzified by 0.5;
   [...]
   One_urine_culture :=
     Organisms_in_1_urine_culture >=
       1e5 fuzzified by 5e4;
   [...]
   Two_urine_cultures :=
     Organisms_in_2_urine_cultures >=
       1e5 fuzzified by 5e4;
```

```
   [...]
   ;;

logic:
   if (Fever OR Urgency OR Micturition OR Dy-
       suria OR Suprapubic_tenderness)
     then conclude false;
     endif;
   if (Catheter is present AND time of Cathe-
       ter is at least 7 days fuzzified by 2
       days before Urine_culture_time)
     then if One_urine_culture
       then conclude true; endif;
     else if Two_urine_cultures
       then conclude true; endif;
     endif;
   ;;
```

As to be expected, the expression `fuzzified by` is used to create some tolerance around a sharp real value. Formally, the expression

```
38 fuzzified by 0.5
```

is a triangular fuzzy set, namely the following one:

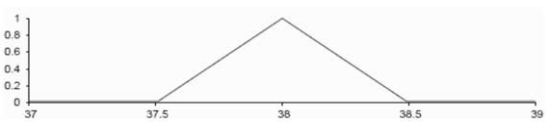

Figure 2- Example of a triangular fuzzy set

We recall that a fuzzy set is a mapping u from some universe of discourse M to the real unit interval [0, 1]. u typically models a natural-language concept, and for any $T \in [36, 42]$, the value $u(T)$ is then the degree to which T is in accordance with the concept modeled by u. The universe is typically R, the reals, and in Fuzzy Arden Syntax, we may use any fuzzy set over R provided it is piecewise linear, at each point left- or right-continuous, and constant outside a finite interval.

A fuzzy set like the displayed one can be used for a comparison: typically, a number like `Temperature`, which in our context is also called a *crisp number*, is compared with a fuzzy set, also called a *fuzzy number*. The expression

```
Fever:= Temperature >= 38 fuzzified by 0.5
```

no longer returns necessarily one of the sharp truth values `true` or `false`. The displayed case rather works as follows; let T be the value in `Temperature`. If $T \geq 38$, then the result is 1, or `true`, in accordance with the original MLM. If T is just slightly smaller than 38, the resulting value will still be close to 1 and in particular not reflect falsity; in the sequel the same consequences will be drawn, but with reduced weight. Falsity is the calculated outcome only if $T \leq 37.5$. This follows from our choice to fuzzify by 0.5. We conclude that `Fever` is no longer a two-valued, but a many-valued concept, with the effect that jumps from one extreme to the other are avoided.

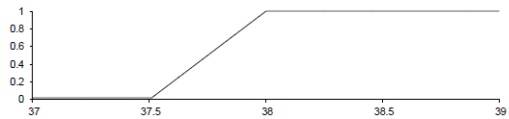

Figure 3 – Fuzzy logic and temperature

We see in particular that the specification of the conditions under which `Fever` applies requires more than determining one delimiting value. It is rather required to determine when this concept clearly applies and when this concept clearly does not apply. Accordingly the width of the transitional region must be set.

The same can be said mutatis mutandis for the variables `One_urine_culture` and `Two_urine_cultures` in our example.

The next question is what happens when an if-then-else construct depends on a many-valued condition. In Fuzzy Arden Syntax, the program splits. If the condition is evaluated to t such that $0 < t < 1$, the "if" block and the "elseif" block are executed in parallel. To any point in the program, there is associated a *program weight*; prior to the execution of the two branches this weight is multiplied by t or $1-t$, respectively.

Test case

We shall next illustrate the effect of this concept. To this end, we shall check the behavior of the above Fuzzy Arden MLM with some specific values, and we will see if the result is in accordance with the conclusions which we would draw intuitively.

Consider the following scenario. The patient does not suffer from urgency, micturition, dysuria, or suprapubic tenderness, and has a temperature of 37.6 °C; a catheter is reported to have been removed eight days before the first urine culture; he has two clearly positive urine cultures where however the number of microorganisms of coinciding species is only $6 \cdot 10^4$.

Let us guess how a clinician would judge this situation in view of the criterion UTI-C. The condition of UTI-C about the absence of symptoms is practically fully fulfilled; the height of the body temperature is not significant. Furthermore, the catheter was removed eight days, so roughly one week, before the first positive culture. Finally, there is some evidence of a second positive culture. All in all, the picture is presumably not entirely clear but rather well compatible with the conditions of UTI-C. In any case, the decision seems natural that the situation should be further examined.

Let us now compare these informal considerations with the result provided by the Fuzzy Arden MLM. We shall trace, step by step, the execution of the logic slot.

The expression

```
Fever OR Urgency OR Micturition OR
Dysuria OR Suprapubic_tenderness
```

returns, if `OR` is interpreted according to default, the largest of the values of the conjuncts. We have that `Fever` is 0.2 and `Urgency`, `Micturition`, `Dysuria`, and `Suprapubic_tenderness` are all 0; thus the result is 0.2.

The program splits; however, the line `conclude false`, to be executed with weight 0.2, terminates the MLM. So the remaining part of the program is continued with weight 1− 0.2= 0.8.

Next, we have that the expression

```
Catheter is present AND time of Catheter is at
least 7 days fuzzified by 2 days
```

is evaluated 0.5. Consequently, the program splits again; the `if` block and the `else` block are executed in parallel, both with weight $0.8 \cdot 0.5 = 0.4$. In the first branch, the program executes `conclude true` under the condition `One_urine_culture`. As this variable contains the value true, i.e., 1, the action slot is executed with weight $0.4 \cdot 1 = 0.4$. In the second branch, the program executes `conclude true` under the condition `Two_urine_cultures`. This variable contains the value 0.2 and the action slot is executed as well, but in this case with weight $0.4 \cdot 0.2 = 0.08$.

The action slot sends to the host the message that asymptomatic bacteriuria is present. This message will be endowed with a value expressing the fact that the program weight is decreased. In our case, the host will get independently twice the same message, once with weight 0.4 and once with weight 0.08; it could add up the two values 0.4 + 0.08 = 0.48. So as the final result, we are provided a message together with a truth value of only 0.48.

The value 0.48 implies that the message is to be understood with great caution. We conclude that the message is weaker than the informally drawn conclusion. But in accordance with our informal considerations it is clearly suggested that the situation needs to be examined.

We may finally observe that the corresponding Arden Syntax MLM would not report anything. We furthermore note that the modified MLM encoding UTI-C is not essentially longer or more complicated than the original one.

Conclusion

Clinical decision support systems depend on clear specifications: criteria must be provided which do not leave room for interpretation. This is the nature of a computer program as opposed to the way a human reasons who always allows some tolerance in considerations. An extended version of Arden Syntax, named Fuzzy Arden Syntax, aims at reducing the undesirable effects of sharp delimitation of situations.

Fuzzy Arden Syntax is based on the principles of fuzzy logic and uses a continuous set of truth values, namely the real unit interval. We have demonstrated on the basis of an example, a criterion of a nosocomial infection which is in practical use, the benefits of this approach. Answers to yes-no questions, like the presence of a specific symptom, need not be decided if they are actually not well decidable. Furthermore, values separating the normal from the abnormal range of a parameter can be specified in a rough manner. Finally, the changes of an Arden Syntax program to benefit from these possibilities are minimal.

If the concepts of fuzzy logic are fully applied, there are no more any discontinuities in the output. However, since the inference becomes more sophisticated, also the output is possibly more differentiated. Namely, the user might be presented a list of alternatives together with weights. But this is not to be considered as a price to pay; it is just natural in the present context. When an input parameter is in a borderline area, more than one alternative in the output should be expected.

The work on the Fuzzy Arden compiler is in progress; the compiler will be available in the first quarter of 2010. The application of Fuzzy Arden Syntax in the above-mentioned system Moni/Surveillance-ICU is scheduled and extended practical experiences can be expected in the course of 2010.

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Design of a continuous multifaceted guideline-implementation strategy based on computerized decision support

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Abstract

Implementation of clinical practice guidelines into daily care is hindered by a variety of barriers related to professional knowledge, collaboration in teams and organizations, and practicability of the guidelines. Clinical computerized decision support (CCDS) has been shown to be one of the most effective instruments to improve compliance to practice guidelines by tackling barriers related to professional knowledge. To address other barriers, however, additional interventions are needed. In this study, a continuous multifaceted guideline-implementation strategy was developed which is based on CCDS but extends beyond the professional knowledge barrier. Two additional interventions were designed and embedded with CCDS in a continuous quality improvement framework. First, to address barriers within teams and organizations guideline compliance data are periodically aggregated into feedback reports for care providers. Second, barriers related to practicability of the underlying guidelines are addressed in a guideline-maintenance cycle. A case study in the field of cardiac rehabilitation is presented to demonstrate the feasibility of the developed strategy.

Keywords

Practice guidelines as topic, Cardiac rehabilitation, Health care quality, access, and evaluation

Introduction

Application of clinical practice guidelines can improve patient outcomes, reduce practice variation, and reduce costs of healthcare [1;2]. However, care professionals' often do not follow the recommendations of practice guidelines, for a variety of reasons [3]. A main challenge in contemporary healthcare is therefore to increase the implementation of practice guidelines in routine care [4]. Dissemination of practice guidelines on paper alone has generally proved to be insufficient. Instead, a carefully designed strategy for change usually needs to be used for effective implementation of guidelines [5].

Before designing such a strategy it is important to identify the various barriers that professionals face when trying to incorporate practice guidelines into daily care [6]. A frequently used classification of those barriers to guideline implementation is the division into internal and external barriers by Cabana et al [6]. Here, 'internal barriers' relate to the professional's knowledge of and attitude towards the guidelines. For instance, a professional may not know the details of a particular guideline by heart, or may in certain cases disagree with its recommendations. To overcome internal barriers, different implementation strategies exist such as professional educational, outreach visits, clinical computerized decision support (CCDS), and reminders [5]. Of those strategies CCDS is known to be highly effective because it provides relevant knowledge at the time and place clinical decisions are made [7,8].

However, modern medicine is no longer a matter of individual health care professionals but largely practiced as part of a team and embedded within complex organizations. Appropriate knowledge and attitudes of the individual are necessary but not sufficient for compliance to clinical standards. Professionals may also encounter so-called 'external' barriers which hamper their ability to execute guideline recommendations. These barriers stem from environmental factors related to the team, organisation or health system they work in [9]. Finally, glitches and impracticability's in the guidelines in question (e.g., ambiguities, omissions, and contradictions) may impede execution of the guidelines' recommendations [6].

Several studies have shown that for improving the implementation of clinical guidelines it is important to apply a multifaceted intervention with supplementary components [3]. In addition, to ensure that implemented changes persist over time, interventions preferably have a continuous character [10].

This paper presents a continuous, multifaceted guideline-implementation strategy that is based on computerized decision support but extends beyond the level of the individual professional. The strategy is illustrated with a case study in the field of cardiac rehabilitation.

Materials and Methods

Several systematic reviews have been conducted concerning the effectiveness of different guideline-implementation interventions [3,11,12]. We based our strategy on the recurring conclusion in these reviews that multifaceted interventions targeting different barriers to change are more effective than single interventions. However, there is limited evidence concerning which combination of guideline implementation strategies is effective under which circumstances.

To guarantee a continuous character of the strategy, the continuous quality improvement (CQI) framework was taken as a starting point [13]. Within this framework an improvement is put into practice by planning it, trying it, observing the results, and acting on what is learned [14]. We note that to support these steps, it is necessary that data of the process being improved is collected, stored, and analyzed.

We chose to direct our strategy at two specific types of external guideline barrier, namely organisational barriers and guideline-related barriers. The key element is to use the CCDS as an input module for a clinical registry that collects data from similar care processes in different clinics into a central database. The CCDS registry will be the basis of two continuous improvement processes, a feedback process and a guideline-revision process. This is depicted in Figure 1 and will be described in more detail below.

The first component of our strategy consists of a CCDS system that is based on a formal (i.e., computer-interpretable) representation of the guideline to be implemented, and that is used in daily patient care to assist clinical decision making [15]. In a review of Shiffman et al it was shown that guideline adherence improved in 14 of 18 guideline-based CCDS systems in which it was measured [16]. In a later review of Kawamoto et al it was shown that CCDS systems in general significantly improve clinical performance [8]. In our strategy an existing CCDS system, aiming to overcome the professional knowledge barrier, is also used to collect clinical data in a central data registry. These data cover demographic and clinical characteristics of the patients, recommendations that were given by the system, the actual decisions that were made by its users, and outcomes of care. Using these data, compliance to the guidelines can be assessed at patient level by comparing system recommendations and actual decisions.

The second component is a benchmark-feedback loop. All clinics using the CCDS system and delivering data to the clinical registry receive feedback reports with benchmark information on a regular (e.g., monthly or quarterly) basis. The feedback reports contain graphical and descriptive (numerical) summaries of all clinic-specific data over the time period in question, with comparison to benchmark values (e.g. national target values or average performance within a peer group). Viewing personal performance within the context of peer performance is an effective motivator for change [17].

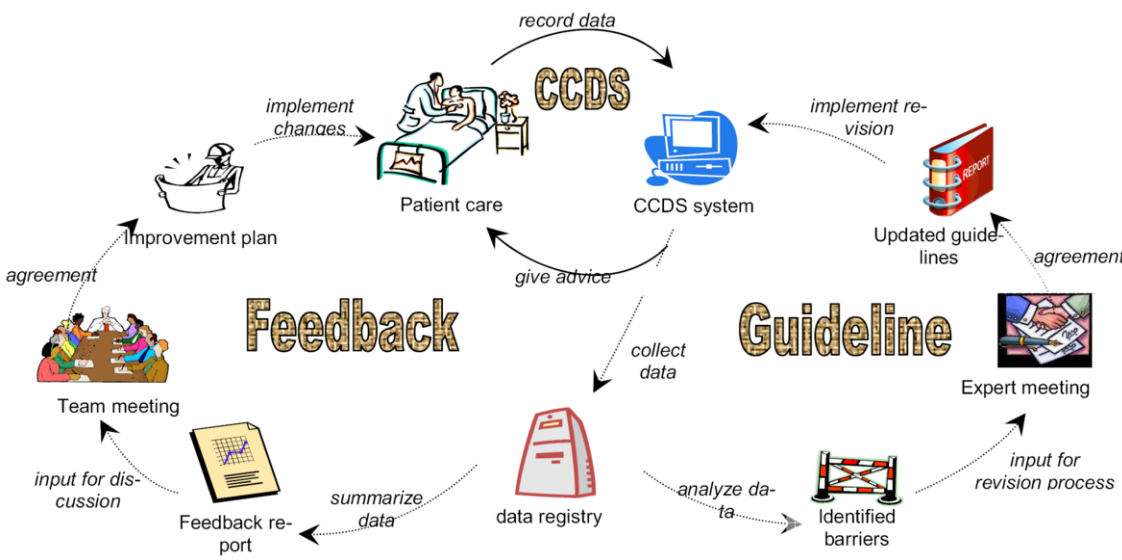

Figure 1 – Schematic depiction of proposed guideline-implementation strategy

CCDS loop: *CCDS system provides guideline-based decision support to clinical professionals in daily care, based on data that are recorded at the bedside.* ***Feedback loop:*** *Data from CCDS systems at different clinics are collected and stored in a central data registry and used to generate feedback reports for each of the clinics. Reports steer discussions in team meetings where a quality improvement plan is formulated, which is subsequently implemented in daily patient care.* ***Guideline loop:*** *The data registry will also serve as input for a guideline revision process by analysing compliance levels. This is supplemented with qualitative information from the users and used by domain experts to formulate the revision, which is subsequently carried through in the knowledge base of the CCDS.*

An essential part of the benchmark-feedback loop is that the reports are discussed during team meetings, and explanations are sought for deviations from benchmarks. Subsequently, organisational improvement initiatives should be formulated and implemented at the shop floor. An example where the benchmark-feedback loop is typically effective is absence of a resource needed to enable patients receiving a particular treatment. The individual professional will be confronted with CCDS advice to offer that treatment but will be unable to comply. The problem is that individual professionals are usually neither responsible nor empowered to acquire resources. When a feedback report reveals the non-compliance for this particular treatment, a team representative empowered to do so (typically a manager) can decide to acquire the resource, resulting in increased compliance to the guideline.

The third component of our strategy consists of a guideline maintenance cycle in which the CCDS data registry is used to identify guideline-related barriers for implementation. The first step of this cycle is to analyze the compliance data in the clinical registry in order to identify possible bottlenecks for carrying out the guideline's recommendations. For instance, excessive complexity of a guideline can result in a consistently low compliance on specific parts. When a procedure is difficult to execute in daily practice professionals may choose to systematically replace this procedure by a simpler one. Another example is the existence of vagueness or ambiguities in the guideline. These may result in high inter-practice variation. When the guidelines are unclear how to assess a specific patient item, different clinics will choose their own assessment method, often resulting in variation among the clinics. A third example is the presence of inconsistencies within the guideline itself or with other guidelines. When the recommended treatment for a subgroup of patients differs between two guidelines, this can result in significant treatment variation for this subgroup, among the clinics.

The second step of the guideline-maintenance cycle is to identify the underlying causes of the phenomena that were observed in the first step. For this purpose the compliance data should be complemented with qualitative information gathered from professionals who use the CCDS, for example during interviews or focus groups.

The final step is to revise the guidelines based on the results from the first two steps in one or more meetings with domain experts. In these meetings identified bottlenecks for guideline implementation are discussed. When proposing revisions experts should be involved to guarantee accordance with the latest scientific evidence. Participation of professional associations in the revision process is advisable to guarantee approval and adequate support of the revised guidelines.

Results

We describe the results of applying the developed strategy to a case study in the field of cardiac rehabilitation (CR). CR is a multidisciplinary treatment to help patients recover quickly from a cardiac incident or a cardiac intervention and improve their overall physical, mental and social functioning [18]. It has proven to be cost-effective in different economic evaluations conducted in North America and Europe [19]. However, in many Western countries cardiac rehabilitation services are under-utilized, poorly standardized, and do not follow the available scientific evidence [18]. Consistent with international standards [18, 20], the Dutch Guidelines for CR 2004 state [21] that professionals should conduct a needs assessment procedure where data items concerning the patient's medical, physical, psychological, and social condition and lifestyle are gathered. Based on the needs assessment procedure an individualized rehabilitation programme should be offered which consists of four possible therapies: exercise training, education and counselling, lifestyle change therapy, and relaxation and stress management training.

For our case study we used data from a recent trial with the CArdiac Rehabilitation Decision Support System (CARDSS) system [22, 23]. This system was developed in a combined guideline-development and formalization process of the Dutch Guideline for CR [24]. Via a structured dialogue CARDSS actively guides its users through the needs assessment procedure and formulates a preliminary rehabilitation programme containing the recommended therapies. Furthermore it contains an Electronic Patient Record (EPR) for CR.

In a multicentre cluster-randomized trial CARDSS was provided to care professionals in 31 Dutch outpatient clinics to stimulate the implementation of the guideline. Participating clinics worked during a minimum of six months with either of two versions of CARDSS: an intervention version with full functionally or a control version with the EPR services but without the therapy recommendations from the CDSS. The trial data from 21 clinics, including 2787 patients, were analyzed on compliance with respect to guideline recommendations, assessed separately for each of the four rehabilitation therapies. CARDSS increased compliance with the recommended decisions for exercise training, education and counselling, and for relaxation therapy. For lifestyle change therapy there was no improvement. All data of the trial were collected in a central registry database. For further details of the trial, we refer the reader to Goud et al [23].

The registry database included data on patient demographics (age and sex), reason for referral to cardiac rehabilitation (e.g. myocardial infarction, CABG, angina pectoris), objective exercise capacity, subjective (i.e., self-perceived) exercise capacity, psychological and social status, marital status, employment status and three lifestyle parameters (smoking status, eating habits, physical activity). These data were used to generate a feedback report for each of the 21 participating clinics. The reports summarized the deployment of needs assessment instruments, assessed risk behaviour and lifestyle parameters, and therapeutic decisions, outlined in the form of tables and charts. For each of the variables that was summarized in the report, also the grand mean and standard deviation (i.e. averaged over all 21 clinics) was reported as benchmark value. In order to leave sufficient room for interpretation and discussion in the team meetings, no other targets were included in the

reports. The feedback reports were positively received by the clinics although there were some doubts about the quality and reliability of the data. Several clinics reported that they created facilities to offer lifestyle change programs to their patients after reading the report. However many clinics found it difficult to create time to discuss the report.

For the guideline-revision process, patterns of compliance to the guidelines were analyzed in the registry database. It appeared that for all the parameters relating to rehabilitation needs, there was significant variation among the clinics. The largest variation was found in the percentages of patients judged to have an insufficient exercise capacity, which ranged from 54.5% to 89.8%. Large variation was also found in the percentages of patients judged to have an unrealistic subjective exercise capacity (37.7% – 63.9%) and to have social problems (31.1% – 60.9%). To identify the causes of this variation, semi-structured interviews with 29 users of CARDSS were conducted. Barriers to change that were mentioned in the interviews were lack of facilities (e.g. to measure all patients' exercise capacities with a bicycle test), vagueness/ambiguity in the guidelines (e.g. unclear how to assess anxiety and depression) and lack of agreement with the guidelines (e.g. criteria for a healthy lifestyle).

The combination of the quantitative compliance data with the qualitative data from the interviews showed that the variation and non-compliance were partly caused by guideline-related barriers. The results of both studies were discussed in a professional focus group set up with representatives of several professional associations (cardiologists, rehabilitation and sport physicians, company doctors, nurse practitioners, physiotherapists, psychologists, social workers and dieticians). They were asked to present revisions to solve the assessed barriers which would fit into daily care practice using their knowledge of the literature. Because of the large variation in assessed patient needs between CR clinics, the revised guidelines advise against using clinical judgment only to assess any rehabilitation needs. In addition, it was decided to add specific instruments to assess the anxiety and depression and a healthy life style and cardiovascular risk.

Discussion

In this study a continuous, multifaceted strategy to implement clinical practice guidelines was developed, and applied in a case study in the field of cardiac rehabilitation. The strategy combines CCDS with a benchmark-feedback loop and periodic updates of the underlying guidelines. As such, our strategy addresses not only the decision-making process of individual professionals but also decisions at higher levels of clinical organisations and in knowledge-management cycles.

A first limitation of our intervention is the need for a CDSS with data registry integrated at the point of care. Another potential limitation of the benchmark-feedback loop is the assumption that a conferring structure with regular team meetings is present at the participating clinics. If this is not the case, sending feedback reports will probably not have impact as they are simply not discussed. Probably this was true in most clinics that participated in our case study because structural follow-up actions on the feedback reports were rare. A recent Cochrane review states that the effects of feedback are likely to be stronger when it is combined with educational meetings directed towards actively involving care professionals in the improvement process [25]. It may therefore be sensible to extend the benchmark-feedback loop in our strategy with educational meetings. A final limitation is that the general professional mentality towards quality assurance should be positive, as professionals must be willing to think and work on quality improvements.

A notorious difficulty in benchmarking is choosing the appropriate target values. We choose to report the mean of all clinics but this can result in an undesirable, passive attitude in clinics whose performance is above average but not optimal. A different option is use full compliance to guideline recommendations as target value. However, this will often be unrealistic. In many clinical domains specific patient characteristics (such as comorbidities) require professionals to deviate from the guidelines. It is then unclear what the ideal compliance rate should be. A possible solution may be found in the Achievable Benchmarks for Care tool. In essence, this tool represents the average performance of the top 10% of the clinics being assessed. It encourages providers to strive for superior performance knowing that the target level of excellence has already been achieved by a select group of their colleagues [26].

Another explanation for difficulties during implementing changes in clinical practice is the presence of patient-related barriers [6]. This group of external barriers to guideline implementation is not specifically addressed in our strategy but could have played a role in our case study, for instance when patients were resistant or perceived no need for guideline recommendations.

The clinical registry based on the CCDS data is used for both the feedback to professionals as well as for the analyses of guideline related barriers for guideline implementation. Results are depending on the data entered in the systems and it is important to avoid data entry errors. Professionals should be thoroughly trained to work with the system and it is advisable to perform periodic data audits to identify data entry errors. In addition, users of the system should be aware that data from all patients that are treated should be entered into the system to prevent a selection bias.

The main novelty in our strategy is found in the combination of different components that supplement each other in a single continuous quality improvement strategy. Our implementation strategy can be used to implement guidelines on multiple levels in health care as part of continuous quality improvement which is advocated as an important mechanism for promoting the implementation of best practices in medical care. However, in our case study the different components were only once applied to the field of CR. Continuous data collection and analyzing is necessary to assess the long-term utility. Further the strategy should be applied during other guideline implementa-

tion projects to learn more about its application in other health care settings.

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MET3-AE System to Support Management of Pediatric Asthma Exacerbation in the Emergency Department

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Abstract

A decision making process behind the management of pediatric patients with asthma exacerbations in the Emergency Department includes three stages: data collection, diagnosis formulation and treatment planning. These stages are associated with activities involving different types of clinical knowledge: factual, conceptual and procedural. Effective decision support should span over the entire decision making process and facilitate the use of diversified clinical knowledge. In this paper we present MET3-AE – a point of care decision support system that satisfies this requirement. The system helps emergency physician collect data, evaluate exacerbation severity, plan corresponding treatment and retrieve clinical evidence associated with a given treatment plan. It was developed using ontology-driven and multi-agent methodologies and implemented with open source software. The system is accessible on tablet and desktop computers and smartphones, and it interacts with other hospital information systems. It was successfully verified in a simulated clinical setting and now it is undergoing testing in a teaching hospital.

Keywords:

Decision support systems, Clinical, Pediatrics, Asthma, Patient management, Emergency care.

Introduction

Asthma exacerbations are one of the most common medical conditions for children that are brought to the Emergency Department (ED). These visits, and subsequent hospitalizations required by many of these patients, account for nearly 65% of all direct costs of asthma care. Children with asthma, compared to other non-asthmatic patients use more prescriptions and require more ambulatory care and ED visits.

A decision making process associated with the management of pediatric asthma exacerbation in the ED is presented in Figure 1. It reflects a hypothetico-deductive model of clinical decision making [1] with three main stages: data collection, diagnosis formulation and treatment planning. Activities associated with specific stages are diversified and require different types of clinical knowledge (indicated in Figure 1).

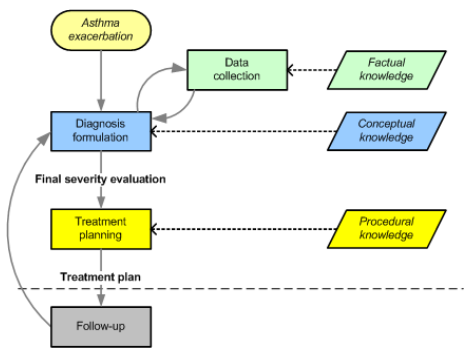

Figure 1 - Decision making process for the management of pediatric asthma exacerbations

The management process starts with the emergency physician (EP) formulating a diagnosis by assessing the severity of exacerbation. This initial evaluation is revised in an iterative way when more patient data is being collected until a final severity evaluation is established. Establishing the severity of exacerbation involves *conceptual knowledge* that is acquired during formal training and life-long learning. The collection of patient data requires the knowledge of what to collect and how to collect it efficiently and accurately. Use of this *factual knowledge* can be supported through a variety of structured data collection tools.

An established asthma severity level drives the development of a treatment plan for the patient. Knowledge required for developing a treatment plan (*procedural knowledge*) is associated with the notion of evidence-based medicine, i.e., making clinical decisions on the basis of the best available evidence. Existing research shows numerous benefits of supplementing a treatment plan with underlying clinical evidence [2].

The goal of effective decision support is to help with all stages of the entire decision making process presented in Figure 1. Moreover, according to [3] such decision support needs to be available in a computerized form and easily accessible at the point of care. All this should contribute to more efficient management of a patient during an encounter. The clinical decision support system (CDSS) described in this paper, called MET3-AE, meets these requirements. It helps collecting and accessing data, evaluating the severity of exacerbation and developing appropriate treatment plans relatively early (at around 2 hours after nursing triage), and it links each treatment plan with evidence – systematic reviews of clinical trials – extracted from The Cochrane Library[1]. Moreover, the system runs on various computing platforms including mobile devices and it can be used directly at the point of care during an encounter.

The paper is organized as follows. In the next section we describe detailed requirements for the MET3-AE system. Then, we discuss the architecture of the system and its implementation. It is followed by an example that illustrates how the system supports diagnostic and treatment decisions. In the subsequent section we describe testing of MET3-AE in a simulated setting. Finally, we conclude with a discussion.

Requirements for the MET3-AE System

In order to meet the goal of effective decision support, MET3-AE has to satisfy two main requirements that are derived from research described in [4-6]:

1. Provision of comprehensive support for the entire decision making process,
2. Availability at the point of care during a patient-physician encounter.

The first requirement translates into satisfying information needs of the EP and assisting the EP with the use of different types of clinical knowledge linked to the specific stages of the decision making process.

Satisfying information needs maps into the ability to access patient information regardless of where it is stored. This requires MET3-AE to interact with other hospital information systems (HISs), especially with an electronic patient record (EPR), in order to exchange and share patient data.

Supporting the use of clinical knowledge requires encoding of its different types in form of different abstract models and associating these models with functions that facilitate their use – they are listed in Table 1.

Linking the stages of the decision making process with abstract models and related functions constitutes the main idea behind the MET3-AE design:

- Supporting the data collection implies prompting the EP to consider specific clinical attributes and providing means for structured data entry. This calls for the data model defining the clinical attributes and the user interface model defining the structured data entry components, both codifying the factual knowledge.
- Supporting the diagnosis formulation implies the ability to arrive at an assessment for the exacerbation severity. This calls for a diagnostic model codifying the conceptual knowledge.
- Supporting the treatment planning implies the ability to recommend treatment plans and to provide underlying evidence. This in turn requires having the treatment and evidence models encoding the corresponding procedural knowledge and allowing for retrieval of clinical evidence.

Table 1 - Models and functions supporting the decision making process

Process stage	Abstract model	Function
Data collection	Data model User interface model	Structured collection of patient data
Diagnosis formulation	Diagnostic model	Suggestion of possible diagnosis
Treatment planning	Treatment model Evidence model	Suggestion of treatment plans Provision of clinical evidence

The second requirement for effective clinical decision support translates into MET3-AE ability to run on different computing platforms, thus satisfying the "multi-device architecture" postulate [7]. More precisely, MET3-AE has to be accessible on a tablet computer, desktop computer or smartphone so the EP can use it when and where necessary.

The set of requirements discussed here does not cover issues of security and privacy. However, when implementing the system we used a policy-based encryption to ensure appropriate level of access control and data security.

Implementing the MET3-AE System

Architecture

Comprehensive clinical decision support calls for a distributed architecture that facilitates multiple relatively independent function. These functions should be modeled as independent entities that provide or request services [8]. Such architecture may be implemented following service-oriented or multi-agent principles. In MET3-AE persistence of the entities is crucial, as they need to exist all times to monitor HIS or to respond to user requests. Such persistent existence is normally accomplished in a multi-agent system (MAS).

The MET3-AE architecture presented in Figure 2 was developed using multi-agent methodologies enhanced with ontology-driven design for better maintainability and extensibility. It builds on our earlier research, specifically on the multi-agent

[1] http:///www.thecochranelibrary.com

design process (described in [9]) and on the ontology-driven design for CDSS (introduced in [10]).

MET3-AE includes the following agents:

- *Encounter assistant* that provides a graphical user interface to the EP and interacts with other agents based on the user actions,
- *Model manager* that manages abstract models stored in the *model repository*,
- *Data manager* that manages patient data stored locally in the *data repository*,
- *Diagnosis suggester* that suggest a possible asthma severity level on the basis of patient data and using the abstract diagnostic model,
- *Treatment suggester* that suggests a treatment plan on the basis of the patient data and using the abstract treatment model,
- *Evidence provider* that provides clinical evidence from the *evidence repository* on the basis of the patient data and using the abstract evidence model,
- *HIS synchronizer* that receives and passes the messages between MET3-AE and HISs via the HL7 *interface engine*.

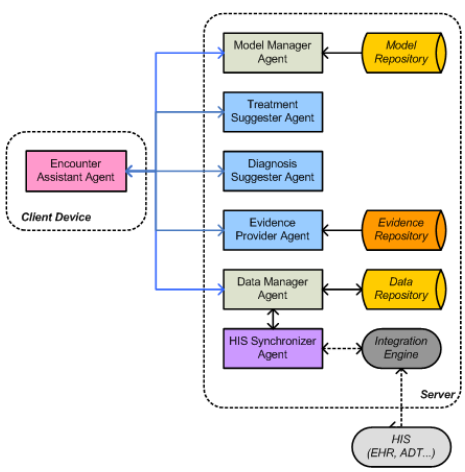

Figure 2 - Architecture of MET3-AE

The encounter assistant agent, acting as the EP's gateway to the system, runs on a "client" device (tablet computer, desktop computer or smartphone), while the remaining agents and repositories reside on a dedicated server.

The MET3-AE system was implemented in two phases discussed in the next subsections. The first phase involved creating the technological infrastructure according to the architecture presented in Figure 2, and the second phase involved implementing all abstract models listed in Table 1.

Technological infrastructure

The MET3-AE agents were programmed using JADE (Java Agent DEvelopment Framework) that provides middleware to manage agents and controls communications between them.

The repositories with abstract models (the model repository) and with patient data (the data repository) were created with Protégé. The evidence repository with systematic reviews from The Cochrane Library was implemented as a MySQL database enhanced with the Apache Lucene text search engine.

We also used Mirth Connect to enable communication between the MET3-AE and HIS. Specifically, we integrated with the ADT (admission-discharge-transfer) system through the HIS synchronizer agent using HL7 messaging.

Abstract Models

The data model for MET3-AE specifies clinical attributes that are routinely considered when managing asthmatic patients. These attributes were defined in cooperation with EPs – they come from the emergency assessment record and the asthma clinical pathway and they describe basic patients' demographics, history of asthma and the current exacerbation episode. The user interface model manages structured collection of values of the attributes from the data model. It was constructed following user- and task-centered design principles [11].

The diagnostic model employs a decision tree to predict asthma severity (research leading to its development and empirical validation is described in [12]). It was developed from a retrospective chart study using data mining techniques. Prior to building the model, collected data was preprocessed by normalizing age-dependent clinical attributes and by removing questionable patient records – we used Pediatric Respiratory Assessment Measure (PRAM) to identify these records.

The treatment model consists of decision rules that assign appropriate treatment given the asthma severity level. These rules were extracted from a pediatric asthma clinical guideline published by the Canadian Association of Emergency Physicians[2].

The evidence model defines terms used for indexing systematic reviews and introduces mappings between attributes from the data model and the indexing terms. These terms were identified using the UMLS Metathesaurus and located in the systematic reviews from The Cochrane Library with the help of the MetaMap Transfer (MMTx) system [13].

An Example of MET3-AE Operations

To provide a better understanding of how MET3-AE works we provide in Figure 3 a scenario of a clinical case in the ED. The scenario focuses on two stages of the decision making process – diagnosis formulation and treatment planning (due to limited space the data collection stage has been skipped). Corresponding agent interactions are presented in Figure 4 and 5.

[2] http://www.caep.org

At the diagnosis formulation stage (Figure 4) Dr. Brown asks for a diagnostic suggestion (1). The encounter assistant agent sends a request (augmented with available patient data) to the diagnosis suggester agent (2), which in turn sends a request to the model manager agent for the diagnostic model for asthma (3). The model manager retrieves the model from the model repository (4) and sends it back (5). Then the diagnosis suggester agent applies the diagnostic model to Peter's data and returns elaborated diagnostic suggestion to the encounter assistant agent (6), which finally reports it to Dr. Brown (7).

Peter Smith, a 2-year old boy with asthma exacerbation, has been brought by his parents to the ED in a pediatric hospital. Following nursing triage, Dr. Jane Brown takes care of Peter's management. After the first round of standard treatments according to hospital's asthma pathway, Dr. Brown continues Peter's assessment and is using MET3-AE running on her tablet computer to record patient data and to get decision support. Her initial hypothesis is that Peter suffers from severe asthma exacerbation. She consults MET3-AE for diagnostic advice and in return receives a suggestion pointing towards moderate asthma exacerbation. Dr. Brown decides to continue with observing the patient and monitoring oxygen saturation level. After short period of observation she assesses Peter again and diagnoses him as having moderate exacerbation (confirmed by MET3-AE). According to asthma practice guideline embedded in the MET3-AE, administration of systemic corticosteroids is a recommended treatment. Dr. Brown asks the system for the evidence regarding such treatment for a young boy and MET3-AE responds with a ranked list of abstracted systematic reviews. After consulting the summaries, Dr. Brown prescribes systemic corticosteroids and proceeds to discharge Peter to care of a family physician.

Figure 3- A scenario of a clinical case

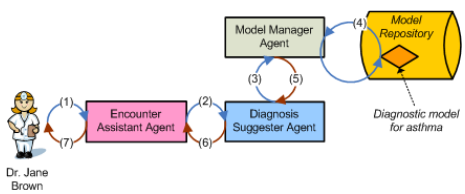

Figure 4- Agent interactions during diagnosis formulation

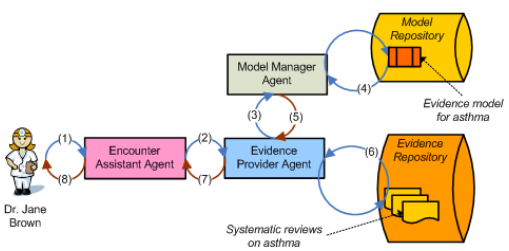

Figure 5- Agent interactions during treatment planning

At the treatment planning stage (Figure 5) Dr. Brown asks for a treatment suggestion and for evidence supporting suggested treatment. Agent interactions for providing treatment suggestions are very similar to the interactions described above, therefore they are not repeated. After MET3 has provided treatment suggestions, Dr. Brown asks for evidence supporting the use of systemic steroids (1). In response the encounter assistant agent sends a request to the evidence provider agent (2). This request includes all Peter's data, as well as the initially suggested treatment. The evidence provider agent sends a request to the model manager agent for the evidence model for asthma (3). The model manager retrieves the proper model from the model repository (4) and sends it back (5). Then, the evidence provider agent applies the model to the patient data and obtains a set of indexing terms that can be used to query the evidence repository for relevant systematic reviews (6). Retrieved reviews are ranked according to their relevance and passed back to the encounter assistant agent (7) that finally presents them to Dr. Brown (8).

Testing MET3-AE Operations in a Simulated Clinical Setting

MET3-AE is currently undergoing a clinical testing in the ED at the Children's Hospital of Eastern Ontario (CHEO) in Ottawa, Canada. The test involves a team of EPs, nurses and residents, who use MET3-AE on a tablet computer (Motion Computing C5). The test aims at evaluating and comparing predictions of EPs with those of the diagnostic model of MET3-AE and PRAM. The secondary goal of the test is to verify computing technology acceptance by EPs.

Prior to starting hospital testing we evaluated MET3-AE integration with a HIS and assessed how the system was handling typical information load. Based on published data we simulated a typical day in the ED at CHEO assuming 120 visits over a period of 12 hours (a relatively heavy workload). Amongst these visits there were 40 patients with asthma exacerbation that needed to be processed by MET3-AE. We simulated 10 concurrent sessions of patient management (i.e., up to 10 patients had to be handled by the system at the same time) covering all functionalities of the MET3-AE. All load tests were successful and system responded with no delays and no operational problems.

We also verified accuracy of advice (suggested diagnosis and evidence documents) produced by the diagnosis suggester and evidence provider agents. The performance of diagnosis suggester agent was tested on 120 unseen retrospective patient records giving sensitivity and specificity of 0.84 and 0.71 respectively. The evidence provider agent was tested using 15 prospective patient records and systematic reviews were retrieved with precision and recall of 0.89 and 0.81 respectively.

Discussion

Management of pediatric asthma exacerbations in the ED involves a complex multi-stage decision making process, where activities associated with specific stages are diversified and require different types of clinical knowledge. An effective CDSS should provide comprehensive support for all stages and be available the point of care. In this paper we demon-

strated that such a CDSS can be designed following the ontology-driven and multi-agent methodologies. We also presented MET3-AE – a proof-of-concept CDSS that provides a comprehensive decision support for data collection, diagnosis formulation, treatment planning and evidence retrieval.

MET3-AE belongs to the latest generation of CDSSs [8] that depending on desired functionality are designed according to service-oriented principles and implemented as web services (for example the SEBASTIAN system [14]), or designed and implemented as MASs. However, even those implemented as MASs do not combine all functionalities required to support all stages of a decision making process and do not offer as comprehensive support as MET3-AE. For example, the PalliaSys system [15] facilitates collecting palliative patient data and alarms physicians about abnormal values and the K4Care platform [16] facilitates execution of personalized treatment guidelines.

To the best of our knowledge, MET3-AE is the first CDSS that supports the entire decision making process associated with management of asthma pediatric asthma exacerbations. The system is accessible on multiple computing platforms directly at the point of care. It supports the HL7 standard to interact and exchange data with HIS. Finally, MET3-AE was implemented using open source software to limit the cost of proprietary solutions and long-term limitations that come with their use, thus this should be seen as is additional advantage.

We successfully tested the MET3-AE operations in a simulated ED setting under realistic load conditions, and now system is being tested in a teaching hospital.

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AALIM: A Cardiac Clinical Decision Support System Powered By Advanced Multi-modal Analytics

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Abstract

Modern Electronic Medical Record (EMR) systems often integrate large amounts of data from multiple disparate sources. To do so, EMR systems must align the data to create consistency between these sources. The data should also be presented in a manner that allows a clinician to quickly understand the complete condition and history of a patient's health. We develop the AALIM system to address these issues using advanced multimodal analytics. First, it extracts and computes multiple features and cues from the patient records and medical tests. This additional metadata facilitates more accurate alignment of the various modalities, enables consistency check and empowers a clear, concise presentation of the patient's complete health information. The system further provides a multimodal search for similar cases within the EMR system, and derives related conditions and drugs information from them. We applied our approach to cardiac data from a major medical care organization and found that it produced results with sufficient quality to assist the clinician making appropriate clinical decisions.

Keywords:

Clinical Decision Support Systems, Multi-modal Analytics

Introduction

As EMR systems are more widely adopted, clinicians are becoming deluged with data. While they may no longer need to decipher illegible handwriting in a hard-copy chart, they now have to review and understand a patient's EMR. This may include records of dozens or even hundreds of clinical encounters with multiple health care providers. As clinicians are increasingly evaluated by the quality of care they provide in diagnosing and treating patients, it becomes critical to quickly extract and understand the relevant parts of the patient's record, develop an accurate gestalt or mental model of the patient's clinical status, make a diagnosis, and then select an appropriate treatment. The speed of the analysis is especially important in Emergency Departments, where physicians make instant life-and-death decisions largely based on the patient's EMR. The daunting task of EMR systems is to support the work of clinicians by displaying a patient's record in a complete, consistent and clear way. In this paper, we address this issue for cardiac related data of a major integrated health care organization through a system that implements advanced analytics on patient records.

One challenge in displaying a patient's health history is the fact that the EMR frequently combines records of multiple clinical encounters of different types and from different health care providers. The record of an encounter may contain progress notes, diagnoses, procedures, test results and/or any type of clinical data. Combining information from these encounters can be difficult, as the information in the records may be imprecise, contradictory, erroneous, or missing. In addition, the information might be distributed among several software systems. Physicians need to absorb this information, reconcile contradicting and/or missing data, and arrive at a diagnosis and treatment plan. To compound the problem, the treatment plan should agree with clinical guidelines, best practices developed by subject matter experts, and the clinician's anecdotal experience with patients of "similar" cases (sometimes denoted as *similar patients*).

Although most EMR systems have user friendly front-ends, they generally only provide an "encounter-by-encounter" view of a patient's longitudinal data. Reviewing a patient's record in this manner is time consuming; moreover it is also challenging to gain insight about the temporal relationships between events. One way of providing a more complete picture of the patient's history is through "problem lists" extracted from the patient's health history. Enumerating past diseases of the patient is an example of such a list. However, such lists usually hide the temporal relationships between events. More sophisticated EMR applications therefore include charts and graphs that allow clinicians to view longitudinal changes in specific tests or measurements.

This paper describes the Advanced AnaLytics for Information Management system (AALIM). The AALIM system extracts information from different data sources and presents the data in a coherent Clinical Decision Support view of an EMR (see Figure 1). It uses advanced analytics to extract diagnostic information from data such as specialist text reports as well as medical imaging. To the best of our knowledge, this is the first system to search and identify a population of patients with

similar cases, diseases, comorbidities and medications. AALIM brings the longitudinal and cross-sectional information of that population to the point of care. It provides clinicians with a consistent view of the patient's history as well as the ability to compare comparing this history with that of other patients with similar test results and disease profiles. This comparison supplies the clinician with a refined insight as to the patient's diagnosis and the comparative effectiveness of different treatments on outcomes. The system displays the information in an easy to use graphical user interface, For the initial demonstration of AALIM, we limited the scope to the field of cardiology. However, the same paradigm can be applied to other medical specialties.

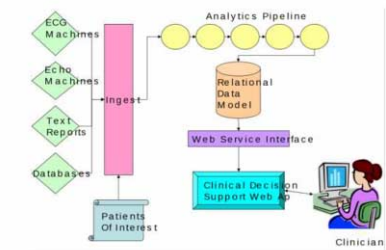

Figure 1 - Simplified block diagram for the AALIM System.

Related Work

The AALIM system, originally introduced in 2007 [1], is a first-of-a-kind in that it combines clinical image data and textual information for patient-search and analysis in a clinical setting.This interdisciplinary work combines multi-modal image and video analysis, signal processing and pattern recognition, text analysis, supervised and unsupervised learning, information fusion and content-based retrieval - in which similar clinical cases are sought. In its multi-modal search for similar cardiac cases, AALIM analyzes, indexes and retrieves information from free text (cardiology reports), patient demographics, temporal data (ECG waveforms), and imaging studies (echocardiogram videos) [2,3,4]. In its goals, AALIM can affiliate itself with Case-Based Reasoning (CBR) as well as Clinical Decision Support (CDS). Furthermore, its front-end provides special visualization and usability features, designed for physician tasks. Due to space limitation we can touch upon only a few of these domains and mention related work in those areas.

Clinical decision support systems and their effectiveness have been studied for decades [5-7]. Early systems, such as MYCIN [8,9], were targeted towards explicitly capturing expert human knowledge and transferring it to other clinicians via rule-based expert systems. It is clear that in some domains rule-based systems are the ideal solution. However, they have challenges in that they are hard to develop and even more difficult to maintain given the rapid progress of modern medicine. Recent publications suggest that this issue can be addressed via case-based reasoning (CBR).

CBR produces conclusions by applying search and retrieval techniques to the EMRs of patients (for a review see [10]). Examples of CBR in the medical domain include the INRECA system [11] for diagnosing intoxications by drugs, the enhanced literature search engine developed by Coiera et. al. [12], and the heart failure decision support tool by Purin et al [13,14], which searches through EMRs stored in the XML format. Most CBRs in the medical domain focus on text searches.and thus ignore important information in a patients' EMR, such as medical scans and videos ([15]).

Decision support systems that analyze image information generally focus on one imaging modality. For example, Drazen et. al. [16] and GE Healthcare [17] built systems specifically for ECG analysis. In [18] Patil and Kumaraswamy applied multi-modal analysis of patient data and trained a neural network to predict heart attacks. However when dealing with a large number of cardiac diseases and many combinations and comorbidities, training for each possible case is not feasible. One way to address the limitation of training for particular cases is via multimodal search systems.

Multimodal search systems fuse data from several modalities, such as text and medical scans. For example, Ruiz et al. [19] designed a multimodal search engine that combined content-based image retrieval (GIFT) with structured data (SMART) and free text (MetaMap). However, their search engine lacks automatic decision support capabilities.

In both its search engine and graphical user interface, the AALIM system uses temporal representation, integration and visualization of data. Chronological description of medical events is imperative to clinical decision making. Time line display of the patient's medical history was proposed in an early work by Cousins and Kahn [20]. Combi and Shahar [21] provided an overview of time-oriented tasks, approaches and systems in several clinical domains including cardiology,

and studied temporal reasoning extensively.

To the best of our knowledge, AALIM medical decision support system is the first multimodal search system that includes decision support. The system uses case-based reasoning [22, 1] and provides multimodal search of the EMRs of cardiac patients. AALIM requires a minimal amount of manual feedback for training as its queries are based on the current patient's status as well as similar cases. Similar cases are extracted from the database via data mining, which does not require any manual data annotation. The remainder of this article describes the system in further detail.

Methods

We previously mentioned the challenges of synchronizing information between multiple sources in an electronic medical record. In this section, we discuss our solution to transfer important information from multimodal reports into a structured diagnosis database. AALIM uses structured databases to provide clinicians with a variety of views on the state of a patient's health and on tracking of disease trends in a served population.

Figure 2 - "At a glance" overview of cardiac health.

The AALIM software package is layered on an existing EMR system deployed in a major integrated health care organization. Like many such systems, AALIM is a "work in progress", providing many features that represent a significant improvement over existing systems but still having gaps in some areas.

Rather than applying AALIM to the entire EMR at once, we focused the application on data related to cardiac diseases. We chose this strategy to target a single domain which allows us to present our system to a specific group of physicians, the cardiologists.

Data Sources

Data for this project was extracted from a variety of sources throughout the target hospital network. Depending on the source and data, the information is structured, semi- or unstructured.

Structured data acquired through routine patient care can be generally captured through fixed database tables and rigidly defined forms. In our target hospital, structured data included International Statistical Classification of Diseases and Related Health Problems (ICD9) diagnoses entered during outpatient visits, lists of significant ongoing problems, patient demographic information and medications prescribed.

In contrast, semi-structured data has defined list of fields whose content is free text. Examples of this type of data are human and computer generated data from ECG reports, the header blocks of echocardiogram reports, and the "signal" trace of an ECG report that is parsed from a printed report.

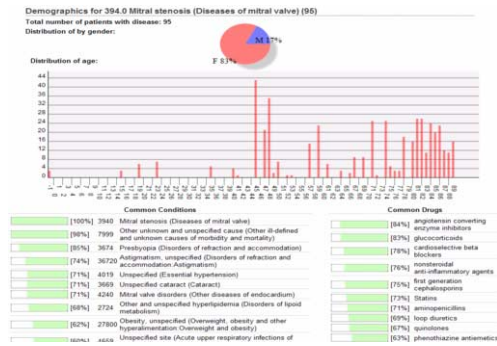

Figure 3 – Associations with comorbidities and drugs

Lastly, some data in our system comes with virtually no structure. Dictated reports for cardiac catheterizations, free text in echocardiogram reports, and streaming video from the echocardiogram procedures all fall into this category.

Once acquired, the information is stored in our data model (a relational data base plus files for binary object data) where it is made available for both analytics and presentation.

Examples of Advanced Analytics

AALIM generally first extracts features from the multi-modal data. These features are then included in the disease database, which AALIM uses to search through the data. In the remainder of this section we provide three examples for such searches.

Given a patient's ECG waveform, AALIM uses an advanced shape matching algorithm based on dynamic shape warping to find other similar ECGs. Different morphological variations of the shape corresponding to the same disease are modeled as a constrained non-rigid translation transform [2]. The ECG interpretations (a combination of computer diagnosis and cardiologist overreading) are then pooled forming a statistical diagnosis profile.

Another example is the automatic extraction of spatio-temporal motion patterns from echocardiogram videos. Our approach combines active shape model-based registration with region extraction and tracking using multi-scale normalized graph cuts [3]. These features, such as septal wall motion and ejection fraction, are added to our information about the study.

Finally, we analyze free text reports by matching keywords and phrases common in cardiac diagnosis via a taxonomy. Furthermore, we perform a shallow parse to identify modifiers and negators of these terms, for example "no evidence of mitral stenosis" or "severe case of atrial fibrillation". As can be seen, the relevant features for similarity differ from modality to modality. As new features are developed they are tested against known diseases for patients in a test set to identify how well they predict presence or absence of a disease.

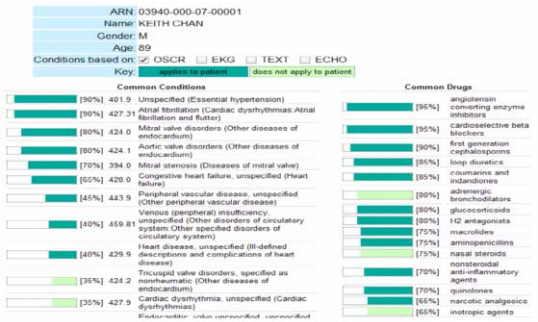

Figure 4 - "Micro cohorts" of related cases

In all cases, these additional features developed with AALIM analytics are added to the patient record as "derived" features. These features are generally considered of lower confidence than those specified by physicians. However, this type of data often provides important and valuable cues for selecting and presenting information on a patient's overall health.

Ultimately, each modality creates its own rank ordered list of most similar patients. These lists are then combined through a voting method [23] to generate a candidate list of similar patients for use in the presentation. Each modality chooses how many candidates to return based on its internal confidence thresholds.

Presentation

Our goal in the presentation of the collected information is to provide the physician with a complete overview of cardiac status of the patient. The presentation system (and thus all the underlying analytics that drive it) was motivated through interaction with clinicians, and seeks to explicitly present information about patients and diseases in a way that clinicians implicitly do when considering a patient. The difference is that instead of working with anecdotal and population studies, the system has thousands of complete medical records to draw upon for making comparisons of results and comorbidities.

We display this information via a few different "perspectives". The first perspective gives a patient overview, including a history of recent studies, current diseases and drugs (Figure 2). This gestalt view is useful especially in cases where a doctor sees a new patient that has an ongoing disease history.

The second kind of display is an overview for a selected disease (see Figure 3) such as the disease demographics, common comorbidities, and common drug prescriptions. Clinicians use this perspective to learn about common characteristics of a disease, such as the fact that mitral stenosis is more common among women than men.

The third screen (see Figure 4) helps with differential diagnosis. It shows diseases and drugs common with patients similar to the case being looked at. We define the similarity between patients by analyzing a combination of their ECG, echocardiogram, cardiac catheterization, diagnoses and other data. Users can influence this matching process by selecting specific criteria to define commonality between patients.

Heart Rate Extraction	91%
Arrhythmia detection	94.5%
Ejection Fraction	81%
Mitral Stenosis Detection	99%

Figure 5 - Selected results of the advanced analytics

Results

Today's EMR systems frequently require human intervention to accurately extract important information from multimodal reports into a structured diagnosis database. This is especially true for diagnosis information captured in non-structured modalities. An example would be a transcription of a catheterization procedure or visual evidence in an echo video.

We applied AALIM to several different collections and measured the accuracy of the tool to a given reference set. In the first experiment, we used our advanced analytics to recognize and tag patients with arrhythmia from the ECG database, which contains 20,077 12-channel ECG scans. Of these, our method could reliably extract heart rate for 18210 cases (91%). We found 1952 cases of tachycardia and 1066 cases of bradycardia. The accuracy of our approach reached 94.5% for arrhythmia patients. In all cases accuracy was computed by comparing with disease labels from an expert following the American Heart Association guidelines.

The automatic tagging capability enables AALIM to notify clinicians in the patient's "overview" screen (such as in Figure 2) of important medical conditions, such as arrhythmia. These notifications are important as they may be symptoms or complicating factors of other diseases. We note that some ECG scanners provide arrhythmia information. However, our approach can generate this tag from any (even historical) ECGs resulting in a consistent presentation of the labeling.

Ejection Fraction (EF) captures the pumping efficiency of the left ventricle, an important metric for identifying ventricular diseases. Our analytics automatically estimate the EF from the videos, which are then compared to written cardiologist reports. Out of 1604 echo videos, the algorithm agreed in 81% with at least one human manual interpretation. AALIM flags those reports where it failed to extract an EF and had to provide an estimate, and encourages the cardiologist to re-examine and correct the estimate, if necessary.

In the last experiment, we discuss the issue of diagnosis propagation. In our test set of 1173 cardiac patients, the original EMR system listed 95 patients with mitral stenosis. However, our analysis tool on the echo and textual data identified 128 cases. Of the 128 patients flagged, a cardiologist examined 105 cases in detail which included all of the 95 cases already flagged in the system. Using all available evidence, the cardiologist concluded that the assessment of disease/no disease done by AALIM was correct in all but one case, whereas the recorded diagnosis was correct only in 54 of the 95 cases.

These examples highlight the potential of advanced analytics in EMR systems. While our prototype system is still being

validated using expert supervision, the tool already allows clinician a quick presentation and a more complete view of a patient's complete health. It is clear that such a tool can be of use in many different specialties of medicine, although the underlying advanced analytics will of course differ in extracting information from the tests and procedures of each specialty.

Conclusion

Modern EMR systems are often hampered in their ability to present comprehensive, complete and coherent views of patient health due to misaligned and missing data. Such challenges can be mitigated via advanced analytics.

We found that our analytics are of sufficient quality to improve aligning records from disparate sources as well as providing estimates for missing values. We used this more complete and comprehensive data set to produce and present gestalt overviews of a patient's health status. We also identified micro-cohorts of related patients for which we computed statistics of disease prevalence and medication usage. These statistics can then assist in the differential diagnosis.

Although the AALIM system is still under development, in preliminary evaluations we found that our advanced analytics are useful to assist clinicians in improving the quality of care. Results of user studies indicate that such consolidated presentation of information is extremely helpful to clinicians, especially for emergent cases in which they may have no prior information about the patient. Further, continued development will enable clinicians to make informed decisions from multimodal analytics and promote “meaningful use” of cardiac data.

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TADAA: Towards Automated Detection of Anaesthetic Activity

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Abstract

Task analysis is a valuable research method for better understanding the activity of anaesthetists in the operating room (OR), providing evidence for designing and evaluating improvements to systems and processes. It may also assist in identifying potential error paths to adverse events, ultimately improving patient safety. Human observers are the current 'gold standard' for capturing task data, but they are expensive and have cognitive limitations. Our current research – Towards Automated Detection of Anaesthetic Activity (TADAA) - aims to produce an automated task analysis system, employing Radio Frequency Identification (RFID) technology to capture anaesthetists' location, orientation and stance (LOS), and machine learning techniques to translate that data into low-level and high-level activity labels. In this paper we present details of the system design and promising results from LOS sensing testing in laboratory and high-fidelity OR simulator settings.

Keywords:

Anesthesiology, Task performance and analysis, Automated pattern recognition, Radio

Introduction

Anaesthesia, generally regarded as more complex than aviation [1], seems a suitable and worthwhile field for the application of similar techniques. Numerous studies have found that human factors, such as poor record keeping, ignorance of standards or failure to adhere to them, and lack of communication, are major contributors to preventable adverse events during anaesthesia [2].

Weinger, an authority in anaesthetic task analysis, sums up his motivation: "A scientific description of the anesthesiologist's task patterns and workload would aid in our understanding of the nature of the anesthesiologist's job and provide a more rational basis for improvements" in processes, equipment, OR layout, training and other aspects of anesthesia [3]. Having a 'scientific description' is particularly important in medicine, with its requirement for improvements to be evidence-based [4] . However, existing methods for anaesthetic task analysis are limited in their ability to produce scientific data in a timely, cost-effective way.

This provides the motivation for our current research project, Towards Automated Detection of Anaesthetic Activity (TADAA). In the next section we briefly introduce anaesthesia, review recent literature on anaesthetic task analysis and automated activity detection, and describe our prototype TADAA system. We then present initial results from evaluation of the system in our lab and in simulated anaesthetic procedures. Finally we outline outstanding issues and plans for future development.

In New Zealand hospitals there is always one anaesthetist present during an operation. They are assisted by a technician and possibly a nurse. Additional anaesthetists may be present as supervisors, trainees, or assisting in complex procedures.

Anaesthetic Task Analysis

Anaesthetists currently record some of their own activity in an anaesthetic record completed for each procedure. While this is a clinically important task, treating the patient always takes precedence. Thus parts of the record are often completed from memory, or with normalised activity [5], and its accuracy cannot be guaranteed.

When more rigorous activity recording is required, the gold standard approach is to employ independent observers [3, 6]. The observers, either in the OR or viewing video recordings, classify anaesthetists' activity into a number of *a priori* categories. A typical list of categories is shown in Table 1.

Table 1 - Anaesthetic activity categories used in [3]

Manual - Prepare drugs, Line placement, Give drugs, Mask ventilation, Bag ventilation, Suction, Manipulate airway, Intubation, Laryngoscopy, Adjust anaesthetic machine, Adjust monitors, Adjust IV
Communication - Attending, Nurse, Surgeon, Patient, Teaching, Other
Observing - Anaesthetic machine, Monitors, Patient, Airway, IVs, Surgical field, Other
Other – Anaesthetic record, Position patient, Clean up, Other

But human observers are not the ideal instrument for recording scientific data. They may make errors when fatigued, distracted, or their view is obstructed. Maintaining intra- and inter-observer consistency in classifying activities can be difficult [7].

Automated Activity Detection

Automation in anaesthesia is nothing new. Computerised systems that record patients' vital signs, and raise alarms when certain conditions occur, are widespread [5]. However systems to record anaesthetists' activity are rare, with none seeming to have progressed beyond very limited use [11, 13-15].

Activity recognition systems can be characterised in various ways, including:

- The type of sensor(s) used.
- Whether sensors are part of the environment or worn or carried by the research subject(s).
- Whether sensors detect body motion, location or movement around an environment, or object use.
- Whether sensor data is analysed for activity using *a priori* rules, or machine learning.

These were the four aspects that most informed the design of our TADAA system.

Methods

TADAA System Design

We selected RFID as the most suitable sensor technology. The TADAA system uses RFID to perform location sensing. An RFID-tagged person can be located by readers embedded in the environment, using the received signal strength (RSS) of their tag's transmissions. The RSS varies by the distance between tag and reader, as per the principle of lateration-by-attenuation (LAT) [12]. However, location sensing is complicated by the fact that RSS is affected by many factors other than distance (such as tag orientation, intervening objects or people, interference from other electronic devices, atmospheric conditions) in ways that are difficult to quantify.

Nevertheless, real time location systems (RTLSs), a common RFID application in hospitals, employ this approach to locate tagged people or equipment in wards, floors or entire buildings, generally to within a few metres. Research suggests that more precise location is possible over smaller areas [13, 14].

To support activity recognition, the TADAA system is intended to detect an anaesthetist's orientation and stance in addition to their location. An anaesthetist located next to a patient may be performing a number of activities, but the list of possibilities can be greatly reduced if it is known, for example, that they are facing the anaesthetic machine, or that they are seated rather than standing. The TADAA system therefore has an anaesthetist wear two tags, one front and one back.

Several tags are also placed at 'landmark' locations within the anaesthetic triangle, such as the drug trolley, anaesthetic machine, and the patient.

Finally, a few tags are suspended from the ceiling to act as 'canaries in the coalmine'. Since these tags do not move, change orientation, or get obstructed, their RSSs should remain relatively stable. Any changes would indicate a general environmental effect that may also affect other tags.

RFID Equipment

The TADAA system uses Wavetrend active RFID equipment, operating in the 433MHz radio spectrum. Tags transmit every 1.5 seconds. The readers can process only one tag transmission at a time. So if multiple tags transmit at the same instant, then all but one transmission will be lost. The reader ID, tag ID, date, time, and RSS are captured for each transmission. (RSS is expressed in an arbitrary unit that doesn't appear to correspond to any standard unit of power or signal strength.)

Accurate LAT requires a fine-grained and relatively stable RSS, and a predictable RSS-distance relation [13]. Effective activity recognition requires that the time between tag reads should be less than the shortest activity duration of the activities being performed [13,14].

Tests were performed in the AURA Lab to determine how well the RFID equipment satisfied these requirements:

- Time between reads, for 20 tags with 1 reader.
- RSS-distance relation, over distances from 0.5m to 6m. This was done once with the tag stationary at each 0.5m interval, and then with the tag moving.

No specific tests were performed for RSS granularity and stability, as the existing tests provide the necessary data.

Tests were also performed to gauge the impact on a tag's RSS when an anaesthetist:

- Wears the tag.
- Changes tag-reader orientation, by changing stance.
- Obstructs the tag, by standing between it and the reader.

LOS Sensing

The TADAA system was deployed in a high-fidelity OR simulator. Data was first collected from two dry runs during which one of the authors simply adopted 17 typical LOSs, without performing any activity.

The main data collection was from 40 simulated procedures, performed over 20 days by 20 different anaesthetists. Along with the RFID data, the procedures were also videotaped and recorded by a human observer. Each anaesthetist was asked to rate the distraction caused by the RFID tags, the RFID readers, and the observer on a visual analog scale (VAS).

The videos served as the ground truth, with an LOS determined manually for each second of video. The RFID data was aggregated to produce one record per second, combining the

RSSs for all tags and readers. Missing RSS values (due to the 1.5s transmission rate and lost transmissions) was filled in with the average RSS for the relevant tag, reader and known RSS values.

The RFID data was then clustered using the Self Organizing Maps (SOM) functions in MATLAB's neural network toolbox. Analysis was first performed on the dry run data. SOMs were trained with the data from dry run 1 and tested on the data from dry run 2, using different combinations of SOM size and tag subsets.

SOMs were evaluated using precision, or positive predictive value. Each cluster was assigned to the LOS which contributed the largest number of records. Those records were considered true positives (TP). Any other records in the cluster (from other LOSs) were considered false positives (FP). The SOM's precision was calculated as total TP / (total TP + total FP).

Results from analysis of the dry runs informed further analysis of data from the simulated procedures.

Results

RFID Equipment

The average time between reads was approximately 2.5s, with a standard deviation of 1.7s.

The minimum RSS value recorded during testing was 89 and the maximum 212. RSS granularity, up to distances of 6m, was therefore 123 points. The standard deviation in RSS was approximately 0.8% of the average RSS value.

RSS did vary by distance for all tags, but not in a predictable way. The RSS-distance relations shown in Figure 1 are typical: an overall downward trend, but with peaks and troughs. Different tag-reader combinations exhibited different RSS-distance relations. As Figure 1 illustrates the RSS at a given distance varied by up to 40 points depending on whether the tag was moving away from or towards the reader.

Table 2 shows the maximum effect on RSS of common interactions between anaesthetists and tags.

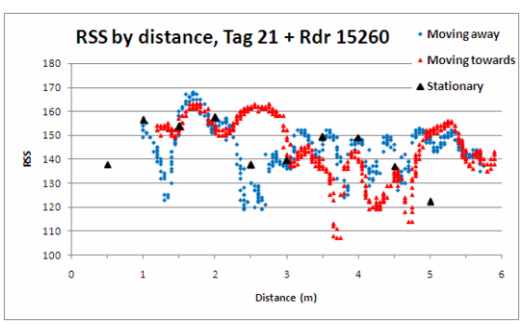

Figure 1 - Example RSS-Distance Relations

Table 2 – RSS effect of anaesthetist-tag interactions

Condition	Maximum Change in RSS
Change tag orientation	+30 points
Wear tag	-20 points
Obstruct tag	-10 points
Wear + obstruct tag	-35 points

LOS Sensing

Table 3 shows the maximum precision achieved by training SOMs on the data from dry run 1. When the most precise SOM was tested on the data from dry run 2, it gave only 39% precision. Similar results were found with SOMs trained on dry run 2 data and tested on dry run 1 data.

Given the results of dry run testing, a few changes were made for the analysis of simulated procedure data :

- Tag subsets were removed as a variable since there was minimal difference between the various combinations at the larger SOM size. All tags were included.
- RFID data cleaning method was added as a variable. Given the variation in RSS values across the two dry runs, we expected there might be differences in SOM precision depending on whether missing RSS values were filled in with averages based on other data for the procedure (as had been done for the dry runs), other data for all procedures on the same day, or other data for all procedures. For the sake of completeness we also tried no data cleaning.
- Larger SOM sizes were tried, since video analysis identified 150-200 LOSs per procedure, rather than the 17 used in the dry runs.

Table 4 shows the maximum precision achieved by training SOMs on the data from one procedure. When the most precise SOM was tested on data from another procedure on the same day, precision decreased to 54%. When the SOM was tested on data from procedures on different days, precision fell within the 40%-50% range. Similar results were found when repeating the SOM analysis starting with different procedures.

The anaesthetists' VASs for distraction were converted to values in the range 0 (No distraction) to 100 (Worst distraction). Table 5 shows a summary of results.

Table 3 - Maximum SOM precision for dry run 1 data

Tags	SOM Size 5	SOM Size 10
Anaes.	84.1%	95.2%
Landmark	98.3%	99.7%
Ceiling	80%	98.9%
An. + Lnd.	98.9%	99.7%
An. + Clg.	80%	99.8%
Lnd. + Clg.	80%	99.9%
All	80%	99.8%

Table 4 - Maximum SOM precision for procedure 39 data

Cleaning	SOM Size 10	SOM Size 20	SOM Size 30
None	17%	40%	77%
Proc.	58%	92%	96%
Day	56%	84%	92%
All	39%	61%	78%

Table 5 - Distraction Ratings (n=20)

Distraction	Min	Max	Average
Tags	0.25	25.5	5.55
Readers	0.75	10.75	3.94
Observer	1.00	70.00	3.94

Discussion

Based on the laboratory test results, the Wavetrend RFID equipment seems suitable for LOS sensing in most respects. The average time between tag reads of 2.5s is significantly better than the 7.5s - 30s reported in [13,14]. Likewise, tag granularity of 123 points is significantly better than the 8 points reported in [13]. The RSS standard deviation is small in relation to the average, indicating that RSS is very stable.

The major challenge presented by the RFID equipment is the RSS-distance relations. While we didn't expect the tags to exhibit ideal inverse square relations [12], we were surprised at so much variation between different tag-reader combinations. This would seem to preclude the use of LANDMARC-style RSS comparisons across tags [14]. But it doesn't disqualify the equipment from use for LOS sensing; the inherent tag-reader differences can be regarded as simply another source of RSS variation, alongside movement, orientation, and so on.

Our assumption that the RSSs of the ceiling tags would remain relatively stable was proven to be true only for the tags closest to each reader. They can continue to serve as 'canaries'. For the ceiling tags directly over the anaesthetic triangle, RSS does appear to be affected by anaesthetists' movement. We were surprised to see that, at larger SOM sizes, the landmark and ceiling tags both seemed to be more useful for LOS sensing than the anaesthetist tags (see Table 3).

The very high precision scores of SOMs trained on the dry run data (see Table 3) was encouraging, albeit achieved in a very 'sensing-friendly' environment with only one person and a small number of LOSs. We expected much lower precision in the more realistic simulated procedures, so 90+% scores were surprisingly high. Such scores clearly won't be possible in a real-time system, since they rely on having all the data for the procedure / day. Having to fill in missing RSS values using data from previous days, or even earlier in the same day, can reduce precision significantly, although is still an improvement over no cleaning at all (see Table 4).

Some decrease in precision when testing SOMs across procedures / days was expected, but such large decreases were surprising. Comparing the RFID data for matching tag-reader-LOS combinations across the two dry runs revealed that the RSS values in dry run 2 were up to 30% higher. The 'canary' tags showed increases of up to 10%, suggesting that some general environmental effect may have accounted for some of the difference. The remainder likely reflects changes in the location and orientation of anaesthetic and landmark tags between procedures. For example, the operating table is frequently moved between procedures so that the floor underneath can be cleaned. If it's not replaced in the same location and orientation, even a small change could result in large differences in RSS (see Figure 1 and Table 2). These differences could possibly be detected, and corrected for, with a calibration process before each procedure or at the start of each day.

Unsurprisingly, the anaesthetists found the RFID tags and readers much less distracting than a human observer (see Table 5). The cost of the TADAA system's hardware is approximately the same as a human observer's tablet PC. The system's ongoing cost, replacing active RFID tags every 5 years, is significantly less than an observer's remuneration.

Future Work

We continue to develop the TADAA system's RFID data cleaning, and SOM analysis approaches, and to prepare Hidden Markov Machine (HMM) algorithms for activity recognition testing.

In the medium term, we intend to complement RFID with additional sensors. RFID is best suited to LOS-specific manual activities (see Table 1). Detecting LOS-independent activities would be better done by other sensors. Communications, for example, might use a microphone suspended above the anaesthetic triangle. We are also considering means of recognising not just when a drug is administered, but which drug and how much. Analysis of patient vital signs may assist this, as in [10].

We ultimately see the TADAA system as a tool for improving patient safety. "In anaesthesia every complication has the potential to cause lasting harm to the patient. Therefore deviations from the norm must be recognised and managed promptly and appropriately" [5]. Activity data collected over time could be mined to produce 'norms' for procedure types, patient conditions, and so on. These would be as detailed as the Hierarchical Task Analysis (HTA) in [15] but based on actual practice. Anaesthetic activity detection in real-time could then compare actual activity with the norm, recognise deviations and raise alarms.

Conclusion

Task analysis has the potential to "provide more rational basis for making improvements" in anaesthesia, and ultimately to improve patient safety. But to do so it must capture scientific data to satisfy the requirements of evidence-based medicine, and not be too intrusive or expensive to implement in practice. Current task analysis methods, based on theory or observation, are unlikely to meet these criteria.

The TADAA system is intended to automate anaesthetic task analysis, through use of active RFID technology, and a combination of SOM and HMM machine learning informed by existing task analysis data. Testing in our lab and in high-fidelity

OR simulations suggest that the TADAA system is less intrusive and expensive than observers. However accurate location sensing, a first step towards activity detection, remains a challenge in the face of a complex interaction of factors affecting RFID's radio signals.

As development of TADAA continues we envisage adding new sensors, and means of storing, mining and visualising activity data. We see the system as potentially a valuable tool to improve patient safety in anaesthesia, and in other medical disciplines.

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A Model Driven Approach to Imbalanced Data Sampling in Medical Decision Making

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Abstract

Classification is an important medical decision support function that can be seriously affected by disproportionate class distribution in the training data. In medical decision making, the rate of misclassification and the cost of misclassifying a minority (positive) class as a majority (negative) class are especially high. In this paper, we propose a new model-driven sampling approach to balancing data samples. Most existing data sampling methods produce new data points based on local, deterministic information. Our approach extends the idea of generative sampling to produce new data points based on an induced probabilistic graphical model. We present the motivation and the design of the proposed algorithm, and compare it with two representative imbalanced data sampling approaches on four medical data sets varying in size, imbalance ratio, and dimension. The empirical study helped identify the challenges in imbalanced data problems in medicine, and highlighted the strengths and limitations of the relevant sampling approaches. Performance of the model driven approach is shown to be comparable with existing approaches; potential improvements could be achieved by incorporating domain knowledge.

Keywords:

Random sampling, Synthetic Minority Over Sampling (SMOTE), Model driven sampling, Imbalanced data learning

Introduction

Classification is an important medical decision support function that is often seriously affected by disproportionate class distribution in the training data. A main motivation of this work is the data imbalance challenge we have encountered in building classifiers in many real-life medical domains, including head injury, asthma, breast cancer, etc. An imbalanced data set contains a disproportionately high number of data in one or more classes than those for a class that is of interest. Traditional machine learning methods cannot work well with such data to build an accurate classifier; they tend to bias toward the majority class data and result in a low positive rate. In medical decision making, the cost of misclassifying a minority (positive) class as a majority (negative) class is especially high. The imbalanced data problem is increasingly being actively addressed in the field; some recent work include: Mazurowski et al. [1] studied the effect of imbalanced data to neural networks in medical decision making; Cohen et al. [2] deployed existing imbalanced data learning techniques in the surveillance of nosocomial infection.

There are two main categories of approaches to address the imbalanced data problem: 1) Algorithmic level approaches, where new machine learning algorithms are proposed or standard machine learning algorithms are modified to accommodate imbalanced data, *e.g.* learning rare class only [3], cost sensitive learning [4], etc., and 2) Data level approaches, which re-sample the imbalanced dataset to produce a new training dataset with balanced class distribution. We focus on the data level approaches in this work.

In this paper, we propose a Model Driven Sampling (MDS) approach to solving the imbalanced data problem. Unlike existing sampling approaches that use local, deterministic information to generate new data points, MDS learns from the whole labeled data set and possibly domain knowledge to induce a probabilistic graphical network to generate new data points. We also examine the performance of MDS as compared with two representative sampling approaches - Random Sampling (RS), and Synthetic Minority Over Sampling (SMOTE), on imbalanced data sets with different characteristics in medicine. We compare the three approaches on four medical data sets varying in complexity or dimension, data size and imbalance ratio, using different machine learning algorithms to build the resulting classifiers.

Related Work

Random sampling generates duplicated data without creating any new information. Random under-sampling randomly removes instances from the majority class to balance the class distribution. The disadvantage is that there is a risk in deleting useful information. Random over-sampling, on the other hand, randomly duplicates instances in the minority class. The disadvantage is that the decision region for the minority class may become more and more specific and possibly lead to data over fitting. In this paper, random sampling includes both random over-sampling and random under-sampling.

On the other hand, SMOTE creates synthetic data along the line between two nearest data points. In SMOTE, the minority class is over-sampled by taking each minority sample and introducing synthetic examples along the line segments joining with any of the k (k is 5 in the current implementation [5]) nearest minority neighbors. Chawla [5] showed that the synthetic examples generated by this technique cause the classifier to create larger and less specific decision regions as compared to random over-sampling.

Progressive sampling is systematically described by Foster et al. [6]. It was later used in [7, 8] for imbalanced data learning. However, the main advantage of progressive sampling is to improve the system efficiency by making use of minimal training data. The follow-on work [7, 8] either assumes there is sufficient training data, or use random sampling when there is insufficient data [7].

Random sampling is case duplicating based on one data point; SMOTE generates synthetic data based on two data points. They are representative of the sampling techniques that generate data based on local information. Recently, Liu et al.[9] proposed a generative oversampling approach which attempts to generate data based on the probability distribution of the minority data. This is similar to the idea presented in this work, with a major difference in the form of the probabilistic distribution generated.

A Model Driven Sampling Approach

In many biomedical domains, minority data can be sparse, but domain knowledge is commonly available. Model Driven Sampling (MDS) is an approach to learning from the whole training data set (both minority and majority, learning from majority can prevent generating noisy minority), and supports incorporation of domain knowledge into the induced model.

In contrast to the generative sampling approach [9], which builds a probabilistic distribution as the generative model, We induce a probabilistic graphical model or Bayesian Network for data generation. Bayesian Network is a factored representation of a probability distribution, representing the probabilistic relationships among a set of random variables. For example, Figure 1 shows the commonly cited Asia network. In a Bayesian network, the nodes indicate the random variables; the arcs indicate conditional dependencies, and there is a conditional probability distribution embedded in each node, denoting the conditional relationships of the values of the random variables with respect to different configurations of its parent nodes. The advantage of Bayesian Network is that it can easily combine both observational (data) and domain knowledge. For example, the causal relationship between smoking and cancer can be added from domain knowledge if it was unknown from the training data.

The MDS algorithm is as follows: As shown in Figure 2, we first build a model A from the original data set; model A generates new data based on the characteristics of the whole data set; the generated data is combined with the original data to form a new training data set to train classifiers. Specifically, we learn a Bayesian model using the K2 structure learning algorithm [10] from the data set. Then we generate minority data from the model using the Markov Chain Monte Carlo (MCMC) method [11].

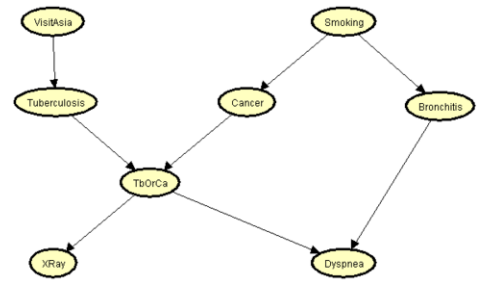

Figure 1 - Bayesian Network model for the Asia data

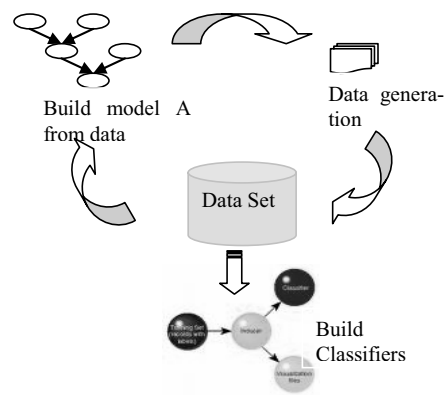

Figure 2 - Work flow in Model Driven Sampling

Comparing to other common sampling approaches, MDS generates new data based on the whole data set, thus the generated data would be more "meaningful" from a global perspective than the data generated randomly (random sampling) or data generated from local information (SMOTE). Due to the lack of domain knowledge and in fairness, we did not consider domain knowledge in the comparison analysis reported below, although we demonstrated the feasibility and promise of its inclusion.

Datasets

The data sets selected for the analysis span a wide spectrum in terms of complexity or dimension, imbalance ratio, and size; they are meant to illuminate the strengths and limitations of the algorithms studied under different conditions in medical domains. The data sets are: Asia, Mammography, Indian Diabetes, Asthma First Visit data. The Asia data set is commonly used in machine learning communities as examples illustrating

Bayesian Network learning. The asthma data set is collected, under proper approval and usage guidelines, from the hospitals in Singapore. The other two data sets are from the UCI Machine Learning repository [12] which were used for imbalanced data learning in [5]. The characteristics of the data sets are: binary data, unevenly distributed with different imbalance ratios (IB) as shown in Figure 3 and Table 1. IB ratio is equivalent to the percentage of minority examples in the training data; the lower of the value the more imbalanced the data is.

Table 1 - Class distributions (in numbers)

	Majority	Minority	IB ratio	Features
Asia	530	42	0.073	7
Indian Diabetes	500	268	0.349	8
Mammography	10923	260	0.023	6
Asthma First Visit	678	213	0.239	40

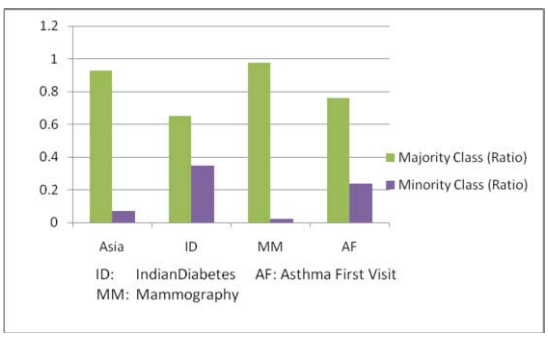

Figure 3 - Data class distributions (in ratio).

The Asia data set is about people who visited Asia and whether they had developed dyspnea or not. In our experiment, the Asia data set includes 42 positive cases, and 530 negative cases.

The Pima Indian Diabetes [12] data set includes 2 classes and 768 samples. The data is used to identify the positive diabetes cases in a population near Phoenix, Arizona. There are only 268 positive class samples.

The Mammography data set has a high skewed ratio: 10923 negative examples versa 260 positive examples. The trained classifier needs to be highly sensitive to detect the positive cases.

The Asthma First Visit data records the information when asthma patients visit the respiration centre for the first time. It has 40 attributes recording patients' general information, asthma history, treatment history, etc. There are 213 positive samples out of total 891 samples. The main problem is to determine whether a patient will encounter any control failure in the future based on the information provided on his first visit.

Experiments

We conducted experiments on the four data sets using three classifiers (C4.5 decision tree, Bayesian Network, Support Vector Machine) and three data sampling techniques (RS - Random Sampling , SMOTE, MDS). The experiment design is as shown in Figure 4, and each experiment ran through 10 fold stratified cross validation. The original data was split into 10 folds, and in each fold, training data was sampled by various approaches to build a new model which would run on the testing data.

Prediction accuracy cannot be used as the evaluation criteria because it is shown to discriminate the minority classes [13]. As shown in Equation (1), we use the geometric mean(g-mean) [14] of the accuracies measured separately on each class (where a^+ is true positive rate and a^- is true negative rate) as our evaluation criteria. The basic idea behind this measure is to maximize the accuracy on both classes.

$$\text{g - mean} = \sqrt{a^+ \times a^-} \quad (1)$$

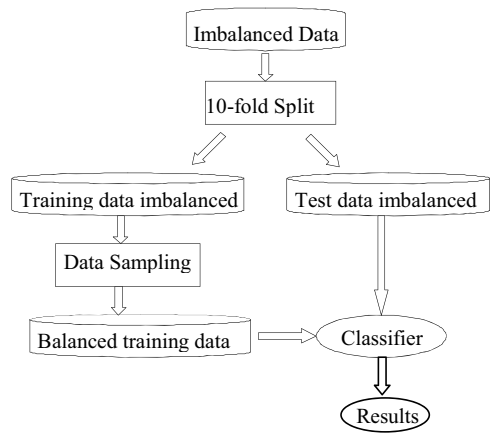

Figure 4 - Experiment design

Only the Bayesian Network (BN) results are reported in detail in this paper. This is because, as shown in Table 2, while the Bayesian Network performance may not always be the best in all experiments, it is generally more stable than others.

Table 2 - Performance of various algorithms on MDS

	Asia	Asthma	Diabetes	Mammography
BN	0.88	0.759	0.759	0.622
C4.5	0.266	0.591	0.771	0.886
SVM	0.428	0.591	0.777	0.874

Asia Data

The Asia data set has the lowest number of minority examples and the second lowest imbalance ratio 0.073. As shown in Table 3, the original data set without any sampling has a high prediction rate on its majority samples (98.7%), but a low prediction accuracy on its minority samples (7.1%), thus the overall performance is the lowest at 26.5%. Random sampling and SMOTE both significantly improve the predictions on minority samples and achieve a much better overall performance. MDS achieves the best performance 88% overall and 90.5% on minority data set.

Table 3 - Asia data running results

	Original Data	RS	SMOTE	MDS
TP[1]	0.071	0.881	0.69	0.905
TN[2]	0.987	0.863	0.925	0.856
G-Mean	0.265	0.872	0.799	0.88

Indian Diabetes Data

Indian Diabetes data is a relatively balanced data set with the highest imbalance ratio at 34.9%. Therefore, without any sampling, the original data set can achieve a satisfying performance on minority data and a good overall performance. The three sampling approaches equally improve the performance especially on minority by11%. The overall performance is not much improved. (As shown in Table 4)

Table 4 - Indian Diabetes data running results

	Original Data	RS	SMOTE	MDS
TP	0.669	0.783	0.787	0.772
TN	0.836	0.741	0.745	0.745
G-Mean	0.748	0.762	0.766	0.759

Mammography Data

Although Mammography data set has the lowest imbalance ratio 0.023, it is still relatively simple as it has only 6 features which result in a low data complexity. In

Table ***5***, the original data set can achieve 85% overall performance. The other approaches can equally improve the minority prediction by 15%. SMOTE has the best overall performance 89%, and MDS has a comparable performance of 88.3%.

Table 5 - Mammography data running results

	Original Data	RS	SMOTE	MDS
TP	0.735	0.888	0.873	0.885
TN	0.981	0.857	0.908	0.881
G-Mean	0.849	0.872	0.89	0.883

Asthma First Visit Data

The Asthma First Visit data has 40 features, the highest dimension among all. In Table 6, none of the approaches can achieve a good performance. Relatively, random sampling gives the best minority prediction (15% improvement) and the best overall performance (5% improvement). MDS approach ranks the second.

Table 6 - Asthma First Visit data running results

	Original Data	RS	SMOTE	MDS
TP	0.419	0.576	0.448	0.5
TN	0.852	0.732	0.805	0.775
G-Mean	0.598	0.649	0.6	0.622

Discussion

There are three important challenges for learning with imbalanced data sets: 1) the imbalance ratio, 2) the absolute size of the minority data, 3) the dimension of the data set. The three factors are common in most medical data sets, and they vary among the four representative data sets chosen in this work. We have examined relatively easy problems which are less imbalanced, low dimensional, with sufficient minority samples (e.g., Indian Diabetes and Mammography datasets), to hard problems which are highly imbalanced, high dimensional (e.g., Asthma), or with scarce minority samples (e.g., Asia).

The three approaches considered represent a wide range of data sampling efforts in tackling the imbalanced problems. They can be categorized by their learning scopes. Random sampling duplicates the data without creating new information; SMOTE algorithm creates new synthetic data based on local information – the nearest neighbors; MDS approach generates data based on global information – the knowledge model built from the full training space. As illustrated in Figure 5, random sampling produces data from a single data point; SMOTE generates data over two data points; MDS generates data from a model built from all labeled data or domain knowledge.

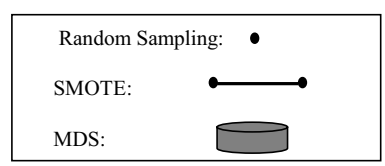

Figure 5 - Learning scopes for 3 sampling approaches

[1] TP is true positive rate for predicting minority samples.
[2] TN is true negative rate for predicting majority samples.

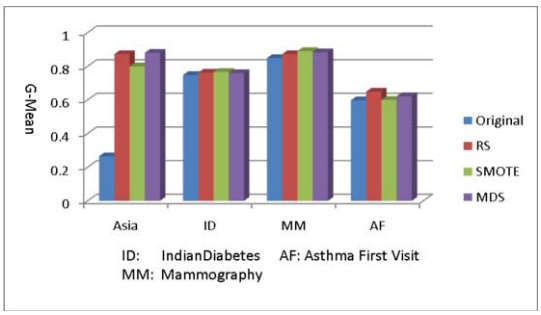

Figure 6 - Overall performance (G-Mean) comparison

Figure 6 shows that all three sampling approaches can improve classification performance on imbalanced data sets, especially on minority data. Comparing these three sampling approaches, random sampling is easy to implement and efficient; SMOTE will perform well especially when the minority data is tense; MDS will perform well when we have a reasonable accurate model to generate minority data, and this model could be from our medical domain knowledge or learning from existing data or both. Thus MDS can potentially address imbalanced problems with scarce or sparse minority data. In future work, we will incorporate domain knowledge into our model. This capability is a major difference from and a potential advantage over the other generative sampling approaches [9].

Conclusions

This work examined and analyzed the challenges in the imbalanced data problems in medical decision support. We proposed a new approach – Model Driven Sampling that can potentially make use of all available data and domain knowledge to sample new data for balancing class distribution. We compared the performance of different major sampling approaches on four representative data sets. We showed that data sampling approaches can improve classification performance to a reasonable level most of the time. In particular, they can significantly improve predictions over the minority data, which is important in medical decision support. We showed that MDS is comparable in performance with respect to the other approaches considered, and can outperform them in certain cases. In future work, we will incorporate domain knowledge into MDS, and extend it to multi-class problems.

Acknowledgment

We thank the reviewers for their valuable comments, and thank Prof Tow-Keang Lim for providing us the asthma data set. This work was partially supported by Academic Research Council grant R252-000-327-112 and grant R-252-000-309-112 from the Ministry of Education of Singapore.

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Feature importance analysis for patient management decisions

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Abstract

The objective of this paper is to understand what characteristics and features of clinical data influence physician's decision about ordering laboratory tests or prescribing medications the most. We conduct our analysis on data and decisions extracted from electronic health records of 4486 post-surgical cardiac patients. The summary statistics for 335 different lab order decisions and 407 medication decisions are reported. We show that in many cases, physician's lab-order and medication decisions are predicted well by simple patterns such as last value of a single test result, time since a certain lab test was ordered or time since certain procedure was executed.

Keywords:

Data interpretation, Statistical, Decision support systems, Clinical, Decision support techniques, Evidence-based medicine.

Introduction

Advances in data collection and electronic health record technologies have led to the emergence of clinical datasets, where data instances consist of sequences of clinical findings, lab values, measurements, and medication actions [7]. Such multivariate time series data provide us with a complex temporal characterization of the patient case. Analyses of these clinical datasets can be extremely useful for building models supporting patient outcome prediction, early detection of adverse events, or clinical decision making [8].

The key challenge when analyzing the clinical datasets is the complexity of the multivariate time series and the number of possible temporal features (patterns) one may generate to characterize such data. Inevitably we ask what types of features are the most important to represent the patient case. Are patterns related to most recent patient history more important than the distant past? What features do the physicians base their decisions upon? Are *values* or *trends* more important? Do physicians tend to look into simple trends and simple time constrains or into more complex temporal characteristics between several clinical variables?

We study this problem by analyzing the importance of various temporal features for lab and medication order decisions. More specifically, we investigate what temporal characteristics of the patient state influence the physician's decision the most.

Our analyzes on a collection of 4486 post-surgical cardiac patient records show that a relatively simple temporal characterization of the patient state is often sufficient to predict well many lab order and medication decisions. Moreover, we identify which of those simple characteristics are the most valuable sources of information for such a prediction.

The paper is structured as follows. First, we introduce the post-surgical cardiac dataset and temporal features used in our analysis. After that, we analyze the data and present statistics reflecting how different features predict the lab order and medication decisions. Finally, we discuss the results and conclude.

PCP Dataset

Post-surgical cardiac patient (PCP) database is a database of de–identified records for 4486 post–surgical cardiac patients treated at one of the University of Pittsburgh Medical Center (UPMC) teaching hospitals. The entries in the database were populated from data from the MARS system, which serves as an archive for much of the data collected at UPMC. The records for individual patients included discharge records, demographics, progress notes, all labs and tests (including standard and all special tests), two medication databases, micro-biology labs, EKG, radiology and special procedures reports, and a financial charges database. The data in PCP database were cleaned, cross-mapped, and are currently stored in a local MySQL database with protected access.

Dataset used in the analysis

To conduct our analysis, we used time-stamped data stored in the PCP database and converted them into a vector space representation of a patient state at discrete time points to get a collection of patient state examples. More specifically, each patient record in the PCP was used to build a sequence of patient state examples reflecting scenarios the physicians faced at 8:00am every 24 hours when managing the patient (Figure 1). Only the information available up to the segmentation points was considered in the vector space representation. Our 24-hour segmentation led to the total of 30,828 patient state examples.

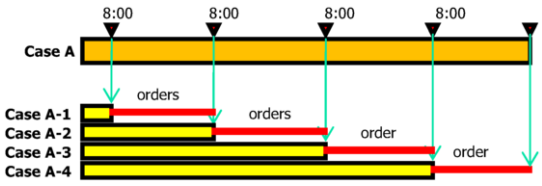


Figure 1 -- A segmentation of a patient case (Case A) to multiple patient state instances (A-1 to A-4) at 8:00am. Lab and medication orders for the following 24 hours are associated with each instance.

Patient-management decisions. In addition, every patient state example in the dataset that was generated by the above segmentation process was linked to lab order and medication decisions that were made for that patient within next 24 hours. Patient management decisions considered were:

- Lab order decisions with (true/false) values reflecting whether the lab was ordered within the next 24 hours or not
- Medication decisions with (true/false) values reflecting if the patient was given a medication within the next 24 hours or not.

A total of 335 lab order and 407 medication decision values were recorded and linked to every patient state example in the dataset.

Features

To represent a patient state we have adopted a vector space representation that is convenient for machine learning approaches. In this representation a patient state is represented by a set of features characterizing the patient at a specific point in time and their corresponding feature values. Features represent and summarize the information in the medical record such as last blood glucose measurement, last glucose trend, or the time the patient is on heparin. These representations were also used in our experimental studies published in [1–3].

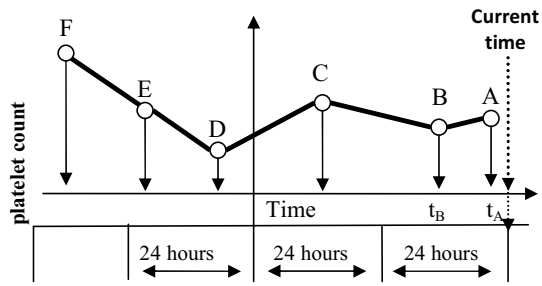
The features used in our experiment were generated from time series associated with different clinical variables, such as blood glucose measurement, platelet measurement, Amiodarone medication. The clinical variables used in this study were grouped into five categories:

1. Laboratory tests (LABs)
2. Medications (MEDs)
3. Visit features/demographics
4. Procedures
5. Heart support devices

We now briefly describe the features generated for clinical variables in each of these categories.

Lab Features

For the categorical labs, for example the ones with POS/NEG results we used the following features: Last value; second last value; first value; time since last order; whether the order pending; whether the value is known; and, whether the trend known. For the labs with continuous or ordinal values we used a richer set of features including features as difference between the last two values, slope of the last 2 values, and their percentage drop/increase. We used the same kind of features for the following pairs of lab values (last value, first value), (last value, nadir value), (last value, horizon value). Nadir and horizon value are the lab values with the smallest and the greatest value recorded up to that point. Figure 2 illustrates a subset of features generated for the labs with continuous values. The total number of features generated for such a lab is 40.



Temporal features:
Last value: A
Last value difference = B-A
Last percentage change = (B-A)/B
Last slope = (B-A) / (t_B-t_A)
Nadir = D
Nadir difference = A-D
Nadir percentage difference = (A-D)/D
Baseline = F
Drop from baseline = F-A
Percentage drop from baseline = (F-A)/F
24 hour average = (A+B)/2

Figure 2 -- A subset of temporal features generated for continuous valued lab tests.

Medication Features

For each medication we used four features: 1) indicator if the patient is currently on the medication 2) time since the patient was on that medication 3) time since the patient was put on that medication for the first time and, 4) time since last change in the status of patient taking the medication.

Visit/Demographic Features

We only have 3 features in this category: age, sex, and race. These are static and same for every time point we generate.

Procedure Features

Procedure features capture the information about procedures such as *Heart valve repair* that were performed either in OR or at the bedside. In our data we distinguish 36 different procedures that are performed on cardiac patients. We record four features per procedure: 1) time since the procedure was done

last time 2) time since the procedure was done first time 3) whether the procedure was done in last 24 hours, and 4) whether the procedure was ever done to this patient.

Heart Support Device Features

Finally, we describe the status of 4 different heart support devices: Extracorporeal Membrane Oxygenation (ECMO), Balloon counter pulsation, Pacemaker, and other Heart Assist Device. For each of them, we record a single feature which describes whether the device is currently used to support patient's heart function.

Altogether, our dataset consists of 9,223 different features describing 30,828 patient states. As noted earlier, we use the patient state to evaluate our ability to predict 742 lab and medication order decisions.

Methods

Univariate AUC analysis

Our objective is to evaluate the significance of a feature for predicting either the lab order or medication order decision.

Feature categories

While one can always analyze predictive relations in between features and individual decisions, the aim of this paper is to understand what kinds of features influence lab and medication orders the most. Hence our analysis focuses on summary statistics across multiple labs and medication decisions, and across multiple feature categories. To conduct these analyses we grouped 9,223 different features into:

(1) Five categories corresponding to lab, medication, demographics, procedures, and heart support device features.

(2) Forty temporal feature categories, each representing the same temporal characteristic of the time series. For example the category 'Time since last LAB' subsumes 'Time since last Platelet count' and 'Time since last Glucose lab' features.

Assessment metric

We used the AUC score to assess the feature significance. AUC score is an area under the Receiver operating characteristic [4] which is used to measure the predictive strength of a feature. To assess the importance of each feature category we computed the number of times the feature in the category is the best AUC feature for predicting the decisions.

Multivariate analysis

The limitation of the univariate analysis is the focus on an individual feature and it ability to predict the order decisions. In general, a better result may be often obtained by combining multiple features into a predictive model. To assess how helpful it is to use information from multiple features as opposed to just a single feature we have conducted a limited multivariate predictive analysis. Due the large amount of data, we used linear SVM classifier [5, 6]. In particular, for each order decision we trained such a classifier using 1) top 1; 2) top 3; and 3) top 30 features according to their AUC score computed on a subset of 2900 patients. After training the performance of the multivariate models was assessed by calculating their AUC on the remaining patient cases.

Results

Prediction of LAB orders

Figure 3 summarizes the most influential category for lab order decisions. The categories considered are labs, medication, procedure, demographics, and support devices features. Clearly, the most influential predictors for lab orders are features derived from lab and procedures data. Briefly, the best predictors for the next lab order are past labs. Intuitively, the lab order decision is typically driven by the existence of previous abnormal value of the same or other lab, and time since this lab has been measured. Procedure features are important as the type of surgical procedure and the time elapsed since the procedure may prompt close monitoring of certain organ functions and hence corresponding lab orders.

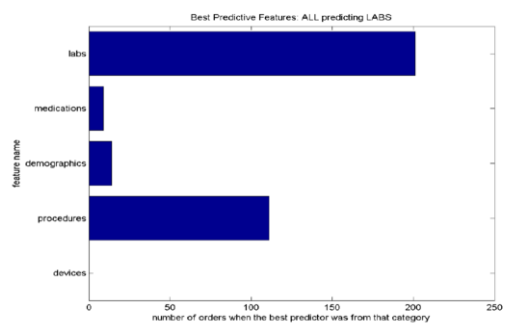


Figure 3 -- The importance of labs, meds, procedures, demographics and support device information for lab order decisions.

The next histogram (Figure 4) shows the top 10 most important temporal lab features for predicting the orders of the same lab. The best feature categories were the times since the last lab order and lab results, in particular last value, nadir, and horizon values. The fact that the time since last measurement is the dominant feature is somewhat surprising but can be explained by the fact that many labs for our cohort of patients are done regularly and routinely, and the time since the last test was done is a good indicator of the upcoming lab order. Also surprising is a relatively low importance of trend features, in general absolute values of labs appear to be more significant for predicting the lab orders. This suggests value based prediction patterns are dominant for lab order decisions and trend information (if used at all) typically refines the pattern.

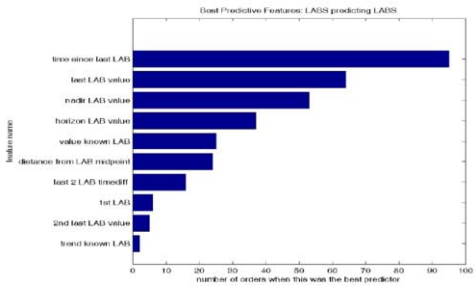


Figure 4 - The most influential temporal lab feature categories for predicting lab order decisions with the same lab features.

Figure 5 illustrates which temporal lab features predict the order of a different lab (i.e. not itself) the best. In this case, we observe that the last lab value is the most significant predictor of the order decision. This can be explained by the fact that an abnormal value of one test prompts the order of the other test. Also some lab tests are organized in panels and panels are typically ordered together creating this dependency.

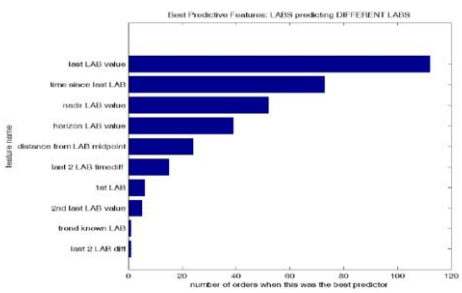


Figure 5 -The most influential temporal feature categories for predicting lab order decisions with other lab features.

Prediction of Medication orders

Figure 6 shows the influence of labs, medication, demographics, procedures, and support device features for predicting medication orders. In particular, we are showing the prediction of a medication *commission*, provided that a patient was not on that medication before. We see that the list is dominated by procedure features as some medications tend to follow certain procedures.

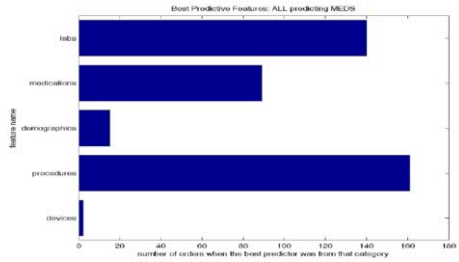


Figure 6 - The importance of labs, meds, procedures, demographics, and support device information for medication commissions.

Figure 7 breaks down the categories shown in Figure 6 and shows the top 10 most predictive features. For many medications the time since last procedure was the most predictive feature. For examples commissions of Papaverine could be most predicted (AUC= 95%) with the time that passed since the last Coronary Artery Bypass for that patient.

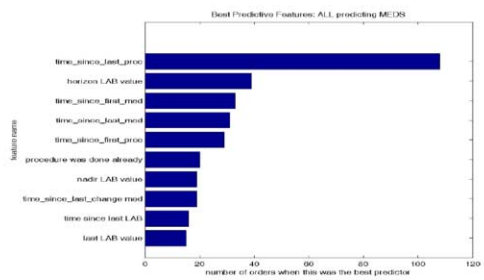


Figure 7 -The most important temporal lab features for predicting medication commissions.

Figure 8 shows the importance of medication features from different medications on the decision. One possible explanation for this dependency is that many medications are complementary and administered together, while other combinations are not used because of possible drug interaction. Therefore, a presence of one medication can often explain (predict) the presence or absence of another one.

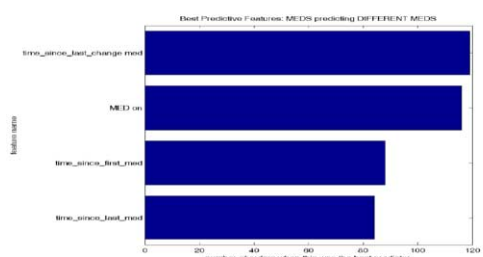


Figure 8 -The importance of temporal features for predicting medication order decisions with other medication features.

Multivariate prediction

The goal of this experiment is to explore the benefit of combining information from multiple sources or features. Tables 1 and 2 show AUC scores for prediction of top 10 highly predictive labs and medications from the linear SVM classifier. The classifier was trained on a subset of all features, in particular top 1, top 3 and top 30 best performing features in the training data. All results are reported on the independent test set.

We note that the feature selection for models with over 9000 feature candidates is an important and challenging problem and that the greedy selection applied in the experiment may not be the best one. However, this (somewhat limited) experiment indicates that a single feature is often a good predictor of the decision, suggesting simple patterns and their refinements may be able to capture well the prevalent lab order and medication order patterns.

Table 1- AUC for linear SVM trained on top 1, 3 and 30 most predictive features, showing 10 highly predictive labs

	top 1	*top 3*	*top 30*
GLU	87.46%	85.97%	87.73%
TCPK	79.56%	81.38%	82.68%
PPO2V	79.71%	79.70%	85.00%
VANMCR	74.15%	79.60%	82.13%
LD	79.22%	79.14%	82.69%
HPA	83.54%	83.03%	84.97%
RETAB2	75.83%	75.67%	81.89%
TEGMA	75.91%	85.36%	84.76%
TEGR	75.91%	85.35%	85.30%
TEGALP	75.91%	85.38%	85.09%

Table 2- AUC for linear SVM trained on top 1, 3 and 30 most predictive features, showing 10 highly predictive medications

	top 1	*top 3*	*top 30*
Nitroglycerin	71.48%	79.50%	80.53%
Papaverine	82.34%	83.83%	89.19%
Ioversol	87.65%	88.58%	89.50%
Aminocaproic	79.49%	79.39%	86.83%
Aprotinin	80.67%	78.65%	85.99%
Thiopental	76.40%	75.62%	85.30%
Eptifibatide	87.22%	89.13%	89.75%
Darbepoetin	86.22%	90.33%	88.85%
Iodixanol	69.62%	87.99%	87.26%
Vitamin K	85.87%	86.08%	86.61%

Conclusions

Our univariate analyses of relations in between patient states and patient-management decisions revealed that the lab and medication order decisions are often driven by simple predictive patterns that involve more recent set of values, or times since the occurrence of some event (e.g. procedures, or previous lab/medication orders). Our (limited) analyses of more complex multivariate models suggest that lab and medication order decisions are likely based on only few clinical variables and their characteristics (features). In the future, we plan to further expand this study by analyzing feature dependencies and by developing more advanced feature selection for building multivariate predictive models.

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Chapter 12.

Security, Privacy and Confidentiality

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Deployment of a Highly Secure Clinical Data Repository in an Insecure International Environment

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Abstract

We have designed and deployed a novel approach to protecting Personal Healthcare Information in environments where a data center is remote and its physical security cannot be assured. Our "KeyServer" methodology uses a server-client-server architecture to dynamically serve keys from a distant server in a separate secure data center in the US. The approach combines pre-existing and novel techniques into a layered protective barrier around compromise of patient data. We describe how this technology provides scalable security that makes security breaches highly unlikely. With some careful planning a Clinical Data Repositories fed by Electronic Health Records can be placed in relatively insecure settings, with a high-level of security surrounding data theft, even in the event of hardware theft. Such security architecture is ideal for not only developing nations, but for the evolution of health information to cloud computing platforms.

Keywords:

Security, Computer hackers, Computer data compromising, Computerized medical record system,

Introduction

In many countries with mature healthcare IT infrastructure, security of Personal Healthcare Information (PHI) is often provided by a multilayered approach that includes robust physically secure data centers, complex network security protocols, and a legal framework with effective enforcement. These approaches may or may not be suitable in developing countries with low evolving IT infrastructure where the risks of data theft by physical and electronic intrusion can be high. A review of the literature

To address health data security issues in high-risk environments with low level technological infrastructure,[1] we designed a novel encryption and authentication pathway. We posit that our approach to protecting PHI will be generally useful for cloud-based computing solutions in healthcare.

Methods

Data security is an important component of any electronic health record (EHR). We have designed and deployed an EHR in a Middle Eastern country that posed numerous challenges including remote data protection in a setting where we were concerned about physical security of the data. Because of low bandwidth between the Middle East and the US, deployment from a US based Tier-3 data center was not an option and we designed the system with the plan to place servers in a small commercial ISP data center located in the Middle East. Ultimately we were able to deploy in a secure government based data center, but this was well after the design phase was complete.

The core systems design consists of a MySQL 5.1 Community Edition relational database management system (Sun Microsystems) with a JAVA based application (Sun Microsystems) running on Apache Tomcat 6 (Apache Software Foundation) application server.

The original deployment strategy posed a number of problems, foremost being loss of control over the server environment. Furthermore, the database is designed for heavy secondary use of data in public health monitoring and research, making openness of the server based Clinical Data Repository (CDR) a high-risk asset.[2] Given these risks, we designed a multitier security strategy that utilizes a novel encryption and authentication pathway to provide network security and physical theft risk mitigation.

We started with the assumption that we could not assure physical security, and that our database and server code could be physically stolen given the lack of high end data facilities available in the region.[1] We were also cognizant of the fact that both the passwords and certain aspects of PHI, even with encryption, are vulnerable to preimage attacks, also known as a "dictionary attack". Passwords are notoriously susceptible to dictionary attacks,[3] and the nature of medical record numbers (MRN) as sequential non-sparse integers make them trivially susceptible to a preimage attack. Although we do have influence over password entry by users, we do not have influence over

existing medical record numbering schemes, so a secondary method of attack prevention is required.

Our initial approach was to encrypt the entire database except for any field that could be used for identification of patients. This is easily accomplished as MySQL natively supports symmetric encryption via full Advanced Encryption Standard (AES-128) support and asymmetric encryption via the Secure Hash Algorithm (SHA1). The AES-128 algorithm is a substitution permutation network encryption algorithm authorized by National Institute of Standards and Technology (NIST) for protection of information classified up to the "secret" level,[4] making it appropriate for storage of PHI. The use of AES encryption is highly secure, as no successful attack other than brute force, has been demonstrated in the literature. However, as in any password-based system, the system is vulnerable if you can discover the key since the data would be freely readable.

JAVA, while a highly secure language, has a vulnerability of being able to be easily human-readable reverse-compiled as it is not fully compiled, but rather partially compiled into byte-code. This means that storage of encryption keys in the code would be easily retrievable by having possession of the server/drives or compiled application. Having the keys in the source code also does not allow for easy changing of the codes as compilation and redeployment of the application is required.

We have created and deployed a novel "KeyServer" methodology that uses a server-client-server architecture to dynamically serve keys from a distant server in a separate secure data center in the US. The concept is that every column of every table in the remote MySQL database that needs to be encrypted, is encrypted with a column key. This key is only held in memory on the application server implementing the KeyServer client, and written to disk only on our secure KeyServer.

Each key can either be human-readable or machine-created thus protecting against dictionary attack by the use of random alphanumeric strings. Various identification attributes of the client network environment are also recorded on the KeyServer, including IP address and a hardware key of a physically separate device on the client network which is sent with every client request. These identification attributes make it very difficult to spoof the client's identity.

On boot the KeyServer client sends a getInitKey request with the identification information gathered from the client network via an encrypted web services call to the US KeyServer, and if authenticated the current keys are returned, and the application will start as shown in Figure 1.

At intervals varying between minutes and hours, the column keys on the KeyServer are changed; the KeyServer client checks its keys via a CheckKey request with the KeyServer master keys. The request sends the identification attributes described above, as well as the client's current keys. The KeyServer then checks the identification attributes, confirms the requesting client's authenticity and returns a pair of keys, the client's current key and the KeyServer's new key. For any given column, if the KeyServer and client keys are the same then the current settings are still valid and no change is made. If the client key is different to the KeyServer key then the master keys have been changed and the column is dynamically decrypted with the old key and encrypted with the new key. Figure 2 demonstrates this.

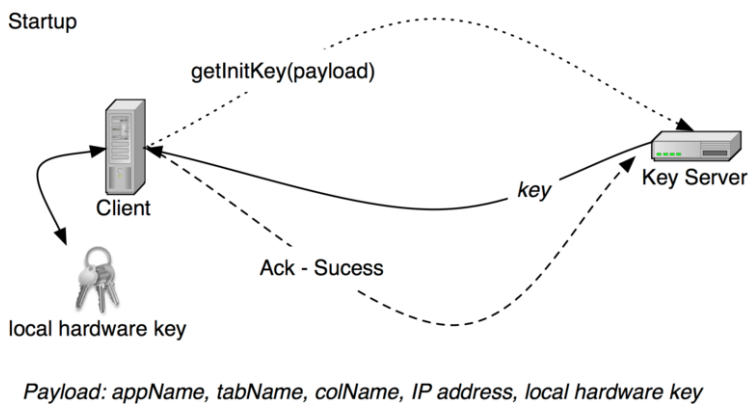

Figure 1 - Initial getInitKey request

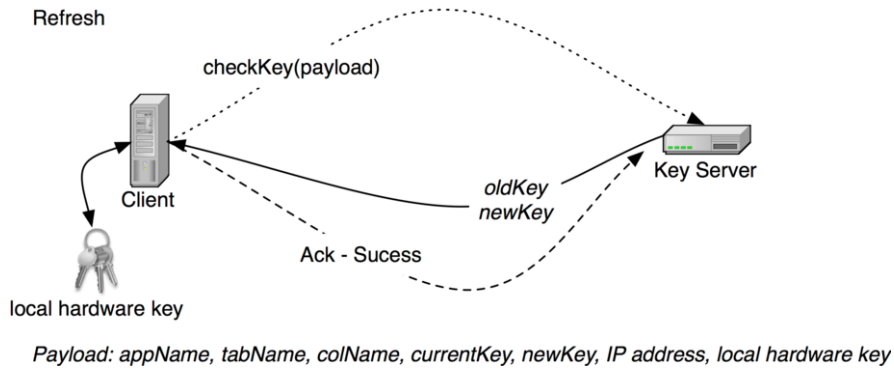

Figure 2 - Subsequent CheckKey request

The KeyServer never updates its own tables until an acknowledgement packet is returned from the client stating it has completed the key change successfully, as a failure could render the data unreadable. The transaction is carefully and securely logged on the server for future auditing. A network failure resets the timer, and the transaction will retry in the future.

A more detailed examination of the encryption process presents further security issues. A problem with PHI encryption is that predictable data, such as the non-sparse sequentially numbered MRN fields or names, require protection against preimage attacks. This is because if one encrypts a simple string using the same algorithm and key pair it will always produce the same hash every time. This is true regardless of the encryption method, whether symmetric or asymmetric, as both methods will produce the same output (a "collision" in encryption parlance) with the same source/key information. This is a much greater problem with asymmetric algorithms such as SHA1 where the key is fixed. It is less of a problem with random text, however patient identifiers, such as medical record numbers are simply sequential numbers 0-*n* and last names are known, so the creation of a preimage attack is trivial. For example, on a typical desktop computer you can generate the 128-bit SHA1 hash value dictionary for 10 million medical records numbers in less than 1 minute. Figure 3 demonstrates a MRN dictionary attack.

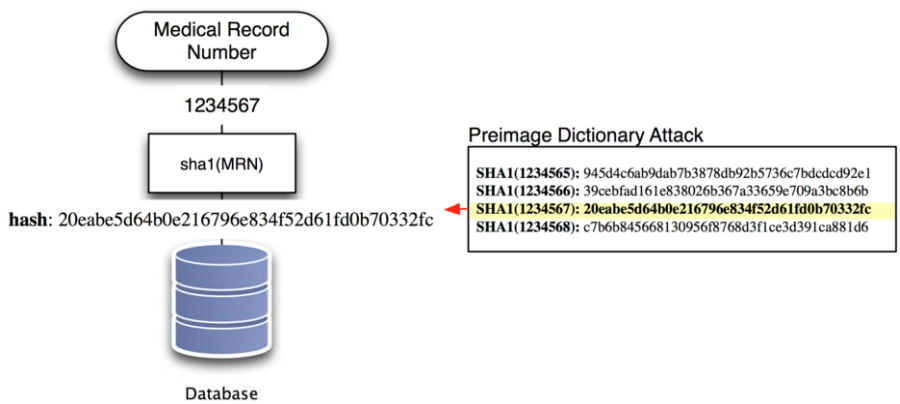

Figure 3 - Dictionary Attack on MRN's

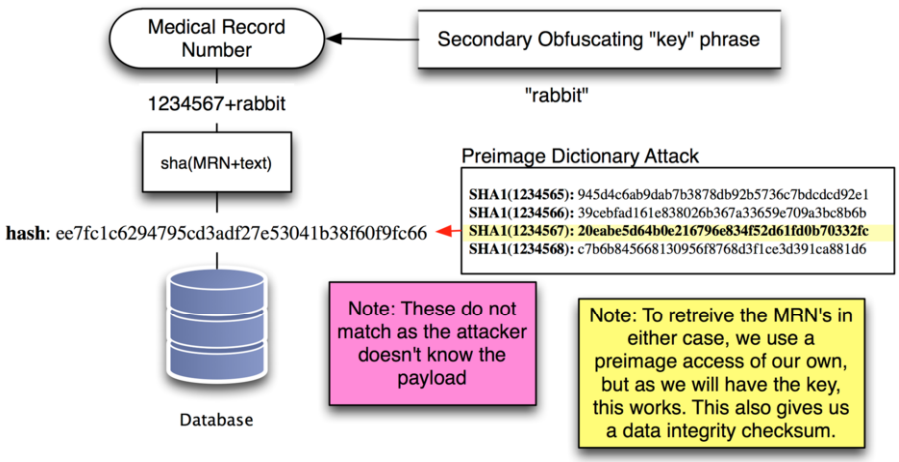

Figure 4 - SHA1 with extra payload

Our solution to solving this problem is to add an obfuscating payload to the medical record number. This payload key is also supplied by the KeyServer and is added to every predictable field on a per-column basis. For example, using "rabbit" as the payload key, MRN "*1234567*" becomes "*1234567rabbit*". For record retrieval we can then use our own "dictionary" knowing what the obfuscating package key was to match against. This is shown in Figure 4. If we wish to change the package key, we manually "decrypt" the column by performing our own mass dictionary attack and parsing the data back to MRN's and encrypting with the new package added. For data such as patient names, we can add this text to the start of every name, and programmatically subtract it after decryption.

While most password systems require the user to comply with various levels of onerous password change and complexity requirements, this makes users do things like write their password down next to their computers. Security breaches against passwords without access to the password file, are generally human-nature attacks such as finding the password written down or guessing familiar terms, which is not protected against by stringent password requirements. Even worse, stringent password requirements are not foolproof in themselves, and simply lower the penetration risk somewhat.[5]

However, we were additionally concerned about password file theft, which means protection against a dictionary attack. Since our passwords are stored as asymmetrical SHA1 hash values, we chose a different method. A simpler task is to take password security out of the hands of the human user, and make the file inherently highly resistant to preimage attack. Again an obfuscating payload makes a useful barrier to mass preimage attack.

Rather than forcing the user to remember these obfuscating elements, we can programmatically change their password on entry/storage on database entry to include these elements, but without access to the originating code, and knowledge of the obfuscating payload, decryption is unlikely. For instance instead of the password sent to the encryption algorithm being "*password*" it is "*passwordrabbit*" where *rabbit* is a secret key kept only within the system. The user is unaware of these changes. One downside of this, is that this package cannot be dynamically rewritten, as we have no ability to perform our own dictionary attack, since the system does not retain the passwords as entered by the user.

Discussion

We have successfully designed and deployed a highly secure clinical data repository using our novel KeyServer technology. The technology combines pre-existing and novel techniques into a layered protective barrier around compromise of patient data. We start with network security by use of encrypted connection with RSA-certificate signed servers. We then further the identification of clients via secure session management with IP address verification and separate local hardware identification of clients. Onto this we add loading of the client side keys into memory means that if the server is stolen, on restart the local keys are destroyed, along with column level encryption. Scalable security timing of master key changing and authentication calls using system generated encryption keys make preimage attacks highly unlikely. Finally adding additional payloads to predictable data such as passwords, names and patient identifiers, makes these more resistant to preimage attacks.

There are some potential disadvantages with this configuration. Firstly, unexpected server shutdown automatically voids all keys

from memory. Depending on the reliability of server side support services, this will either be likely or unlikely. In any event, the keys can always be reloaded from the US KeyServer. Another limitation is the absolute requirement for a reliable network connection between the client and US KeyServer. Multi-column encryption and decryption processes potentially could affect overall performance, however our experience is that this is negligible.

There has been published work done that has demonstrated a cryogenic attack at retrieving keys from computer DRAM chips is possible,[6] this is a level of attack, that we choose not to protect against. This level of sophistication is outside of the level of perceived threat that PHI is likely to be subjected to. If this threat becomes more realistic, the referenced article suggests one practical countermeasure to this technique which is writing the keys to memory with large amounts of garbage data around them greatly lengthening the time required for key reconstruction, but even this is vulnerable.

With some careful planning an EHR/CDR can be placed in relatively insecure settings, with a high-level of security surrounding data theft, even in the event of hardware theft. This is made possible through advanced security practices and distributing the security apparatus across international boundaries with the primary security codes being in a highly secure data center, with no ability of the remote system to recreate its own codes. Another key to this approach is a reliable method for local client proof of identity even if stolen and booted outside of its home environment; this is the key to prevention of stolen code and database being usable on any computer not in its predefined network environment even if network hardware and soft IP addressing is spoofed. We believe these methods are generally useful for cloud-based solutions in healthcare.

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Healthcare System Evolution towards SOA: A Security Perspective

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Abstract

Healthcare providers often face the challenge of integrating diverse and geographically disparate IT systems to respond to changing requirements and to exploit the capabilities of modern technologies. Hence, systems evolution, through modification and extension of the existing IT infrastructure, becomes a necessity. This paper assumes a healthcare systems evolution towards a service-oriented architecture (SOA) and places emphasis on the development of an appropriate authorization model and mechanism that ensures authorized access to integrated patient information through web service invocations.

Keywords:
Healthcare systems, SOA, Context-aware authorization.

Introduction

Healthcare delivery is undergoing radical change in an attempt to meet increasing demands in the face of rising costs. In this context, healthcare providers adopt new ways of delivering healthcare involving a major shift to information systems that enable authorized access to integrated patient information anytime, anywhere [7,9]. Thus, healthcare providers are faced with the challenge to safeguard their significant past investments in the development of large and complex information systems by modifying and extending them in response to changing requirements in addition to capitalizing on modern technologies [8]. To this end, a systems evolution process is often designed and implemented with the objective to achieve interoperability among diverse systems that may have been developed at different times and with different technologies. Such evolutionary processes are operating on legacy systems, are directed toward long-term user needs and are usually conducted in an iterative and incremental manner [7,10].

Contemporary system evolution processes are increasingly directed towards Service-Oriented Architectures (SOA) since such system architectures are thought to maximize IT support to business processes that are subject to constant change in response to a changing environment. In this respect, SOA allows users to rapidly build, reuse and reconfigure business processes as healthcare priorities, regulatory requirements or environmental conditions change [6,10]. Hence, it responds to the need of exchanging medical information between diverse systems on the web and can form an ideal architectural basis for evolving legacy healthcare systems [7,8].

In most cases, a SOA is not built from scratch but rather the functionality of legacy systems and their components are being wrapped to web service interfaces. Thus, as contemporary SOA is intrinsically reliant on web services, an evolution process towards developing a SOA often uses the transformation of legacy systems into web services as the first step. The SOA architecture assumed in this paper, as part of an evolution process, is based on an ESB/BPEL software infrastructure that enables legacy systems to be synthesized so that they serve as a unified whole. Hence, uniting legacy systems into healthcare processes involves exposing each system as a web service and, then, using BPEL to combine the web services into healthcare processes.

When the healthcare system envisaged as a result of an evolution process is SOA-based, developers are faced with the challenge not only to ensure that the evolved system supports the delivery of healthcare services within and across organizational boundaries but also to meet global security requirements that were not applicable when disparate systems were in place. Thus, developers are called upon to ensure that component sub-systems constituting a SOA can interact and exchange information subject to an appropriate level of privacy and disclosure regulations based on state of the art practices for access control [1].

This paper presents a security framework that addresses the authorization and access control issues arisen in an interoperable healthcare system that accrues from the evolution of legacy healthcare systems into a SOA-based system. The need to also evolve security has led to the development of a context-aware authorization model which is based on the role-based access control (RBAC) paradigm. This model is then used in a prototype interoperable, SOA-based healthcare system that has resulted from an evolution process to enable authorized access to integrated patient information during the execution of healthcare processes.

Motivating scenario

The basic motivation for this research stems from our involvement in a recent project concerned with defining a prototype SOA-based system architecture by evolving legacy healthcare applications. To illustrate the security aspects of the

adopted approach to systems evolution, a sample evolution project is described which is concerned with patient referrals among healthcare providers within the boundaries of a health district.

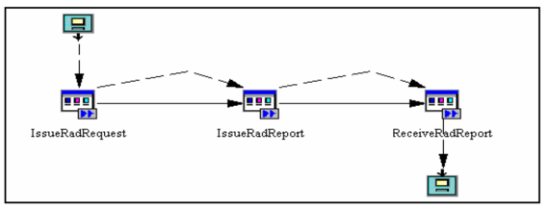

Figure 1- A high-level view of the healthcare process concerned with radiology orders.

The sample process considered here is concerned with patient referrals to a radiology department of a hospital. Suppose a healthcare delivery situation where a physician situated within a health district issues a radiological request for one of his/her patients. The request is submitted to a radiology department of a hospital which schedules the radiological procedure requested and notifies the requesting physician on the date and time scheduled. After performing the radiological procedure requested, the radiologist consults the relevant portion of the patient's record and writes a radiological report, incorporating both the radiological images and the associated text, which is sent to the requesting physician. Figure 1 shows a high-level view of the radiological process considered. This process consists of three composite tasks: *IssueRadRequest*, *IssueRadReport* and *ReceiveRadReport*.

A SOA-based evolution

The sample process described above involves two separate legacy healthcare systems which, in general, are based on different technologies:

- *Radiology Information System (RIS)*: A system that manages radiological requests and produces radiological reports.
- *Electronic Medical Record (EMR)*: A system where patient data is stored and managed.

To protect healthcare providers' investments, these legacy systems can become component applications of a loosely-coupled interoperable system (i.e. the system resulted from the evolution process). With regard to the sample healthcare process of Figure 1, all or parts of these legacy systems can be expressed as orchestrated web services (consisted of interconnected tasks) and the whole system can be a SOA implementation on an ESB/BPEL software infrastructure [4]. For example, the EMR system above may be converted into a number of web services and each web service may consist of a number of interconnected tasks. A detailed description of the system evolution approach adopted (including technical and operational requirements) is presented elsewhere.

To benefit from the advantages of SOA, the composition of two or more web services is implemented using BPEL which requires sophisticated solutions for securing web services [6]. Such an implementation may pose security problems not encountered in traditional, not SOA-based, systems. In particular, the authorization to execute a web service task built-in a SOA needs to be externalized and this authorization may be subject to certain contextual constraints that are extracted and evaluated from every request and for every application of the system [5].

An authorization perspective

Typically, role-based authorizations with regard to web service tasks and related data accesses are specified when the SOA is designed and the exact user-to-role and role-to-permission assignment relationships are decided. Context-aware authorizations are intended to provide more flexibility by taking context into account when deciding on the permission(s) that should be granted to users at run time [2,7]. Hence, these authorizations are bound to specific web service invocations and incorporate such constraints as those based on the data content, the user identity, the valid time and the location of attempted web service task accesses.

Table 1 - Extract of authorization requirements for the healthcare process of Figure 1

1	PHs may issue requests for radiological procedures on their patients. (IssueRadRequest)
2	RDs may issue radiological reports for patients on request by PHs. (IssueRadReport)
3	PHs may receive patient radiological reports issued by RDs only if requested by them. (ReceiveRadReport)

From a role-based authorization perspective, the healthcare process of Figure 1 involves two roles: the role of the physician (PH) and the role of the radiologist (RD). An extract of the authorization requirements regarding web service task execution and related data access privileges assigned to these roles is shown in Table 1. It is seen that the tasks "IssueRadRequest" and "ReceiveRadReport" can be executed by a user holding the role PH and the task "IssueRadReport" can be executed by a user holding the role RD. Also, during the execution of these tasks the users holding the roles PH and RD can have certain access rights on relevant data objects. In addition, the healthcare process of Figure 1 surfaces some additional requirements with regard web service invocations and associated task execution involved in data accesses. These requirements include the following:

- **Data content** – Some role holders should be allowed to exercise a set of permissions on web service invocations and task executions that result in accessing certain data objects only. For example, a physician is allowed to invoke the relevant web service and execute the "IssueRadRequest" task for reading patient records and issuing (write, edit and send) radiological requests only for his/her patients.

- **Permission propagation** – Some role holders should receive additional permissions on web service invocations and task executions that result in accessing certain data objects in order to effectively execute a task but these permissions should cease holding upon successful execution of the task. For example, for an effective execution of the "IssueRadReport" task with regard to a patient, in response to a request submitted by a physician, a radiologist should receive the permission to access the relevant web service and read a relevant portion of the patient's record but he/she should not be allowed to retain this permission after successful task execution. Thus, the permission for reading the patient's record, held by the patient's physician, is passed on to the radiologist who performs the radiological procedure requested for as long as is required to complete the execution of the relevant task.
- **Restricted task execution** – In certain circumstances the candidates for a web service invocation and associated task executions should be dynamically determined and be either a sub-group of the authorized users or only one, specific authorized user. For example, if the radiological procedure requested by the patient's physician is an MRI, then the radiologist who is allowed to perform it, and the one who can execute the "IssueRadReport" task, is among the radiologists holding the relevant sub-specialty. Also, the radiological report issued by the radiologist can only be read by the requesting physician who is allowed to execute the "ReceiveRadReport" task.

The authorization requirements of Table 1 suggest that permissions on web service invocations and task executions that result in certain data accesses depend on the process context. In particular, contextual information available at access time, like temporal, location or user/patient relationship or user/medical specialty relationship, can influence the authorization decision that allows a user to invoke a web service and perform a task.

Authorization model

Within a SOA resulting from an evolution of legacy systems there is a need to address authorization globally, while incorporating component system authorization policies in order to enforce the least privilege principle [2]. In turn, this requires ensuring that access permissions with regard to web services and associated tasks are only awarded dynamically, thus allowing users to assume the absolute minimum role required for web service invocations and task executions. Hence, there is a need to enforce context-aware authorization constraints regarding web service invocations and associated task executions that result in accesses to patient information.

The context

From a SOA authorization perspective, context can be defined as any information which is available at run time and is considered relevant to web service invocations and associated task executions that result in data accesses [5]. Thus, every SOA-based system may be assumed to be associated with a context which is defined as an evaluation of a set of pre-specified, domain-dependent and domain-independent context types. Domain-dependent context types are those related to the subjects and objects involved in the particular healthcare process under study as well as the relationships between subjects and objects (e.g. user and patient as well as the "proximity" relationship between them) while domain-independent context types are those related to the environment (e.g. time and location).

In a typical RBAC environment, roles are often defined as named collections of capabilities and privileges intended to perform healthcare functions [2]. In our context, roles are divided into two main classes: strong and weak. Strong roles correspond to existing organizational structures and define the division of work and the lines of authority based on job functions and seniority (e.g. "physician" and "radiologist"). On the other hand, weak roles are derived from strong roles and are subject to domain-dependent contextual constraints (e.g. "attending physician" and "attending radiologist"). For example, a radiologist can only assume the weak role "attending radiologist" when a physician has issued a request for performing a radiological procedure on one of his/her patients and the particular radiologist is assigned or chooses to respond to the request.

To alleviate users from the burden to change roles at run time, as required by access needs and the current work context, and to reduce the administrative overhead imposed, a rule-based approach should be adopted that enables automatic role changes (e.g. from strong to weak and vice versa) on the occurrences of specific events which are termed "role change events". These events occur when a web service invocation is initiated (initiation events) and result in granting the appropriate weak role to the current user; they terminate when the web service invocation is terminated (termination events) and result in revoking the current user's weak role. To achieve role changes, event occurrences automatically trigger the processing of relevant rules defined in the event-condition-action (ECA) format [3]. Hence, role change rules can be described as follows:

Definition (Role change). A role change is a 4-tuple (u, r_i, r_j, e_k) stating that a user u holding the role r_i receives the role r_j on the occurrence of the event e_k.

Authorization rules

To reduce the complexity of the authorization model, only positive authorizations are considered, so no explicit authorization conflicts occur. The dynamic authorization model proposed here extends the classic role-based access control (RBAC) for SOA-based authorization, while retaining its advantages, in that it addresses the issue of dynamically changing user roles at run time based on event occurrences. Hence, web service invocation and task execution authorization rules can be described as follows:

Definition (web service invocation). A role-based authorization for web service invocation is a 4-tuple (r, "invoke", WS,

$\{p_k\}$) stating that a user holding the role r is allowed to invoke web service WS subject to contextual constraints $\{p_k\}$.

Definition (web service task execution). Given an authorization for invoking web service WS by a user holding the role r, a role-based authorization for web service task execution is a 5-tuple (r, "execute", WS, T, $\{p_k\}$) stating that a user holding the role r is allowed to execute task T of web service WS subject to contextual constraints $\{p_k\}$.

Such authorization rules contain both domain-dependent and domain-independent contextual constraints. For example, on an attempt to invoke a web service, the contextual constraints are evaluated and applied in order to restrain accordingly the permissible actions of a user.

SOA authorization system

In a SOA environment, a typical authorization architecture involves a subject (e.g. a user) which wants to access an object (e.g. a service). The authorization architecture takes care of requesting authorization decisions and enforces them. To this end, it has to intercept user requests asking whether the user is authorized based on an evaluation of the applicable policies and building the authorization decision (deny/permit) upon that.

A SOA-based system accrued from rendering legacy systems interoperable should not violate any security enforced in these systems but it can itself enforce additional security. Hence, an implementation of a centralized authorization architecture can be made with due regard to the security policies that have been incorporated into the legacy systems.

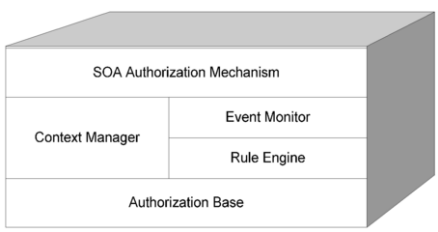

Figure 2- Authorization system architecture

Based on the authorization model defined above, an experimental SOA authorization system has been designed and implemented. This system enforces role-based authorizations that determine who (in terms of role) can invoke which web services, and can execute which web service tasks, and under what conditions. As shown in Figure 2, the architecture of the prototype authorization system consists of the following main components: the authorization base, the event monitor, the rule engine, the context manager and the authorization mechanism. The authorization base records all the elements of the model. The event monitor manages generated events and keeps track of the events that have already occurred in a healthcare process. The rule engine ensures that the rules set about invoking web services and executing web service tasks are enforced. The context manager collects the context information used in making access control decisions. The SOA authorization mechanism maintains user information and intercepts user requests (web service invocation or task execution) asking whether the user is authorized based on an evaluation of the applicable policies and building the authorization decision (deny/permit) upon that subject to contextual constraints.

A. Authorization base

The authorization base records users, roles (strong and weak), web services and permissions as well as user-to-role and role-to-permission assignments. Role-based authorizations are stored in the form of authorization rules with regard to web service invocations and web service task executions, most of which have been converted from legacy system authorizations to retain alignment between old and new system authorizations. Hence, source system security is conveyed. In addition, the authorization base contains role change event occurrences as well as the contextual constraints defined.

B. Event monitor

The event monitor records event occurrences into the authorization base and passes the event occurrence data to the rule engine that triggers the appropriate rule (e.g. for weak role granting/revocation). The event monitor is informed on event occurrences when a user attempts to initiate or terminate a web service invocation.

C. Rule engine

The rule engine stores weak role granting and revocation rules in ECA format, determines the appropriate rule when information on the occurrence of an event is received from the event monitor and triggers the weak role granting (revocation) action when the condition specified in the rule is satisfied. Weak role granting (revocation) amounts to recording (deleting) an entry in the user-to-weak role relationship table of the authorization base. Thus, the rule engine maintains the authorization base information up-to-date regarding dynamic granting/revocation of weak roles to strong role holders.

D. Context manager

The context manager, on occurrence of an event, determines the current work context and communicates the collected information to the rule engine which uses it when triggering the relevant ECA rule. The context manager is realized by a number of context agents which use middleware context collection services to monitor context and interact with the rule engine.

E. Authorization mechanism

The authorization mechanism accesses the permission relationships of the authorization base to enforce access control on users holding a role at the time of an attempted web service invocation or task execution. Thus, on an attempted web service invocation or task execution the authorization mechanism mediates between role holders and web services or tasks to determine whether the requested action should be permitted or denied.

Implementation issues

To illustrate the functionality of the proposed security model, a prototype SOA-based system was implemented that draws on the business rules and authorization requirements of the healthcare process depicted in Figure 1 and on the two legacy systems mentioned above.

Referring to the healthcare process of Figure 1, two web services have been developed: The one is a version of RIS concerned with radiological requests ("RIS_RadRequest" web service) and the other is a version of EMR concerned with medical record activities performed by either the physician or the radiologist ("EMR_RadPortion" web service). Thus, basically, the tasks depicted in Figure 1 belong to the "RIS_RadRequest" web service although these tasks include sub-tasks that are concerned with invoking the "EMR_RadPortion" web service to access medical record data.

Let a physician wishing to order a radiological procedure for one of his/her patients. Then, the following actions are performed with regard to security: On attempting to invoke the RIS_RadRequest web service, a web service invocation event occurs which is identified by the event monitor and is recorded into the authorization base while event occurrence data is passed to the context manager and to the rule engine. Then, the context manager evaluates the contextual parameters specified to determine the current context that constraints authorization rights (e.g. the patients that are currently attended by the physician) and passes this information to the rule engine. The rule engine identifies and triggers the relevant ECA rule to grant the weak role "attending physician" to the user, by inserting an appropriate entry into the authorization base, and passes the weak role to the authorization mechanism. The authorization mechanism consults the authorization base and grants to the user the restrained permissions for invoking the web service, performing the relevant tasks ("IssueRadRequest" and "ReceiveRadReport") and accessing the relevant patient's data only in order to issue a radiological request for one of his/her patients. Due to lack of space, a detailed description of the SOA authorization system implementation will be presented elsewhere.

Conclusion

Healthcare organizations are faced with the challenge to improve healthcare quality and reducing healthcare costs. To these ends, healthcare organizations often attempt to evolve their legacy systems by using innovative information technologies. However, for such a system to reach its full potential in supporting healthcare activities, authorization mechanisms must be in place that can conveniently and cost effectively regulate user access to information while providing confidence that security policies are faithfully and consistently enforced.

This paper presents an authorization model and system for enforcing authorization when migrating existing systems into a SOA. Based on the well known RBAC paradigm, a context-aware authorization model which is focused to the upper layers of SOA (i.e. the integration layer and the process layer) has been introduced and its practicability has been demonstrated using a prototype system based on a sample healthcare process.

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Healthcare Chains – Enabling Application and Data Privacy Controls for Healthcare Information Systems

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Abstract

Healthcare applications that have access control, disclosure management and or privacy enforcement requirements may implement the respective solutions to these issues at the application level or at the database level or in both. Unfortunately, there are technical and non-technical factors that influence what can be done. In this paper we present a flexible, simple and novel approach to seamlessly imbuing current healthcare applications and their supporting infrastructure with security and privacy functionality, while being cognizant of these factors. This approach is called the Chain method. This paper will highlight the smaller design footprint, the increased ease of implementation and use of the Chain method, while demonstrating that it is as powerful and effective as traditional methods.

Keywords:

Privacy, Healthcare

Introduction

Globally, healthcare companies are increasing under pressure to provide technology, which delivers a core functionality, e.g. practice management, X-ray scanning, etc., and protects the sensitive information locked in their systems. Currently, a lot of healthcare vendors have significant investment in their existing product offerings, which tend to be developed with older technical building blocks and does not support the current social, legislative and technical requirements for privacy protection in medical systems.

The first step in enabling current healthcare vendors to augment their systems to address the current market demands, is the provision of non-intrusive technology that allows them to seamlessly handle arbitrary permissions. Unfortunately, these permissions are varied; ranging from storage access rights to "execute" rights for methods of individual classes. The focus of this paper is on the specification and enforcement of access rights to shared data resources, such as Electronic Medical Records (EMRs) and Personal Health Records (PHRs). We introduce novel technology – the Chain method [1] – which enables easy and non-intrusive definition and adherence to easily understood privacy rules.

Methods

Our methodology involved designing the information flow for the healthcare environment of our partner – the Kuwait Hospital, then implementing the Chain method behind a healthcare application at Kuwait Hospital. We then evaluated the technique against comparable technologies in the field.

What is the Chain Method?

The Chain Method [1] (hereafter referred to as *Chains* or *Chain*) is a new and novel paradigm for specifying and enforcing access controls on both applications and data; by formalizing the stakeholders, the acts that they perform and the entities that they act on. The intuition is that in modeling the actors, entities and their interactions (i.e. the private information handling model), one gets a more realistic view of the system's workflow. This model is then refined into a permissions matrix and then sent to an enforcement mechanism.

At the conceptual privacy level, Chains allow for the transformation from purpose-based systems into systems built on chains of limited acts. This is highly desirable because contemporary privacy research has lighted the fact that specifying or deriving purposes in the real world is a difficult problem [2]. A natural consequence of using Chains is that the approach doesn't need a huge number of purposes and doesn't potentially hide important user information from authorized users.

As briefly mentioned previously, the Chain method enables the simplification of the mapping/translation process from user actions to low-level implementation-level mechanisms. Chains leverage concepts from Role-Based Access Control (RBAC) [3, 4], where users have assigned roles and access purpose permissions are granted to roles associated with tasks or functionalities, not directly to individual users. In traditional RBAC, supporting dynamic changes in purposes may involve the assignment of a role to attributes with hierarchy inheritance characteristics, which allows an access purpose to be assigned

to a specific subset of users in the same role. In the Chain method, roles are assigned to acts.

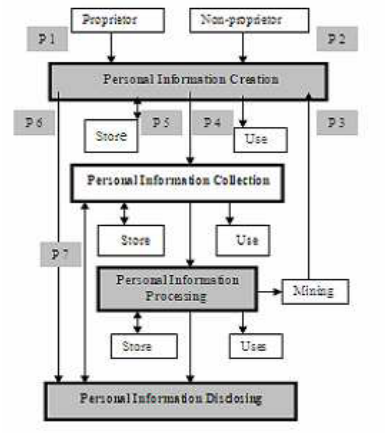

Figure 1-Personal Information Flow Model

The Chain method assumes that each purpose, i.e. conceptual task or function, can be translated to a series of actions (i.e. *chain of acts*) on personal information. The implicit assumption in the Chains is that any piece of personal information does not need more than a limited number of acts to be dealt with, such as creating, storing, processing and disclosing. This limited set can be used to design a lightweight and durable database that could safeguard personal information privacy [1]. The Personal Information Flow Model (PIFM) is a representation of the movement of information and the actions taken. The basic PIFM (Figure 1) consists of informational privacy entities and processes and is divided into a limited set of discrete actions. New personal information may be created at one or more points, e.g. P1, P2, and P3 in Figure 1, by proprietors or non-proprietors. The created information is used either at P4 (e.g. a decision for surgery needs to be made), P5 (e.g. receptionist stores patient information), or P6, where it is immediately disclosed (e.g. a physician explains to the patient his health case). Processing involves analysis and use of the personal information, e.g. mining for adverse drug reactions, longitudinal diagnostic analysis for rare conditions, etc.

Prototype

This work is the first practical instance of the Chain method. Using the concept of the Personal Information Flow Model, we built a system that involves the data owner, i.e. proprietor/patient, and healthcare entities and practitioners, i.e. doctors, nurses, clinics, hospitals (Figure 3).

Each of the labeled arrows represents specific actions that can be taken. In constructing the PFIM, we had to define a healthcare ontology (Figure 3) and integrate it with the (industry-agnostic) Chain method.

The classification that the ontology provides defined the meaning of each act. It also enabled the adjudication of the decision concerning the chain that a particular act should be added to. Finally, we specified the users that could access a particular chain or set of chains. The prototype is shown in Figure 4.

The ontology (Figure 3) was used by distributed semantic agents whose job it is to manage access and protect personal information. The actual interface to other systems and actors wishing to access personal information will use web services (Figure 5).

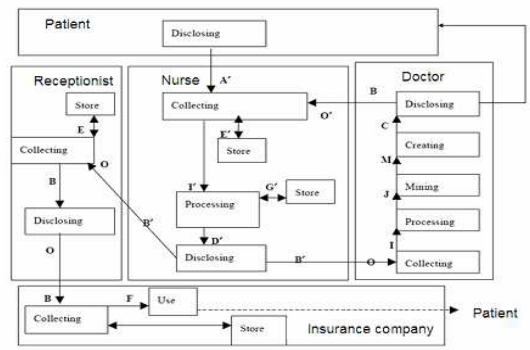

Figure 2- Healthcare PIFM for Kuwait Hospital

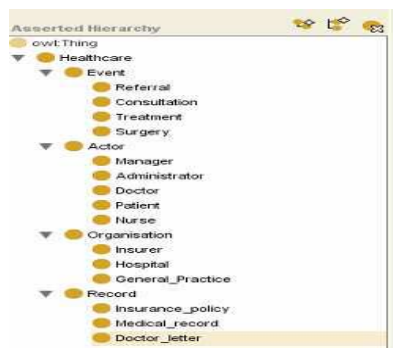

Figure 3- Healthcare Ontology constructed using Protégé OWL environment

These Personal Information Manager (PIM) agents assess information requests, potentially using other agents to verify the request and its circumstance, i.e. current state, using the ontology and analyzing the permitted acts based on the chain approach. This shared ontology is then be mapped onto a local ontology, where appropriate, to map onto the data store, where the personal information is actually stored. The benefit of this architecture is its flexibility to be applied easily to existing systems that store personal information and to manage the access using the shared ontology, while mapping it to the actual data store using a local lower level ontology as described in the ONAR approach [4].

Any request, whether by a user or by a system, in this framework will be dealt with in the following manner:

1. Authenticate the user (locally or through a trusted authentication server)
2. Verify the request to determine legitimacy using the ontology to establish whether the request is reasonable and should be acquiesced to (involves reasoning about the request and checking other systems for verification where needed)
3. Determine the location of information
4. Verify the acts and chains of acts for legitimacy
5. Extract the records
6. Execute the request

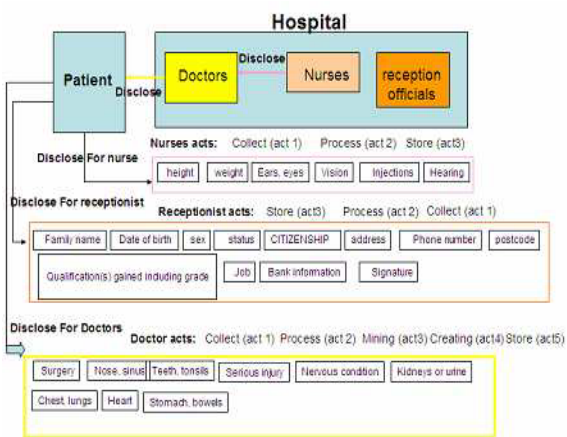

Figure 4- The Prototype

The database was designed based on our findings from a real HealthCare provider in Kuwait. After discussion with physicians, nurses and receptionists to better understand how the work in the hospital is performed, what are the problems of the existing database system they have are, and what are the requirements that should be added to their database system, we have designed the system as shown in Figure 5.

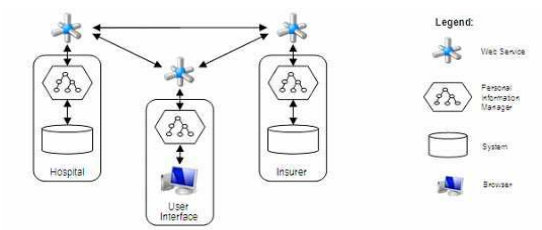

Figure 5- Designed System Architecture

The system in Figure 5 leveraged the chain ontology work and codified the requirements of the current system users.

Experiments

We developed two sets of experiments. The first is a user study, which is still ongoing. This test involves the system users at Kuwait Hospital providing feedback on their experience with Chains. The second is a comparative analysis with other similar technologies in terms of ease of and effort required for enforceability.

The first technology chosen for the comparative analysis was Role-based Access Control (RBAC) [3, 4]. In RBAC, a Role has a list of permissions. By placing a user in a Role, that user is granted access to the systems or resources associated with the Role. Users are assigned to one or more Roles, and each Role is related with a permission or set of permissions to IT resources. Using this method, a Role establishes the relationship between the users and the systems that they are authorized to access and provides a much more efficient way to decide who has access to what resources. An interesting consequence of RBAC is that organizations no longer have to work at the application or system levels, instead they can use roles to assign the appropriate permissions as a group. As a user's job tasks change they are removed from their old roles and placed in new roles based on their job title.

The second technology chosen was Task Based Access Control (TBAC) [6]. This technology is well suited for distributed computing and information processing activities with multiple points of access, control, and decision making such as found in workflow and distributed process and transaction management systems. TBAC varies from traditional access controls and security models in many respects [6]. Instead of having a system-centric view of security, TBAC approaches security modeling and enforcement at the application and enterprise level, which makes it more desirable in real world enterprises.

For our experiments on ease of and effort required for enforceability, we chose real privacy policies[1] found on the websites of the top 100 healthcare companies named in the 2009 Thomson Reuters study [7], as well as the privacy policy from Kuwait Hospital. The results were the same across the board.

For generality, we will walk through the process and show the results for a typical example, the OSF Healthcare System[2]. Given the following HIPAA policy statement[3] from their Web site:

> *"OSF may share your information with a medical care institution or medical professional for the purpose of verifying insurance coverage or benefits, informing you of a medical problem of which you may not be aware, or conducting an operations or services audit."*

We represent and implement it in RBAC, TBAC and Chains. A representational model of the above policy statement in RBAC is shown in Figure 6. We used the standard techniques for mapping from natural language to the each technology [1, 3, 4, 6].

[1] In this context, privacy policy here refers to a virtual combination of the privacy policy and the HIPAA privacy practices notice.
[2] OSF HealthCare is a multi-state corporation operating facilities in Illinois and Michigan.
[3] The full privacy policy is at http://www.osfhealthcare.org/hipaa

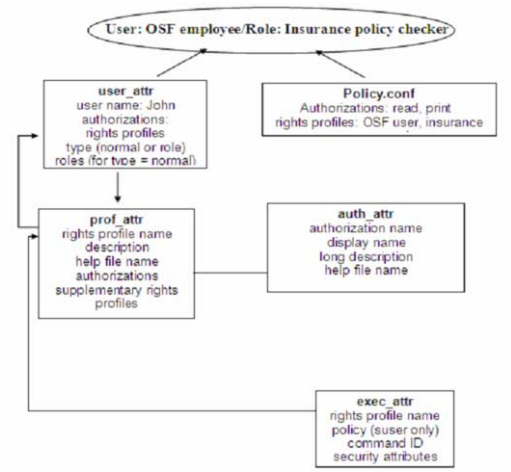

Figure 6- Policy in RBAC

Figure 7 shows the representation of the OSF policy statement in TBAC.

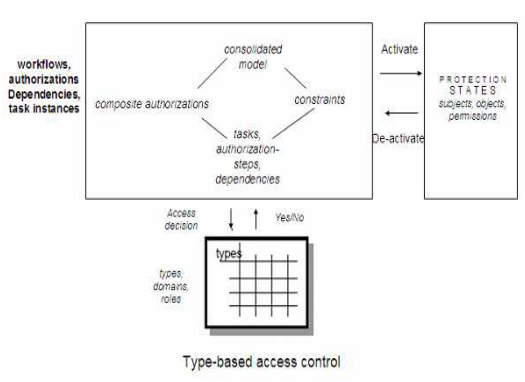

Figure 7-Policy in TBAC

Figure 8 illustrates the Chains representation of the OSF privacy statement.

As these representations will be required to be translated into a standard form, both for healthcare domain reasons and in order to do a fair comparison, each representation was transformed into OWL[4], which has a direct mapping into HL7 [8].

Representing the three models above in the OWL language, we find that the Chain model is the easiest to be translated as it contains less statements and simpler syntax.

[4] OWL (The Web Ontology Language) is a family of knowledge representation languages for authoring ontologies that is endorsed by the World Wide Web Consortium.

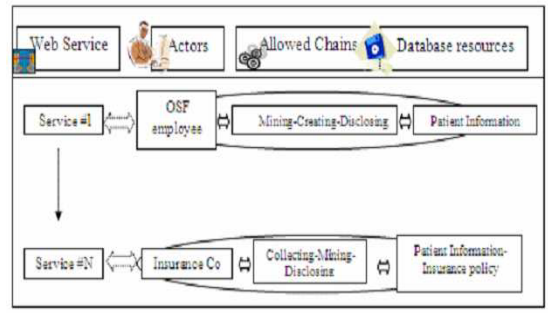

Figure 8- Policy using the Chain Method

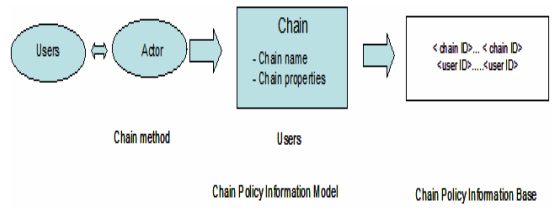

Figure 9- Chain model using OWL

Figure 9 shows that the result of the transformation process would be of the form:

<User ID>.... <User ID>
<Chain ID>.....<Chain ID>
……

Figure 10 shows the refinement process from the RBAC statements to OWL.

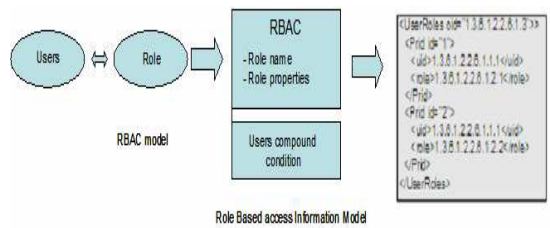

Figure 10- RBAC model using OWL

The resulting policy statement is of the form:

rbac:ssod a owl:SymmetricProperty, owl:TransitiveProperty;
rdfs:domain rbac:Role;
rdfs:range rbac:Role;
.....
<RoleName> rdfs:subclassOf rbac:Role.
<ActiveRoleName> rdfs:subclassOf
rbac:ActiveRole;rdfs:subclassOf <RoleName>.
<RoleName> rbac:activeForm <ActiveRoleName>

As TBAC is based on RBAC, the translation of the TBAC statements is similar to the translation of RBAC statements (Figure 10).

For ease of enforceability, we measure the number of tables that needs to be accessed in the determination of an access or disclosure decision. Table 1 shows that the number of required accessed tables in the Chain method is always the minimum (1), while, for this example (OSF Healthcare), TBAC and RBAC several orders of magnitude more. While the effort required may vary in TBAC and RBAC from policy to policy, the trend is that the effort is always more than Chains (and sometimes the same).

For the effort required in enforcement, this is measured by the work that has to be performed in evaluating the attributes and conditions in a statement (all other things, like low-level enforcement platform details, being equal).

Table 1- Ease of Enforceability

Access Based Method	Chain Method	TBAC	RBAC
Number of tables	1	8	5

Table 2 shows the re-thinking of the underlying representational model in Chains yields benefits in terms of the number of checks that have to be performed during policy enforcement.

Table2- Effort Required in Enforcement

Access Based Method	Chain Method	TBAC	RBAC
Number of attributes/conditions	2	4	5

Discussion

This paper is the first work in literature that has made a comparison between the three privacy preserving methods: Chain, RBAC and TBAC. This comparison was based on scientific criteria that have compared the number of tables, conditions and attributes required to design each of the methods. The chain outstands the two other methods with the small number of required tables and conditions. Also the comparison has shown the complicity of translating the RBAC and TBAC in OWL compared with the simplicity of the OWL sentences in the chain case. We also recognized that EPAL [9], Hippocratic Database (HDB) technology [10] and P3P [11] are related technologies in the field and that it is important to empirically compare them to the Chain method. But we need first to put the HDB and the Chain on same acting level (either to put them both on the application or the data level). This is one of our plans for future work.

Conclusion

In this paper, we have identified that the problem of defining, acquiring, inferring and consistently using purpose-based data disclosure technologies is difficult. We introduced the Chain Method – technology that allows easier specification of (security and privacy) policy at both the application and data level. We have prototyped the Chain method in a real healthcare provider and provided our initial results on the ease and effort involved in enforcement in a Chain-enabled system.

Acknowledgments

Our thanks to Professors Albert Bokma and David Nelson form Sunderland University for their valuable contribution on this paper.

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HIPAA Compliance and Patient Privacy Protection

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Abstract

Recent prosecutions of violations of the Health Insurance Portability and Accountability Act (HIPAA), and the amendments currently in process to strengthen the Act of 1996, has led many companies to take serious notice of the measures they must take to be in compliance. A company's privacy policy states the business' privacy practices and embodies the firm's commitments to its users and is normally a mandatory step in reaching legislative compliance. In the face of this, the patient has to decipher if the company's privacy practices are congruent with their thoughts on the level of privacy protection they should be receiving. This is the core of our investigation. In this paper, we explore the question "Is a healthcare entity's compliance with regulation sufficient to provide the patient with adequate privacy protection?" in the context of the United States of America.

Keywords:

Patient Data Privacy, Compliance, Legislation

Introduction

There is a significant body of evidence that shows that privacy breaches of healthcare data occur far more often than patients believe [1]. The prevailing perception, by most non-corporate healthcare stakeholders, is that the current measures (i.e. legal, social, technological and business safeguards) are weak and not effective [2]. In recent times, enforcement of the legal mandates articulated for covered entities[1] has been on the rise [3].

Though not as prolific as many would like, the record of convictions under HIPAA [4] provides hope. In the first HIPAA-related criminal case (2004) [5], a phlebotomist, Richard W. Gibson, employed by the Seattle Cancer Care Alliance, obtained a cancer patient's personal information from the health record and used that to fraudulently obtain four credit cards, charging $9,000 to the patient's name. That patient, Eric Drew, tracked down the perpetrator on his own, while fighting leukemia. Gibson pled guilty and was sentenced to 16 months in prison.

In Delaware, Linda Danyell Williams, an insurance representative employed by Hospital Billing and Collection Services in New Castle, was indicted in November 2006 for allegedly conspiring to steal the identities of more than 400 of the billing company's clients and selling the data to Richard Yaw Adjei, who used 163 of the stolen identities to file false and fraudulent tax returns, seeking refunds from the Internal Revenue Service. Williams pled guilty to two counts [6].

In 2007, Liz Arlene Ramirez, an employee at a doctor's office in Texas, pled guilty and was convicted of selling confidential medical information belonging to a Federal Bureau of Investigation Special Agent to someone she believed was working for a drug trafficker. She was sentenced to six months in prison [7].

In that same year, the U.S. Attorney Southern District of Florida obtained the first medical privacy criminal conviction after a trial [7]. In that same, Isis Machado, a front desk office coordinator at The Cleveland Clinic in Weston, Florida, improperly obtained Medicare information and other demographic information about Cleveland Clinic patients in Naples, Florida, and sold that information to her cousin, co-defendant, Fernando Ferrer, of Naples, for $5 to $10 each. Machado improperly obtained the patient information of approximately 1,130 patients. That data led to $7 million in fraudulent Medicare claims. Machado pled guilty to conspiracy and testified at trial against Ferrer. Machado was sentenced to three years probation, including six months of home confinement, and ordered to pay restitution of $2.5 million. Ferrer was sentenced to 87 months in prison, three years supervised release and ordered to pay $2.5 million in restitution.

In February 2008, CVS Caremark Corp. ("CVS" for short) agreed to pay $2.25 million to settle a federal investigation into allegations that it violated HIPAA privacy regulations when pharmacy employees threw items such as pill bottles with patient information into the trash [8].

Most recently (in May 2009) [9], California health regulators fined Kaiser Permanente's Bellflower Hospital to the tune of $250,000 due to the unauthorized access, by 23 workers, of the medical records of Nadya Suleman, after she gave birth to octuplets in January 2009.

[1] Covered entities refer to health plans, health care providers and health care clearinghouses.

This stream of legal activity is slowly bolstering patients' confidence in the protection of their data, i.e. insofar as the activities of regulators are concerned. Is this phenomenon encouraging healthcare firms to elevate patient protection in their own business functions? In this paper, we explore the legislative and technical sides of this patient privacy discourse.

Method

The baseline for regulatory compliance in the American healthcare industry is thought to be HIPAA [4], the new security and privacy requirements imposed by the Health Information Technology for Economic and Clinical Health (HITECH) Act [10] and the changes to HIPAA mandated by the American Reinvestment and Recovery Act (ARRA) [11]. We used these to measure legislative compliance.

However, as the HITECH [10] and ARRA [11] Acts are still open for public comment and not been implemented by organizations, they were removed from our study. A high-level summary of the five key principles in the HIPAA Privacy Rule are:

1. *Notification* - Patients should receive a notice of a covered entity's privacy practices.
2. *Authorization and Consent* - Written authorization is required for disclosures not permitted under the Privacy Rule.
3. *Limited Use and Disclosure* - Covered entities must use or disclose the minimum necessary PHI for a specific purpose and ensure the development and implementation of policies and procedures governing access and use.
4. *Auditing and Accounting* - Patients have the right to an accounting of all disclosures of their PHI for non-allowed HIPAA operations.
5. *Access* - Patients have the right, under most circumstances, to access the covered entity's designated record set. Covered entities must amend information that is inaccurate or incomplete.

The full descriptions of the principles can be found at the U.S. Department of Health and Human Services' website [4]. For completeness, we have to define *Protected Health Information* (PHI) as individually identifiable health information held or transmitted by a covered entity or its business associate, electronically, on paper, or orally.

For this project, a sample of 78 patients, commissioned from Amazon's Mechanical Turks[2] [12], were randomly selected and provided their expectations of privacy protection with regards to the principles above. The study population ranged from 23 to 68 and their county of residence covered 31 states. Each participant was given five options for each principle and asked to indicate the choice they associated most with their expected level of privacy protection.

As stated previously, a healthcare entity creates and publishes privacy documents, which describe their behavior (and implicitly establishes an agreement between themselves and their patients). A typical covered entity in our study provided an electronic copy of their HIPAA Notice of Privacy Practices[3], as required by regulation. Most organizations in our study also posted a separate Website Privacy Policy[4]. For our purposes, we use the terms "policy" and "privacy policy" to mean the virtual combination of both.

In order to answer our initial question, "Is a healthcare entity's compliance with regulation sufficient to provide the patient with adequate privacy protection?" we analyzed a sample set of privacy policies from twenty healthcare companies (chosen from the Thomson Reuters Top 100 Hospitals list [13]) with respect to patient expectations (obtained from our Amazon Mechanical Turks survey [12]). The companies in our study included Norton Healthcare, CIGNA Healthcare, West Virginia University, Interim Healthcare, Mount Auburn hospital, OSF Healthcare System, PharmaCare, Oakwood Healthcare, St Joseph's Hospital, AETNA, Blue Cross Blue Shield, Kaiser Permanente, Kindred Healthcare, United Healthcare, Camino Medical Group, Veterans Health Administration, Thomas Jefferson University Hospital, University of Michigan Health System, University of Chicago Hospital and St. Louis University Hospital. Table 1 shows the locations of the policies used.

Table 1 - Companies and their Policy Locations (Accessed October 15, 2009)

Norton Healthcare	http://bit.ly/aZYZoP	http://bit.ly/c6hsSb
CIGNA Healthcare	http://bit.ly/91x8VY	http://bit.ly/b824n6
Healthcare at West Virginia University		http://bit.ly/9DXGI4
Interim Healthcare	http://bit.ly/b7dCv0	http://bit.ly/azNBKj
Healthvision (Mount Auburn Hopsital)		http://bit.ly/9VDACT
OSF Healthcare System	http://bit.ly/9jvy25	http://bit.ly/9jvy25
Pharmacare	http://bit.ly/aQ826Q	http://bit.ly/aQ826Q
Oakwood Healthcare	http://bit.ly/aA5RVw	http://bit.ly/aA5RVw
St. Joseph's Hospital	http://bit.ly/bqu3Rj	http://bit.ly/bqu3Rj
Aetna	http://bit.ly/a3xJpD	http://bit.ly/bSUy3O
Empire Blue	http://bit.ly/csrCZc	http://bit.ly/csrCZc
Kaiser Permanente	http://bit.ly/cnN1uo	http://bit.ly/cnN1uo
Kindred Healthcare	http://bit.ly/cFVS0x	http://bit.ly/9HpG7O
United Healthcare	http://bit.ly/b0BNDF	http://bit.ly/ddByBa
Camino Medical Group	http://bit.ly/9xAJFt	http://bit.ly/aKkXs0
Veterans Health Administration (VHA)	http://bit.ly/cDHi7D	http://bit.ly/9pzumX
Thomas Jefferson University Hospital	http://bit.ly/bGQPdG	http://bit.ly/96qTgf

[2] Mechanical Turks is an online marketplace where mechanical tasks can be assigned to human workers to be completed at their own pace.

[3] The HIPAA Notice of Privacy Practices (NOPP) is a document that specifies how the organization maintains the privacy of members' medical information. Its electronic copy is posted on their website.

[4] The Website Privacy Policy only applies to information collected, used and or disclosed through the company's website.

Table 1 (continued)

University of Michigan Health System	http://bit.ly/bNPMa2	http://bit.ly/dyl3dN
University of Chicago Hospitals		http://bit.ly/cJwkNq
St. Louis University Hospital	http://bit.ly/atX8IQ	http://bit.ly/cRKZYQ

Results

Generally, the surveyed companies structured their policies to convey information on the following areas: Collection of Information, Information Types, Information Use and Changes to Information. There were slight differences in terminology amongst the policies, but the higher level concepts were equivalent. We found the policies clear in their articulation of the information that they collect. This information falls into one of three classes: 1) *Protected Health Information*, which includes name, address, social security number, email address, licensure, certifications, education and employment history, etc. and is normally assumed critical for the delivery of care and the company's normal business functions, 2) *Derived Information*, which includes individual access history and usage patterns, which is gathered through cookies in order to improve their site and allow personalization or customization, and 3) *Aggregate Information*, which is statistical information, consolidated from IP addresses, computer information and locations (amongst other things), for promotion and marketing.

From the Mechanical Turks study, the top choices for each of the principles in the HIPAA Privacy Rule were:

1. *Notification* - Patients expect notifications sent to them of privacy practices' changes within days of the change.
2. *Authorization and Consent* - Patients expect authorization and consent for each non-authorized disclosure.
3. *Limited Use and Disclosure* - Patients expect healthcare payers and providers to enforce rules that ensure their business partners do not abuse their information.
4. *Auditing and Accounting* - Patients expect timely (a few days) response when they request an accounting of who touched their PHI.
5. *Access* - Patients expect to be able to see the information a healthcare entity has on them and they expect to be able to quickly correct any inaccurate information.

When analyzing each privacy policy, we examined the policy stipulations against the requirements of the HIPAA Privacy Rule and the expectations of patients. The results show that a all the policies were in a satisfactory compliance state with regards to legislation but fell short of patient expectations.

Each of the following sections goes into more detail on our findings.

Notification, Authorization and Consent

At the start of their policies, the healthcare companies either stated (1) that they do not collect personal information from web page visitors, but do collect web usage statistics in the aggregate form and if one wishes to register with them, then personal information will be collected or (2) that by accessing the companies' web pages you have consented to their privacy policy. Both cases lead to a situation where the patient is assumed to have implicitly consented to the privacy policy through the action of browsing the companies' web pages. It is debatable if this is in the spirit of the HIPAA Privacy Rule. However, it is clearly outside of patient expectations.

There was also an interesting trend present in the statements about the communication of policy updates to the patients. From the companies' policies, a majority of them were content with simply updating the policy on the website, and making it the responsibility of the user to check for policy changes. It is a general theme that privacy policy changes are communicated with very little concern for the patient. There were a few exceptions to the rule which actually indicated that they would alert the patient (via email, etc.) in case of a policy update.

Limited Use and Disclosure

For all the firms in the study, use and disclosure of information are associated with a purpose and specific purposes are defined for information. However, we found that all organizations defined very broad and all encompassing purposes, which may be used to exploit exceptions in the HIPAA Privacy Rule. For example, the policies mention collecting information for the purpose of "administering healthcare". They settled for a granularity so coarse that it could subsume a huge category of uses and disclosures of information. As a result, a whole host of activities, which the patient may not be in agreement with, could be interpreted as included within these purposes.

For disclosures to third parties and affiliates, it is common to see the phrase "we require the third parties to comply with Policy". However, there are two significant hurdles here. Firstly, a proposition to either "comply with policy" or to have "use limited by policy" is only meaningful if the policy is not broadly defined and implicitly inclusive of a wide range of business functions. Secondly, apart from business associate contracts with the third parties that perform services, requiring PHI, for them, there are no guarantees of the actual enforcement of policy on the third party. Ideally, covered entities should proactively monitor third parties to assure that they comply with the business associate agreements. However, the policies make no mention of the (general) terms and ramifications of such agreements.

None of the privacy policies surveyed provided a fine-grained list of roles or employee categories who have the authorizations to view specific categories of patient data. For internal use, the collected information is available to all "members of medical staff". This is the only requirement for being an "authorized" employee. Nowhere are the precise conditions for being "authorized" stated, nor is there any criteria specified under which any exception-based accesses may be granted (such as in "break the glass" scenarios). Overall, the counsel or consent of the patient is not incorporated in assigning more specific access privileges to employees.

Audit and Accounting

The privacy policies of all organizations advise that patients can obtain audit records for information disclosures. They also mention that protected health information may be disclosed to government and regulatory authorities for compliance with law. Although not explicitly stated on the websites, the literature from the medical community [14] suggests that most organizations advocate the use of audit trails of all actions pertaining to patient medical records to meet the audit reporting and accounting requirement. Our experience with clients indicates that audit trails do not record all the necessary context information, such as purpose and recipient amongst other attributes. More alarmingly was the tendency of corporate executives to turn off audit systems because of the storage and performance burden incurred when they ran.

Access

The privacy policies posted on all the websites in our survey indicated that patients have the right to access or update their personal information maintained by the company through phone or email or an online account. However, the response time was in the order of weeks and normally in written form.

Discussion

For each of the principle areas examined in our study, there was useful insight that we gained while examining the policies. Here we share some of these lessons.

Notification, Authorization and Consent

Current practices around issuing a notice and obtaining consent are not sufficient unless they provide the patient an opportunity to clearly and easily understand the policy and negotiate any objectionable provisions. This will continue to be a manually intensive task unless the policies are presented to the patient in a format that not only highlights the key segments in the policy, but also allows reasonable modifications to be made by the patient at his/her discretion. The use of P3P[5] technology, for example, may facilitate this task. Though recent studies have shown that privacy policies are unreadable by their target audience, irrespective of their format, [15] and that less than 26% of Internet users read privacy policies [16], we assert that the codification of policy would enable computer to analyze them and visualize potential problems, perhaps based on a specification of the user's concerns or hot buttons.

None of the websites actually published a policy in machine-readable form using an electronic privacy language, e.g. P3P, and only the natural language version is available online for manual review. This precludes anyone from performing automated interpretation and analysis.

[5] Platform for Privacy Preferences (P3P) enables Websites to express their privacy practices in a standard format that can be retrieved automatically and interpreted easily by agents (machines or humans).

Limited Use and Disclosure

While HIPAA requires organizations to obtain unambiguous authorization of the patient before use or disclosure of information for a purpose other than what it was collected for, and recommends adoption of the principle of minimum necessary disclosure, HIPAA-compliant policy can be constructed that allows organizations to design policies with broadly defined purposes. This concern has also been highlighted in the public media [17]. For instance, while "marketing" is identified as a purpose that requires authorization, various sub-categories are defined, such as "communications for treatment of patient", that are exempt from the rule, making it possible to disclose patient data for marketing under the assumed purpose. Therefore, it may be assumed that the levels of disclosure post-HIPAA will not necessarily shrink, and in fact a data disclosure previously considered a breach may now fall within the folds of the policy to which the patient has consented. Anton et. al. [18] observe a similar phenomenon, where the number of information disclosures increased post-HIPAA.

Audit and Accounting

The fact that current healthcare audit systems do not capture the required context information in order to provide an accounting was the most striking observation. Even though HIPAA requires organizations to account for all activity (including data disclosures) and provide detailed reporting for audit purposes, fulfilling this requirement by itself would still not be effective in improving levels of privacy protection unless measures are taken to compensate for shortcomings in the data disclosure and access rules in the privacy policy.

When the purpose or authorization is not established at a fine granularity before any disclosure or access is allowed, the burden falls on the audit mechanism to be able to capture any action that may actually constitute as a violation of the policy. Additionally, when an exception-based mechanism is in place that allows users to override normal access controls, the need for audit-based controls is further accentuated. While an argument can be made that the deterrent factor of audits is more suited to the healthcare sector because of the critical nature of the services provided, it should certainly not become an excuse for failing to do better.

Access

Meeting this requirement may not translate to adequate privacy protection for patient. There are several reasons for this. First, the ability of a patient to access or update personal information maintained by the organization provides no measure of how much information is actually protected unless the patient is also in control of the use and disclosure rules, and, based on our preceding discussion, this is not the case. Second, navigating the processes of information access and update can be simple or laborious for the patient depending on the organization. In some cases, data retrieval may be a matter of few mouse clicks online. In others, one may have to wait up to 60 days to receive a paper copy of one's information.

Further Observations

From our analysis, the language used in the privacy policies appears to be unnecessarily convoluted. This is corroborated by other researchers in the field [19, 20] for healthcare and finance. Given this, it will likely not be understandable by the average patient. In other cases, the language was clearly ambiguous. For example, one policy in the study states "…will not sell, license or transmit to anyone any personal information that members or practitioners provide to us online. We may disclose information obtained online to our partners involved in administering or providing services for our health benefits plans". These are possibly two seemingly contradictory, yet consistent statements that seem to have a nullifying effect on each other.

Conclusion

The overall message from our study was that even though the privacy policies cover enough ground to enable healthcare organizations to claim regulatory compliance, they are not adequate to communicate understandable privacy practices to the patient or provide adequate privacy safeguards. Even more importantly, current privacy policies do not reflect what patients think are in their best interest.

We believe that organizations must be required to make their practices more explicit and held accountable for any deviations from the stated policy. It is only a matter of time before gaining customer confidence and trust with regards to privacy concerns plays a more significant role.

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Implementation of a Secure and Interoperable Generic e-Health Infrastructure for Shared Electronic Health Records based on IHE Integration Profiles

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Abstract

Introduction: The ubiquitous availability of medical or care data for authorized clinicians and nurses is expected to increase quality while reducing costs in the health care sector. The standardized, distributed provision of medical or care data is capable to support the vision of patient centered shared electronic health records (SEHRs). A main contribution to cross-institutional data exchange is provided by Integrating the Healthcare Enterprise (IHE). However, holistic implementations of IHE based eHealth infrastructures for SEHRs are currently rare and security and privacy regulations are not fully covered by existing IHE Integration Profiles. This work aims to point out our experiences and lessons learned from five years of development and the implementation of IHE compliant products.

Methods: Cross-Enterprise Document Sharing (XDS) describes the base components for exchanging medical or care data. A unique patient Identification is described by the Patient Identifier Cross-referencing (PIX) and the Patient Demographics Query (PDQ) Integration Profile. All interactions are logged in an "Audit Record Repository" deployed once per Affinity Domain and defined in the Audit Trail and Node Authentication (ATNA) Integration Profile.

Results: Based on the IHE Integration Profile XDS and other Integration Profiles high-level components for eHealth infrastructures and applications, supporting a holistic, secure concept and, based on these concepts, software products for a technical cooperative care infrastructure, has been developed. The products are practically evaluated in a project for setting up an IHE XDS Affinity Domain in the Austrian district of Tyrol and a number of lessons have been learned.

Keywords

Medical records, Medical record linkage, Data security

Introduction

The ubiquitous availability of medical or care data for authorized clinicians and nurses in a timely manner and in appropriate representation is expected to increase quality while reducing costs in the health care sector [1-3].

Currently health care institutions are experiencing a transformation in cross-institutional data exchange from proprietary solutions, mainly for point-to-point communication of selected medical data, towards a standardized provision of various document types including (radiological) images and multimedia content as virtual electronic patient records [4].

The standardized, distributed provision of medical or care data is capable to support the vision of patient centered shared electronic health records (SEHRs) [4]. As an extension to the exchange of medical or care data between health care providers, the patients with SEHRs are empowered to add content to their records (i.e. self assessments, medical diaries), to view audit events and to define security policies, as well as to access their own medical or care data [4, 6].

A main contribution to cross-institutional data exchange is provided by Integrating the Healthcare Enterprise (IHE), an international initiative which aims to support interoperability by widely accepted international standards such as Web services, HL7 and DICOM. Common workflows for standard-based sharing of clinical data are compiled as so called IHE Integration Profiles [7]. IHE Integration Profiles represent building blocks for the realization of holistic e-Health infrastructures (and other common clinical processes) in a broad sense [8].

Holistic implementations of IHE based eHealth infrastructures for SEHRs are currently rare and broad experience is missing. Apart from missing practical experiences with the implementation also the IHE frameworks shows some weaknesses. IHE describes the technical interoperability between systems of several vendors well, but does not focus on additionally re-

quired organizational interactions. Security and privacy requirements are only covered on a basic level by existing IHE Integration Profiles.

However, the importance of privacy aspects seems to vary between different nations in a European but also in a worldwide scope. This may have to do with historical events and possible data misusages in the past. Such strong privacy expectations in several regions require slight extensions of standardized IHE Integration Profiles.

Therefore our work aims at the identification and description of gaps between theory and practical experiences in implementing IHE Integration Profiles by pointing out our experiences and lessons learned from five years of development of IHE compliant products for the realization of a SEHR in Tyrol, the western part of Austria.

Methods

In order to ensure the highest possible degree of interoperability with other vendor's systems an IHE compliant architecture is a strict requirement. The design of the architecture followed standardized software engineering processes [9] incorporating architectural paradigms predetermined by the following IHE Integration Profiles relevant for SEHRs:

Cross-Enterprise Document Sharing (XDS) describes the base components for exchanging medical or care data between different institutions participating in an organizational framework called "Affinity Domain". XDS defines "Repositories" as data storage units which can reside locally in the institutions where data is produced. "Registries", deployed once per Affinity Domain, hold metadata about documents stored in the Repositories.

Registries serve as index services which allow predefined queries to find documents. Services used for registering Documents are called "Source" and services for retrieving documents "Consumer".

A unique patient Identification is described by the Patient Identifier Cross-referencing (PIX) and the Patient Demographics Query (PDQ) Integration Profile. The first allows mapping of locally used patient Identifiers to a unique Identifier per Affinity Domain, the latter provides services for identification of patients based on their demographic data.

As traceability of interactions is a key requirement for extended privacy aspects all interactions are logged in an "Audit Record Repository" deployed once per Affinity Domain and defined in the Audit Trail and Node Authentication (ATNA) Integration Profile. ATNA furthermore defines the use of Transport Layer Security (TLS) for encrypted communication and mutual authentication of services based on client certificates.

Apart from the use of IHE Integration Profiles the successful implementation of an e-Health infrastructure is also dependent on the fulfillment of a variety of other elements. To guarantee a high level of quality modern principles of software engineering were applied and intense testing was carried out through the whole process of development.

In order to assure compliance to IHE Integration Profile the software products has to be periodically tested at so-called Connect–a–thons, where different vendors are able to test and prove interoperability of their product with other vendor's software based on IHE Profiles. The products developed successfully took part in 4 Connect–a–thons.

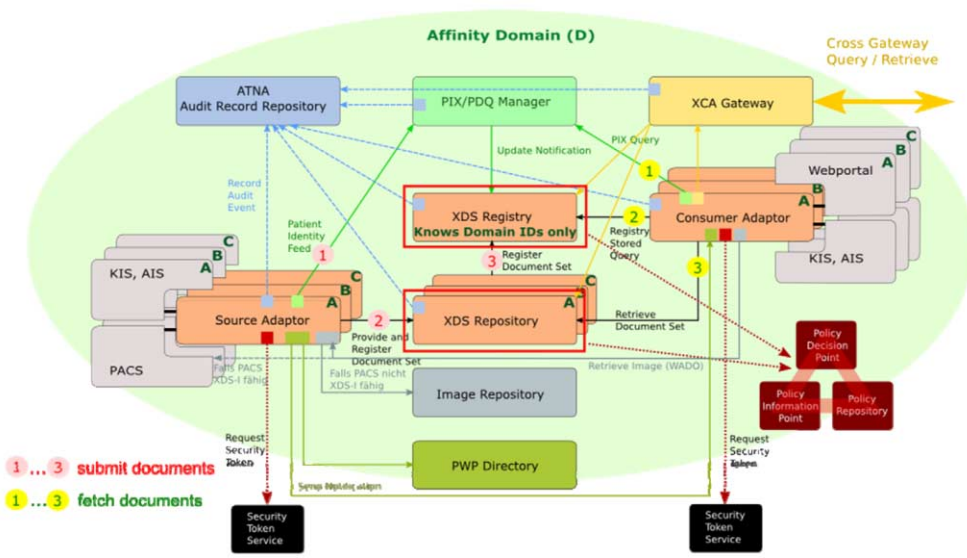

Figure 1 - Overview of sense Architecture based on several IHE Integration Profiles. Actors are depicted as boxes and Transactions as lines.

Results

Development of IHE compliant products

General considerations

Interoperability is required to support trans–institutional clinical data exchange in the context of SEHRs [10].

IHE describes the above mentioned building blocks for standardized e-Health infrastructures as so-called "Actors" and their interactions as so-called "Transactions". The IT-Infrastructure Technical Framework of IHE facilitates distributed data storage and also distributed index services. One of the main advantages is that medical or care data can reside in the institution, where they have been produced, and can be accessed by other institutions, provided that access rights are sufficient.

Based on the IHE Integration Profile XDS high-level components for eHealth infrastructures and applications, supporting a holistic concept for cooperative care, has been developed. Originally this development started five years ago as a research project [5] of universities in cooperation with industrial partners.

System Architecture for e-Health infrastructure

The software products are designed as modular components incorporating the Service-Oriented-Architecture (SOA) approach using Web service technology. Figure 1 shows an illustration of the architecture. The product family is called "sense® – smart eHealth solutions" owned by ITH icoserve technology for health care GmbH [11], which is a subsidiary company of a regional hospital holding company and Siemens. The products are available worldwide.

Workflow for transmission of documents

Workflow for registration of documents (cf. Figure 1, red numbers): Documents are submitted from the Clinical Information System (CIS) to the sense Source Adaptor which triggers the following IHE Transactions for (1) Adding patient identification to PIX/PDQ, (2) submitting the document to the Repository and (3) submitting metadata to the Registry.

Workflow for retrieval of documents (cf. Figure 1, green numbers): Documents are retrieved from the sense Consumer Adaptor which triggers the following IHE Transactions for (1) obtaining patient Identification, (2) querying the Registry and (3) retrieving the document from the Repository.

Java-based Web services offer a high degree of flexibility in implementation while supporting interoperability, as required by IHE, with other vendor's products, independent from platforms and programming languages. Therefore Apache Tomcat and Axis2 have been selected as application server and Web service runtime environment. For the sharing of clinical documents highly configurable services are deployed locally (sense® Localnodes) in health care institutions as well as centrally (sense® Communitynodes), operated for example by a large hospital, forming the XDS Affinity Domain as described above. Localnodes provide XDS Repositories as data storage and adaptors for the connection of existing, proprietary systems such as Clinical Information Systems (CIS) or GP's systems. Communitynodes provide XDS Registries as index services, a PIX/PDQ master patient index for unique patient identification and an ATNA audit record repository for central storage of audit events.

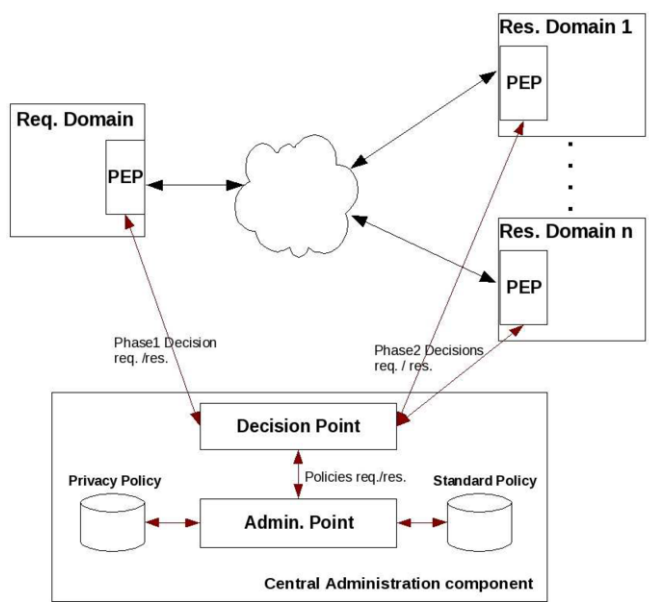

Figure 2 – Design of the security architecture

Security Concept

The sharing of patient data requires a sophisticated security concept reaching from Transport Layer Security (TLS) to provide authenticated and encrypted data exchange on Network Layer as well as an advanced authorization framework based on the Security Assertion Markup Language (SAML) [12] and extensible Access Control Markup Language (XACML) [13] on the application layer, which – in future – should empower the patient to decide who may access his health information.

The security concept [14] tackles privacy and access control in IHE systems from two perspectives: a Policy and an Enforcement. Two types of policies were defined: standard and privacy policies. While standard policies represent data security regulations in Austria, privacy policies enable – in future – citizens to define their own personal preferences and conditions. From the enforcement point of view, two phases' enforcement and decision making process was defined (cf. Figure 2). The difference between the two phases is the granularity. In the first phase the whole patient's record is considered as one virtual object and the enforcement is done at the requesting side. In the second phase a finer granular decisions can be taken for each part of the patient's record. Due to the fact that the parts of a patient's record are stored in different domains, the enforcement in this phase is done at the responding side, i.e. affinity domains that store parts of the requested record.

Implementation of a SEHR in Tyrol

Based on these components in the Austrian district of Tyrol a virtual electronic patient record with capability to future extension to a shared electronic health record has been set up.

Tyrol is located in the western part of Austria, with alpine topography. It has approx. 750.000 citizens, 12 hospitals with together approx. 4000 beds and 2.000 physicians (in- and outpatient).

Prior and during the implementation, a couple of important lessons have been learned, which are of interest to other similar projects:

- The financing and the assignment for projects related to e-Health is one of the most difficult tasks. The benefits are mostly in the public economics and less in the business economics. This means that public bodies are the main beneficiaries. This leads to the fact, that health care institutions are often not the buyers of such systems and are not willing to invest in such solutions.
- In general, the benefits of e-Health (infrastructures or applications like SEHRs) are not easy to verify. Big saving potentials with regard to macroeconomics are regularly published [1]. But health professionals do mostly not think in big numbers but in small steps assisting their personal work. Therefore it's very difficult to create acceptance amongst health professionals.
- In Tyrol, several independent health care providers requested in common a standardized e-Health infrastructure to improve cooperation. This common appearance at public bodies got the ball (for assignments) rolling.
- After assignments a working group for common coordination, consisting of all participating health care institutions has been established.
- The introduction of standards for medical document formats or metadata was one of the most labor intensive steps. With currently available technology such as CDA, a very fine–grained structure can be applied to clinical data. Structuring of clinical data influences the workflow of data capturing. This is an organizational rather than a technical challenge as health professionals must be motivated to switch from flexible free text to a rigid framework for data capturing.
- Austrian data protection regulations require a 2-level access control mechanism. The fist level requires that a current treatment relationship exists between physician and patient. The second level requires consent of the patient. In the consent document restrictions can be applied for institutions, departments, document type and time range. Level 1 is covered by a service, provided by the operators of the so called "e-card" (Austrian health insurance card). Level 2 requires extensions to the XDS Document Registry and an organizational framework.
- In order to support patient-controlled restrictions as described above, new queries had to be added to the Document Registry which allow filtering particularly for institutions and departments. Level 2 restrictions are currently not evaluated technically. Physicians querying for documents have to obey the patient's restrictions when setting search criteria in the user interface. In order to assure that those restrictions are actually applied all queries are logged to the ARR. Health care professionals participating in the SEHR have to obligate themselves to respect the patient's consent and to store the consent document paper-based or electronically. Furthermore health care professionals have to agree to periodic inspections of consent documents with the aim to prove that issued queries, logged in the ARR, match the consent of the patient given in the consent document. However in future versions of the software the patient's consent will be covered by access control policies.
- Early usability evaluation revealed that a seamless integration of the SEHR application in the Clinical Information System (CIS) or the GP's system is vital for end-user acceptance. A web portal solution is only the second-best choice. The concept of the sense Source and Consumer Adaptor proved to be important to facilitate the development effort for those systems as complex IHE transactions and the handling security validations is covered by the Adaptor services.
- Operating the SEHR in a dedicated physical network, strictly separated from the Internet improves security and therewith also end-user acceptance.
- Although IHE dramatically improves interoperability between different systems, test effort remains high.

This seems to be rather caused by semantic then by technical issues.

- End-user and system administrator training is a key factor for success and acceptance of SEHRs. The challenge is to create awareness of the sensitivity of retrieved data, which implies that restrictions issued by patients in the consent document have to be strictly obeyed.
- A professional project management from acquisition to routine operation of a SEHR is a vital success factor. E-Health projects are complex and risky as there are many players involved with partly distinct interests, level of technical understanding and organizational objections. Advanced project and also conflict management skill is required to reach the goal. However this is a time-consuming process.

Discussion and Outlook

IHE Integration Profiles leave details open for implementation, which is, from the economic point of view, expected to support the market. Technically this might lead to slightly different interpretation of the specification, which may prevent successful communication between different systems.

The concept of IHE is interoperability testing and not certification. This means that systems attested conformity to an Integration Profile can be further developed. This "snapshot" approach allows vendors to further modify and improve their systems even after conformity has been attested, which furthermore allows modifications carried out during the Connect–a–thon to be stabilized to a mature system. We however would like to create awareness that changes to a successfully tested system might lead to side effects that can, in the worst case, break interoperability.

Particularly the upcoming seamless integration of the security concept shows that especially in the health care sector technical challenges can be solved rather easy in comparison to organizational challenges such as a nation-wide role definition for medical personnel or such as required changes in medical or care workflows.

Interoperability between computer systems in health care seems to be adequately solvable using state-of-the-art technology such as Java and Web services. Semantic interoperability which should provide for identical, language independent interpretation of the submitted content is expected to remain one of the major challenges for the next years.

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Desiderata for a Computer-Assisted Audit Tool for Clinical Data Source Verification Audits

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Abstract

Clinical data auditing often requires validating the contents of clinical research databases against source documents available in health care settings. Currently available data audit software, however, does not provide features necessary to compare the contents of such databases to source data in paper medical records. This work enumerates the primary weaknesses of using paper forms for clinical data audits and identifies the shortcomings of existing data audit software, as informed by the experiences of an audit team evaluating data quality for an international research consortium. The authors propose a set of attributes to guide the development of a computer-assisted clinical data audit tool to simplify and standardize the audit process.

Keywords:

Data auditing, Data quality, Software design

Introduction

Analyzing low quality study data produces meaningless results, which is why interventional clinical trials focus so heavily on data quality control [1]. Many international, multi-center research networks that pool and analyze observational data, however, do not report a similar emphasis on data quality assurance. Without methods to assess and improve data quality, studies using the resulting observational databases may generate false research conclusions based on unreliable information.

Data auditing is a proven method of assessing the quality of routine clinical care data that have been reused for research[2]. Unfortunately, most verification audits of clinical data use paper audit forms, which have been shown in general to be less effective and efficient than electronic tools [3, 4]. This work aims to identify the core weaknesses of paper forms when used for clinical data auditing, as motivated by a series of data monitoring visits to seven clinics participating in an HIV observational research network. The authors propose a set of functional requirements for a computerized audit tool that may simplify the audit process and encourage research networks to measure and improve the quality of their data.

Auditing is an established technique for evaluating and improving the quality of products, services, or information, and has been a staple of quality control activities for over a century [5, 6]. Audits take many different forms depending on the domain: in accounting, they identify fraud; in manufacturing, audits help assess both the quality of a product lot and the producer's compliance with Good Manufacturing Practice; and in information security, audits allow for the inspection of the security and reliability of computer systems and of the information they contain [7, 8]. In medicine, researchers have employed audit techniques to detect inconsistencies in terminologies, evaluate the quality of patient care and verify that medical services are properly documented, coded, and billed [9-11]. The U.S. Federal Drug Administration also requires auditing of many clinical trials to ensure that the operators of the trial are properly monitoring patient safety, accurately recording data generated by the study, and adhering to the study's protocol and Good Clinical Practice [12, 13].

Protocol-driven studies such as clinical trials often engage teams of clinicians and data managers to perform research data audits. These auditors compare research data to the source documentation, which often includes paper clinical charts, laboratory reports, or the contents of electronic medical record and laboratory systems at the study sites. Most tools to support clinical data audits are paper forms with lists and checkboxes, with various examples freely available online [10, 14, 15].

Although paper-based audits are still common in medicine, computer-assisted audit tools (CAATs) have improved the quality of audits in finance, manufacturing, and IT security by facilitating more thorough audits, generating more consistent documentation, and saving both time and money for auditors and auditees [16, 17]. CAATs can aid auditors during many stages of the audit process, from merging and analyzing data to generating audit reports. Auditors often use statistical or data extraction software as a CAAT in order to detect anomalous patterns in large data sets. Other software packages specifically designed for auditing (e.g., Audit Command Language (ACL) and Interactive Data Extraction and Analysis (IDEA)) even assist auditors in selecting the audit sample size and audit methodology [18, 19]. Each single-user ACL or IDEA license provides access to powerful data analysis tools, but also costs thousands of dollars. Less expensive audit-specific software includes TopCAATs, a Microsoft Excel audit plug-in, and Picalo, a Python-based, open-source data analysis and fraud

detection toolkit [20, 21]. Most of the advanced CAATs also require computer programming skills.

Unfortunately, these software packages focus on analyzing an existing, electronic dataset for errors and unusual patterns, rather than facilitating the comparison between the dataset and a physical source document. Indeed, in many accounting and security audits, the electronic database *is* the source document and no other records exist. As a result, these advanced software packages are not helpful for auditing paper source documents. Furthermore, the cost of tools such as ACL and IDEA makes purchasing them unfeasible in resource-limited settings.

Motivation

Data Audits at Seven HIV Clinics

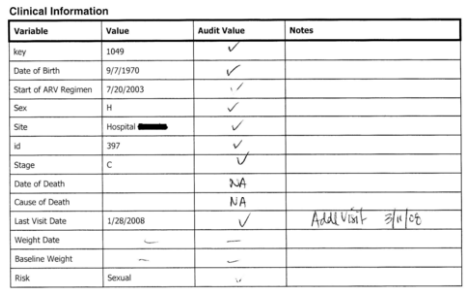
The Caribbean, Central and South America Network for HIV research (CCASAnet) is one of seven collaborative research groups participating in the International Epidemiologic Databases to Evaluate AIDS (IeDEA) [22]. CCASAnet brings together researchers from HIV clinics in Argentina, Brazil, Chile, Haiti, Honduras, Mexico, and Peru to create an HIV observational database using routine patient care data. The project's data coordinating center (DCC) at Vanderbilt University conducts Good Clinical Practice-based audits on datasets submitted by CCASAnet member sites to identify sources of error in data collection, abstraction, and representation, and help the DCC determine the structure, quality, and reliability of the submitted data.

Between March 2007 and April 2008, a two- or three-person team including at least one physician and one informaticist visited each member clinic to compare the on-site medical documentation to the contents of the electronic database that the site previously submitted for analysis. The audit team used a multi-page paper audit form to record the results of the database-to-clinical record comparison. Data on the form were divided into categories such as demographics, clinical visit data, antiretroviral regimens, and laboratory results.

Two items per data element were preprinted on the form: the variable name (e.g., birth date, date of death, viral load result), and the database value for that variable. The team used the blank "audit value" field to record whether a data element was present in the source documents and whether the source value was correctly represented in the database. A small notes field – as well as the margin of the paper – was used to record additional information or possible causes of the error. Figure 1 shows a sample page of a completed audit form.

At the end of an audit visit, the auditors presented their preliminary findings during an exit interview with the site investigator and staff. After returning to the DCC, the audit team produced a report describing its findings and recommendations, which was sent to the site for review and comment.

The audit team inspected 184 records and 4223 unique data elements during seven audits. The average time between the end of an audit and the completion of the audit report was 101 days which meant the site data personnel rarely received immediate, implementable recommendations on how to improve data quality.



Clinical Information

Variable	Value	Audit Value	Notes
key	1049	✓	
Date of Birth	9/7/1970	✓	
Start of ARV Regimen	7/20/2003	✓	
Sex	H	✓	
Site	Hospital [redacted]	✓	
id	397	✓	
Stage	C	✓	
Date of Death		NA	
Cause of Death		NA	
Last Visit Date	1/28/2008	✓	Add'l Visit 3/11/08
Weight Date	—	—	
Baseline Weight	—	—	
Risk	Sexual	✓	

Figure 1- A neatly completed form from a CCASAnet site audit.

Benefits of a Computer-Assisted Audit Tool

Feedback on data quality is most effective when it is communicated shortly after the audit takes place, but the use of paper audit forms makes generating reports a challenge [6]. In post-audit debriefings, the auditors identified several causes for delays in producing the audit report, including difficulties with

- handling multiple audits and reports simultaneously,
- reading other auditors' handwriting,
- interpreting underspecified notes without the presence of the source documents,
- deciding how to handle partially completed audit forms,
- classifying errors during post-visit audit form reviews,
- assessing whether an error was clinically meaningful,
- consulting with other auditors abut error classifications or unclear information,
- sharing a single set of original audit forms among a team of auditors,
- tabulating errors,
- double-checking other auditors' error tables,
- calculating error rates,
- composing a thorough and detailed audit report, and
- formatting error tables for the final document.

A computer-assisted audit tool that replaces the paper forms could help standardize the audit process and increase the timeliness and reproducibility of audit results. A CAAT for clinical data auditing could guide users through the process of importing their study data, selecting records to audit, recording and categorizing data discrepancies, and generating audit results. The audit findings would be immediately available in an electronic format that could be used to generate tables or to feed corrected data back into the source database.

Key Attributes of an Audit Tool

To improve the audit process, computer-aided software for source document verification should provide flexible functionality in five main areas: networking, audit data management, error categorization, audit decision support, and results reporting. The audit team's experiences that motivated these requirements are described in the text. The requirements are outlined as desiderata in Table 1.

Requirement 1: Networking

Paper forms functioned as an excellent sharing tool during audits. Although each auditor worked independently on a set of records, difficult cases or records with cascading errors often required a group review in which the source document and audit form were passed around the table. A suitable CAAT should facilitate the same real-time communication between multiple auditors and allow collaborative editing of a shared database, in settings where Internet access is not guaranteed. CCASAnet data audits, for example, often take place in the record storage or meeting rooms of clinics in resource-limited settings, where auditors work collaboratively on complex records. An effective paperless audit tool needs to accommodate multiple users manipulating a single copy of the data. However, because of the unreliability of local network connections, a useful tool should take advantage of portable routers or alternate network structures, such as wireless ad hoc networks between auditor laptops.

Requirement 2: Audit Data Management

Preparing paper audit forms in advance of each audit was a laborious, multi-day task for the audit team and the CCASAnet data manager. An audit tool that allowed users to import preformatted datasets could reduce the preparation time significantly. A standard XML data specification would permit auditors to load a copy of the audit data, as provided by the study data manager, before the audit begins. A standardized import/export format also allows the audit results to be routinely converted for use in statistical software packages.

Although the ongoing CCASAnet audit program evaluates the accuracy and completeness of HIV-related clinical and laboratory data, the proposed audit tool should be able to accommodate datasets with different medical content, such as data collected for studies of cancer or tuberculosis. The software's internal representation of the audit data, therefore, must be flexible enough to adapt to different content types. Such types include not only standard data representations, such as integers, character strings, or Boolean variables, but also the frequent irregular data forms that the audit team catalogued, such as malformed, partial, and approximate dates, miscoded values, and integer variables with character content (e.g."<400").

Requirement 3: Standardized Assessment of Errors

CCASAnet's paper-based audit process relied heavily on memory, interpretation, and opinion, and was difficult to replicate and standardize across sites. Indeed, when the DCC undertook a reevaluation of the audit findings in mid-2008, the authors had a difficult time applying a standard error categorization system devised for the task, as the original paper forms had required auditors only to describe errors, not to classify them according to a formal error taxonomy.

A robust audit tool should assist auditors in assessing and classifying errors during the audit visit, rather than weeks afterward when the source documents are no longer accessible. The auditor should be able to import the most appropriate error categorization scheme for a given audit task, as errors in HIV data, for example, may be distinct from errors in cancer or tuberculosis data. The tool should also accommodate complex error classifications that prompt auditors to evaluate data errors on multiple axes, including the type of error, the severity of the error, the clinical relevance of the error, and the probable direct cause.

Requirement 4: Audit Decision Support

Selecting the number and type of records to audit is a challenge for novice auditors. The audit team consulted a statistician in advance of each audit, but a useful CAAT could provide basic guidance on sample size calculations and selecting records for audit, using selection metrics that have been described in the literature.

The system should also allow the auditor to import an optional rule set that would guide the automatic classification of errors based on the data class and error type. A mismatched weight value of 37.5kg in the clinical record vs. 38kg in the database, for example, is likely to be a rounding error of limited clinical significance. This functionality could be useful in labeling complicated errors of drug prescription and discontinuation.

Requirement 5: Results Reporting

The CCASAnet team found that preparing a post-audit report from paper audit sheets required time-consuming counting, description, tabulation, and confirmation of all the data discrepancies. Both auditors had to count the variables in each record, group any recurring errors, double check final numbers, and tabulate the results manually, which delayed preparing the final report. Software support for generating tables, graphing data, and displaying trends based the results of the audit could simplify the post-audit work and help auditors detect patterns of errors across records or data falsification that might be overlooked in manual review. Furthermore, such tools could help auditors adjust their sampling of variables during auditing to focus their efforts on evaluating variables that appear more prone to error.

By automatically generating tables of error rates and lists of specific errors, a computerized audit tool would assist auditors in preparing a summary for the exit interview and the final post-audit report. Audit support software should also provide basic quality improvement suggestions for the site based on patterns of error in the audit data and established user-imported rules.

Table 1- Obstacles encountered during clinical data audits and corresponding desiderata for computer-assisted audit tools.

Obstacles Encountered during Audits	**Solutions / Desiderata for a Computer-Assisted Audit Tool**
Challenge: Collaboration	**Solution: Networking**
Auditors need to work collaboratively on the same copy of a record.	Real-time Collaboration: networked laptops for auditors, shared databases, web-based systems
Audit sites may have no network infrastructure.	Portable Network Infrastructure: peer-to-peer networking, portable server and router
Challenge: Audit Data	**Solution: Audit Data Management**
Paper audit forms take a long time to prepare and validate.	Import Functionality: one-click import of data and data descriptions (metadata) from research database to CAAT, instant generation of basic electronic audit forms
Copying audit results from paper forms into a spreadsheet for analysis is time-consuming.	Export Functionality: export of audit results into structured data formats such as XML
Datasets may contain different medical content (e.g., HIV, Tuberculosis, or cancer data).	Metadata Management: customizable import interface, customizable display of data on screen, data dictionaries for special topic areas (HIV, TB, Cancer)
Data may violate syntactic rules; auditors may need to record corrected values.	Reasoning About Data Types: representing simple and complex data types, data syntax rules, codification of mismatch between research data and native records, handling malformed data
Challenge: Types of Errors	**Solution: Standardized Assessment of Errors**
Errors are not categorized and described clearly on paper forms, making it difficult to analyze and report error types and rates.	Representation of Error Types: hierarchical ontology of errors, clear operational descriptions of error types, specification of domain of error types (applies to specific variables within the audit record or applies to entire record), specification of error labels and default values and whether closed or open world assumptions apply
Auditors discover new and unexpected types of errors during the audit process.	Error Scheme Evolution: support for versioning and collaborative authoring of error schemes, interface to edit error schemes while in use
Some audits require different error classification schemes that are better suited to the data.	Error Scheme Management: storage, import, and export of audit-specific error terminologies
Challenge: Audit Design	**Solution: Audit Decision Support**
Auditors are unsure how many records should be audited to produce meaningful results.	Statistical Dashboard: guidance for sample size calculations, identification of grossly problematic records, pre-selection of records via statistical sampling
Challenge: Analyzing and Presenting Results	**Solution: Results Reporting Tools**
Tallying and tabulating errors by hand is a time-consuming and error-prone task for auditors.	Automatic Report Generation: software support for generating tables and graphs
Manual approaches may miss subtle patterns of data error.	Real-time Trend Detection: automatic checks for patterns of error suggesting data falsification, systematic errors

Discussion

When an audit process lacks standardization, different auditors may produce different audit reports given the same source record. Without standardized quality measures, the changes in an organization's data quality cannot be compared from year to year, nor can audit results be compared from site to site. Flexible audit support tools that have the attributes described will simplify and standardize auditors' work, thereby increasing an audit's potential benefit.

The CAAT recommendations described here stem from audit experiences at HIV clinics in Central America and the Caribbean. The perspective of a single international research network, however, may limit the diversity of experiences that

informed the five suggested requirements. Indeed, these recommendations may represent a necessary but not sufficient set of features needed for a successful paperless audit tool.

Future work will focus on developing a prototype CAAT for audits of HIV, tuberculosis, and cancer data. If the tool proves to be useful within CCASAnet, other similar networks could use it to evaluate the quality of their data, standardize their quality control activities, and identify areas for process improvement.

Conclusion

The quality of routine clinical care data should be assessed before such data are included in observational databases. Current paper-based audit techniques can be both inefficient and inconsistent. Computer support tools may be able to simplify and standardize the preparation for and execution of a source document audit, if certain criteria for such a tool are met.

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Complexities in securing sustainable IT infrastructures in Hospitals: The many faces of Local Technical Support

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Abstract

This paper contributes to an understanding of the complexity of support work and stress the need for local technical support in hospitals in order to maintain a sustainable infrastructure of information systems (IS) and information technology (IT). Given this complexity it is pointed out that a naïve trust in formal stylized models of support organization is problematic. With an increasing number of critical systems in the hospitals technical support is becoming an essential service needed for maintenance, acute failure of systems and help with the everyday use of hardware and software. In order for the health informatics technologies and systems to work, the healthcare institutions need strong IT organizations to support and maintain the IS/IT infrastructure on which these technologies and systems rely. Through a qualitative study of IS/IT support at hospitals I have examined the work and competencies of the service level in the IT organization. On this basis I recommend a nuanced understanding of the complexity of the work of these local technical supporters. I contrast this to the understanding of the organization of IT support through rationalized, formal, 'best practice' models that emphasize centralization and cost-effectiveness through single point of contact. It is argued that there is a need for local technical supporters in hospitals with organizational and local knowledge because a) the local circumstances are key to supplying effective support and b) the supporter supply pro-active support that aid to secure the sustainability of the IT infrastructure.

Keywords:

Technical support, Local, Maintenance, Health informatics, Organization.

Introduction

Sustainable and appropriate use of information systems is not just based on the system design and the way the systems are implemented even though this is important and is the focus of a wide range of research in the field of IS and Health Informatics. An important factor to the functioning of an information system is the way the systems are supported, and as Pentland states "[…] an unsupported product is hardly considered a product at all"[13]. The focus on and importance of supporting systems within the healthcare sector is also central in the strategy from the Danish public organization SDSD (Connected Digital Healthcare in Denmark): "The increase in digitalization results in an increase in demands of the IT solutions on the related operations. IT solutions that are applied in the healthcare sector are often of vital importance to the treatment of patients. It is therefore of critical importance that the solutions of IT operation are handled professionally in order to produce a high level of reliability of operations."[2]

If the technical background (the IT infrastructure) is not working, the best information systems in the world won't do much good. Besides, a large amount of the cost of IT is related to the work carried out after installation [5][[8]. In spite of this there have been very few studies related to the topic of supporting systems in healthcare within the Health Informatics field.

The empirical basis of this article is a study of the IT organizations providing services to the Danish hospitals. These have changed to a large extent since 2007 where the Danish regions, which are responsible for the hospitals, were reduced from 13 to 5. The structural changes were followed by a focus on a new way of perceiving the regions. The new ideal was seeing the regional organization as a corporate group (in Danish; 'koncern'). One of the implications of this change in Region North Jutland and the other regions was that the IT departments began a centralization of services.[17] The organization of the IT departments was further inspired by and based on an English public IT organization model called ITIL, that focus on streamlining the IT organization in a centralized and uniform way in order to increase service and reduce cost. This has proven difficult for a number of reasons, some of which will be addressed in this paper.

Analytical framework

What is support?

Technical support consists in the maintenance, repair and other services done in relation to securing the function of hardware and software: "Technical support is a post-sales service provided to costumers [or users in organization] of technology products to help them incorporate a given product into their work environment."[1] Technical support is the backbone in securing sustainable infrastructure on which the IT systems of the hospital rely. Support can both be organized as both an internal or external service.

Levels of support/service

The support structures of IT organizations are often divided into levels. There are different ways of defining the levels. One way is to divide them into front-end and back-end support. The front-end support is further divided into helpdesk and product support as illustrated in Figure 1.[8]

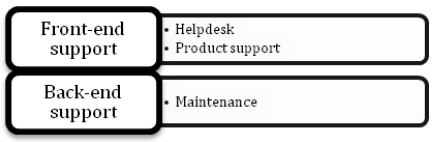

Figure 1- Levels of support

The front-end support is where support has contact with the users or costumers. The first level is the first point of contact for the user and preferably the only one in terms of cost-effectiveness. There are a number of reasons why this structure is preferred. One is to reduce the amount of trivial tasks solved by experts; another is to secure a simple structure for support with easy, one-way contact and tools for managing the technical problems.

ITIL methodology and centralization

Information Technology Infrastructure Library (ITIL) is a paradigm used by or inspiring all the IT organizations of the Danish regions[17], though many have found problems with implementing the paradigm in the organization. ITIL describes different IT practices and provides descriptions of checklists, tasks and procedures that are considered best practice. The focus within ITIL is on the needs of the clients, and on clearly and effectively defined responsibilities and processes for different service tasks within the IT organization. [6][16]

ITIL also divide support work into three levels that determine the level of escalation of a specific problem (incident). First level support is defined by first contact. On this level of support the problem is registered and clarified and attempts are made to solve the problem immediately. This level is also responsible for the communication about the status of the problem to the users. If the problem is too complex (require a higher level of expertise), the task is escalated/transferred to the second level, the expert technical support. The purpose of this level of support is to patch up the more complex problem as quickly as possible. The difference between the first two levels is based on the level of expertise and therefore the cost of the service provided. The second level is, in contrast to the third, generalists in the technical field. The third level of support is the escalation of a problem to highly specialized experts in a specific field. This is often external provides of software or hardware, but can also be internal providers such as server and network maintenance.

Technical support can both be done remotely or as local technical support. In both cases there are a number of tools used for both administering and getting the job done. According to ITIL an incident management tool is essential for recording and managing incident information. A tool like this is also used in Region North Jutland.

Support as interaction and design

Mira Kajko-Mattsson states that "Today, we do not have maintenance models (standards) appropriately reflecting the diversity of maintenance activities. What we have is a very general standard model mainly applicable with perfective maintenance at the third support level."[8] A number of attempts have been made to describe the complexity of support activities. Two of these approaches are described below. One concerning support as mending social situations and another viewing support as design.

According to Julian E. Orr, support is often seen as the diagnostic, repair and maintenance of machines. But this is actually not the whole picture. He points out that "[…] machine problems may actually be problems in the social relationship between costumer and machine, and large parts of service work might better be described as the repair and maintenance of social settings."[15] As illustrated in figure 2 the technician can be seen as a mediator or someone engaged in the reconfiguration and repair of the relation between the user and the machine.

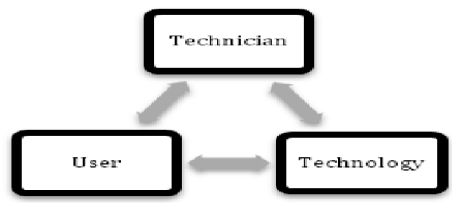

Figure 2- The technical support reconfigures the relation between the user and the technology

This approach sets focus on the fact that being a technical supporter is also being concerned with social relations and consulting the costumer on the interaction with technology.

Another approach to drawing the more complex picture of local support work is to perceive the support activities as a form of local design.[9][10] The concept of local design points toward the constructive features of doing support work. The constructive features of the local support work helps the design of relation between costumers/users and technology in order to secure it "[…] works for people in a context of values and needs, to produce quality results and satisfying experience" [20][9] Anne Marie Kanstrup argues that the local supporters are "[…] domain experts with enough computer knowledge to be able to install, maintain, support, etc., hardware and software in the organization. And they are capable of supporting and teaching other members in the organization with regards to the use of software applications in an efficient way because they take their point of departure in 'the system, the users, and the context all together'."[9] This perspective contributes to an understanding of the importance of a variety of competencies and of having local knowledge along side the technical in order to provide qualified support and systems design.[14]

Methods and Materials

My empirical study is based in the qualitative field and places its studies on a cross between grounded theory and processual research[12][19]. The study of IT support was set up to inquire into the work of IT supporters, but also to uncover features of IT support that could be subject to further inquiry. IT support was in this study taken in the broadest sense as all support of IT systems, involving hardware, software and people-ware.[11] The study is based on 10 interviews (clinicians, secretaries in clinical practices and IT professionals), 6 days of observation of technical IT supporters work and study of reports and other texts. Also an organizational analysis was carried out about the structure of IT support in the organization.

Results

The technical support organization

In Region North Jutland the support organization is build on inspiration from ITIL though the structure is not fully implemented, and is not intended to be. In a document concerning the forming of the regional organization it is written that 'the core in IT maintenance and support will be the implementation of a framework for processes (ITIL) as a means of securing that the appropriate services are delivered to the business at the appropriate price and agreed upon quality.'[3]

IT in Region North Jutland is organized as a centralized function in the organization managing support, maintenance and development projects and tasks across the nine hospitals in the region. The way the Region North Jutland has implemented ITIL in relation to support is by formalizing procedures for contact, escalation and feedback of incidents. This is organized around a problem handling IT tool (software).

The support organization is divided into levels. The first level and front end support is the Virtual Service Desk. On the second level (technical) we have backend support where the service can be done either on-site or remotely through different tools, e.g. remote access to computers. The third level is internal support or repairs of servers and networks or external help from the manufactures of hardware and software. Thus we see that their IT support (in figure 3) is structured similar but not identically to the general model described above.

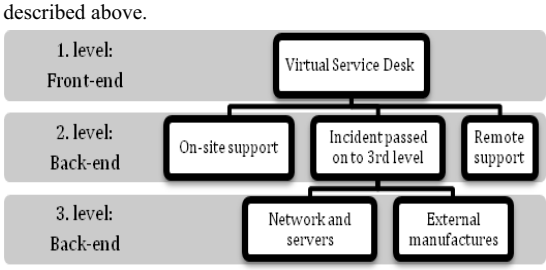

Figure 3 - The structure of technical IT support at Region North Jutland

The virtual service desk is the single point of contact for support. The costumer calls a number and is redirected to the supporter on duty that day. Costumers can call the service desk with acute problems, but must send an e-mail if they e.g. need new hardware or other non-acute services. When service desk receives a call or e-mail they will either solve the problem immediately or escalate the problem to second or third level of support. The hospitals need to call the service desk in order to get in contact with the local supporters. Not even the secretary at the front desk has the phone number to the local technical supporter.

The work tools of the supporters

When using ITIL and IT Service Management strategies, IT organizations usually use problem handling software for logging and managing the incidents. This is also the case for Region North Jutland. They use a system for logging, distributing and acceptance of IT problems/tasks. The system is also used for management of the work of the IT professionals. Most problems are logged in the problem handling system by the supporters at Service Desk, some come in via e-mail with non-acute requests and the local supporters also log some problems that need solving at a later point.

Some of the problems that arise in the local support work stem from the need for completeness from a management/system point of view, not from the usability of the system for managing and distributing tasks. This gives an added workload that seem unnecessary from a work perspective. Lucy Suchman describes this problem through the concept and discussion of visibility of work.[18] The visibility of tasks through an IT system can both mean legitimacy, rescue from obscurity or other aspects of exploitation but it can also create reification of work, opportunities for surveillance, or increase group communication and burdens on the work process. In relation to the problem handling tools these can both prove an effective tool for managing the support services and become a burden to the local supporter given the amount of tasks he needs to solve 'on the fly' while performing other tasks. Even though some supporters expressed uncertainty towards what tasks to log in the problem handling tool, most supporters thought the system was useful for getting a picture of the tasks that need addressing and managing the work.

In addition to the problem handling tool the supporters used a wide range of different, mostly digital tools for managing and performing their work, though I do not have the space to describe these in the present paper. (See figure 4, seond column.)

The work tasks of the supporters

Support of the IT infrastructure is important, but the way of organizing the process is not always as simple as suggested by the formalized ITIL model and the organization model of the support structure in Region North Jutland. This will be illustrated by the following description of the typical work procedures of the supporters.

Roughly two days a week is used on on-site support, solving problems locally in the hospital. Every local supporter also needs to do Service Desk support for half a day once a week. The rest of the time is used on remote support, maintenance of

old equipment and preparation of new equipment. Also supporters participate in projects related to implementation of new technologies in the hospitals.

Because the service desk takes all the calls from costumers the supporter can do his work with fewer interruptions. But this does not mean that he will not be interrupted. When doing on-site support there are often requests for additional help and the supporter is often stopped in the hallways. Despite these interruptions and departures from the plan, the supporters generally expressed a high level of satisfaction with the complexity of their job.

Between levels of support

Though the organizational mode used for managing the support of IT/IS in hospitals is focused on centralization, there are a number of reasons why this can prove difficult. In the explorative study it was evident that the local technical supporters were not just local expert technicians. Their work was also composed of taking tasks 'on the fly' and enquiring about problems they are aware of. In this way their practical work procedures do not fit the model. The supporters can be said to be between levels. They are both IT professionals solving technical problems and tasks takers, taking and solving tasks as they emerge.

Another way in which the local technical supporters did not fit the model is the multitude of tasks they are part of. As described by Orr [15] the technical support task is not just focused on solving a technical problem, they are actually repairing and maintaining a social setting and as described by Kanstrup [9] they are also designing the workplace. This was also supported by the empirical study. In the study a multitude of roles, skills and knowledge emerged as part of the everyday work of the supporter. (Illustrated in Figure 4)

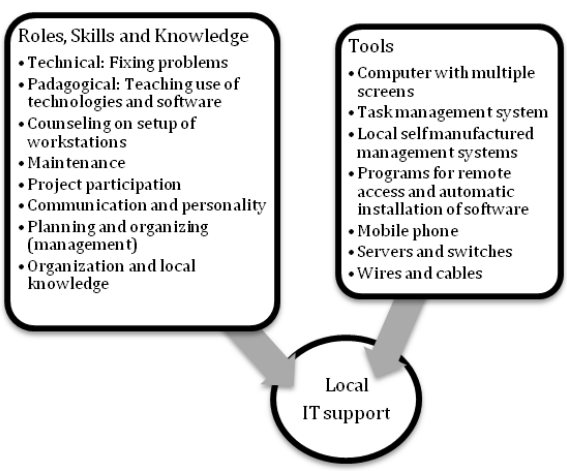

Figure 4- Examples of the multitude of roles, skills, knowledge and tools needed by the local technical supporters.

Meeting the costumer

Generally the customers/users were satisfied with the support they got. However, the problems they mentioned in interviews were generally related to a) problematic communication with supporters, b) insufficient number of local supporters, b) lack of relevant updates to all involved parties when a task was solved, and d) getting more complex support tasks done.

Most of the staff interviewed expressed the desire for knowing their supporter personally. The reasons mentioned for this were e.g. that it made communication easier, because they could continue to build on an understanding that was already established. Another reason was that the supporters generally need a certain amount of knowledge about the clinical practice in order for them to help resolve the technical problems. Even though there are a lot of changes in the support staff, the clinicians thought that the relationship to the supporters was build rather quickly and was needed for securing proper support and solutions of their technical problems.

It was also enlightening to look at the everyday work practice of the clinicians. Their work is characterized by being mobile and structured around the face-to-face communication between clinicians, patients and other staff. The mobility of the work implies that the majority of the clinicians seldom have their own workspace, but share computers and other office related tools among the staff of the wards. The distribution of work is done on daily and weekly meetings. And most of the critical information is documented in writing, but is supplemented and passed on to others in speech. Technical problems are often passed on to secretaries or leading nurses because solving these problems require a break in the work flow. This is also the reason why some technical problems are just left as they are and 'work-arounds' are implemented.

In order for the supporter to communicate efficiently with the clinicians they need to somehow fit in with the practice. It can be argued that this is done best by fitting in with the way clinicians generally communicate, that is face to face. The fact that clinicians often let secretaries or leading nurses pass on their technical problems is likely to lead to misrepresentations of the problems or the omission of certain details that will complicate the solutions of the problems. All in all this view on the daily practices shows that the possibility to have face to face communication with a local supporter would be preferable in order to solve technical problems efficiently. To have a competent person with knowledge and awareness of the local setting fixing the problems is likely to help satisfy the costumer/user.

Discussion and Conclusion

In this paper it is argued that the local supporters, with the multitude of skills, roles and tools at their disposal are needed in order to keep the IT infrastructure of the hospital in working order. They are not just needed in order to fix technical problems, but also as maintainers and designers of the interactions with and around the many technological products in hospitals today. The contribution of this paper to the field of health informatics is an attempt to a) set focus on the complexity of local support work and b) to emphasize the need for this kind of support work as a means to keep the hospitals running with as few technical problems as possible.

The problem when using relatively stylized models like the ITIL model is that the complexity of the job can be forgotten or that the significance of the local circumstances of the job is can be overlooked or neglected by the top level managers. In the case of Region North Jutland there were made efforts of centralization where the local supporters were taken away from the local setting. This was reversed due to protests from the staff of the hospitals in the region. One of the reasons for this, as argued in this paper, is that the supporter is not just solving technical problems, but is also an integrated part of making the work with and around IT systems seamless. The local supporters, with their specific multitude of roles, knowledge and tools, are an important part of securing this repair, maintenance and design of the social setting of users and technologies. The work done by the local IT supporters cannot be centralized because of the complexity of competencies and tasks needed to keep the IT infrastructure running smoothly.

On the basis of this analysis I recommend a general caution towards using general models and seeking centralization in relation to technical support of IT/IS in hospitals. I recommend that we use models that emphasize the close-knitted working relationship between supporters and users as not only a potentially valuable local resource, but also an essential part of having/using information systems at all.

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Chapter 13.

Architecture and Design

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Citizen Centric Architecture Approach - Taking e-health forward by integrating citizens and service providers

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Abstract

In this paper, two related research problems will be discussed in the development of e-health services: First, an architectural approach is needed to provide a holistic view for solving the ICT challenges in e-health development. Second, solving the needs of the citizens should be the focus of the architecture solution. To overcome these problems we suggest a Citizen Centric Architecture (CCA) approach for providing a holistic and appropriately balanced view of the integration. Naturally, enterprises' information systems and citizens' information systems are the key elements of CCA. In addition, for solving the topology challenge brought by a large number of involved parties, a role of trusted third party is proposed to provide an environment for the information exchange and service mediation among the various parties. We believe this approach will enable the large scale growth in citizen centric e-health services that is poorly facilitated by the prevailing models: the improved integration of information will attract more citizens and health care service providers, which in turn, improve the health care information and quality of service.

***Keyword*:**

E-health, Information integration, Citizen informatics, Health care service provider.

Introduction

The term e-health is used to refer to a range of ICT enabled health care services and related businesses. It is in the intersection of medical informatics, public health and business, referring to health services and information delivered or enhanced through the Internet and related technologies [1]. Successfully implementing e-health is believed to have many benefits both for health care service providers and for citizens.

Not surprisingly, e-health faces numerous challenges from social, economical and organizational reasons [2]. According to Eysenbach [1], challenges for the health care information technology industry are mainly (1) B2B: improved possibilities for institution-to-institution transmission of data; (2) B2C: the capability of consumers to interact with their systems only; (3) C2C: new possibilities for peer-to-peer communication of consumers. Haux has also stated the future of health information systems should go from health care professionals to patients and consumers [3]. In other words, achieving e-health would not only require the successful integration of range of health information systems, more important, it should enable the integration of information between service providers and citizens.

As user generated content and consumer health informatics are becoming more relevant in e-health, there is an increasing need of integrating information between citizens and health care service providers. However, current research work related to health information integration has mainly focused on the side of professionals (B2B), with little attention to supporting B2C and C2C communication. Health care, as any other business, needs an architectural solution to guide the changes in all key areas: business models, process design, information management, applications and information infrastructure. Therefore, this paper tries to find out what would be the architecture approach for supporting e-health development, which would solve those appearing challenges.

Methods

The research methodology applied here is design-science, which aim at creating relevant artifacts to bridge the theory and the practice [4]. We start from analyzing the citizens' needs in e-health information systems, and then further investigate current architectures from the perspective of how well they support integration. We aim at designing an artifact, which visualizes the architecture approach needed to support future e-health development.

Step 1: analyzing citizens' needs in e-health

The integration challenges in e-health service development from citizens' point of view can be analyzed by using the B2B, B2C and C2C scenarios as starting point:

- B2B: Most of the citizen's information is in the service providers' hands and it is fragmented into a number of service providers' information systems. Thus, B2B integration is important also for citizens, as it creates integrated access for their own health data. Without proper integration among the organizations neither a service provider nor citizen him/herself can access up-to-date and comprehensive information, which in turn may cause errors in clinician decisions and create many other problems.

- B2C: While the service providers can have a good and specialist view on citizens' health in their respective areas, the people themselves naturally know their own life situation, experiences and expectations best. Possibility to combine the relevant health related information that citizen can provide and the information for the service providers in easily accessible form would both help to serve citizens needs better and to help clinicians and other providers to improve the experienced quality of service. Meanwhile, citizens want to be more proactive and they increasingly seek health information on the Internet [5]. One of the trends is transforming the relationship between physicians and patients [6] as more self-care enables both to reduce health care costs and improve the efficiency. However, without good support of B2C integration this will be hard, if not impossible to achieve.
- C2C: In addition people to interacting with their health service providers they also have the desire to share their experiences, express themselves and seek support from others with common interests. The rapidly development of Internet technologies has enabled them to do it online using tools like SNS, discussion groups, wikis, and blogs to share health knowledge, stay informed and rate health care services etc [7].

In summary, an appropriate and multi-perspective architecture vision should help provision of the key integration needs listed above from the citizens' point of view. In the following we will discuss this extension in the context of the common enterprise architecture frameworks.

Step 2: extending the scope of Architecture

Architecture has been defined as "The fundamental organization of a system embodied in its components, their relationships to each other, and to the environment, and the principles guiding its design and evolution" [8]. An Enterprise Architecture (EA) is used for dealing with the increasing complexity and improving the communication among stakeholders related to information systems in an enterprise. So architecture should help to define highest-level concepts of system integration. Enterprise architecture is normally divided into layers. The most popular way of dividing layers is: business architecture, information architecture, application architecture and technology architecture [9].

Architecture issues have mostly been discussed in the scope of enterprise. In the context of IT, an enterprise can be a whole corporation, a division of a corporation, a government organization, a single department, or a network of geographically distant organizations linked together by common objectives [10]. Therefore, it differs from individuals or citizens. As shown in Figure 1, we can classify architecture issues into two main categories according to the needs of integration: integration inside an enterprise and integration between enterprises (B2B).

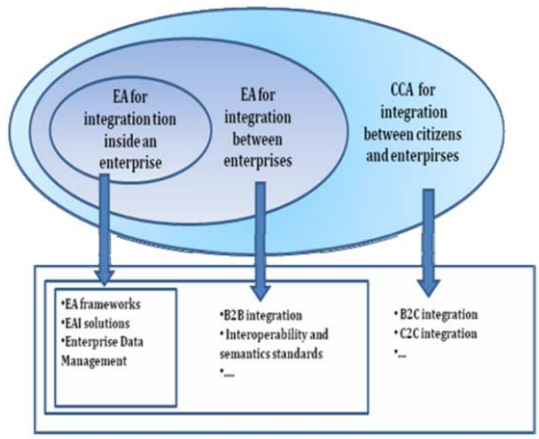

Figure 1- Extension of an enterprise architecture based on the needs of integrating citizens' information

- Architecture for integration inside an enterprise: The development of an architecture starts from the integration needs inside the enterprise. Since Zachman's Framework [11], many EA frameworks have been developed for solving increasing complexity caused by fragmentation of information systems. Integration inside one enterprise usually happens vertically along each layer, so that lower layer provides consistent functions needed by the higher layer.
- Architecture for integration between enterprises: More and more the integration between businesses has raised needs in architecture solutions for achieving better collaboration between enterprises. Integration should happen horizontally in each layer among the organizations to support the business process [12]. Sometimes those two cannot be clearly distinguished. Topics like Business Process Management (BPM), Data Warehouse design, EAI implementations consider both the integration inside the enterprise and among enterprises.

A fundamental principle that can be applied to architecture is: "Always design a thing by considering it in its next larger context - a chair in a room, a room in a house, a house in an environment, an environment in a city plan [13]." With the growing amount of citizen generated information and increasing demand of citizen empowerment, extending the scope of architecture is the natural result of an architecture evolution. As figure 2 shows, while the current architecture issues remain, the extended architecture is meant to solve the integration between service providers and citizens, as well as the integration among citizens or communities of citizens.

Results: Citizen Centric Architecture

Health care service in its essence is all about people. Citizens are the final ones who determine how well the service providers have done their work, i.e. what value have they actually

produced. When the healthcare information systems cannot support the communication of B2C and C2C, the goal of better quality of service would be hard to reach. The observation that the world of health information is still managed in very unbalanced way, putting too much focus in the world of enterprises (or service providers) and ignoring the needs of citizens serves as a good starting point for improvement.

Based on the study we propose to add the citizens into the current scope of Enterprise Architectures, the extended architecture would be called Citizen Centric Architecture (CCA). Also, a Dual Model is sketched for visualizing the integration between citizens and health care service providers. As showed in figure 2, the Dual Model contains two basic elements: Service providers' information and systems and the citizens' information and systems that should work in complementary and harmonious interaction.

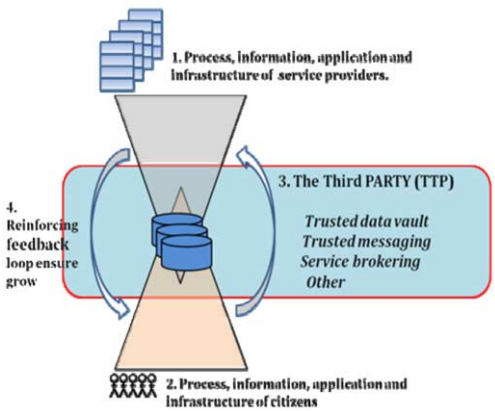

Figure 2- Dual Model of Citizen Centric Architecture

In addition, as CCA is meant to integrate a large number of citizens and service providers the issue of integration topology becomes especially challenging. Integration topology is needed when the design of integration context should specify the locations, structure, and channels to connect all the elements together to form a coherent whole [14]. When the number of parties is increasing the preferred topology is to use a hub in the middle to minimize the number of connections. Therefore, one new element is introduced for connecting many service providers and many citizens together: the "Trusted third party".

Enterprise Information Systems:

Citizens typically use more than one health care service provider in their life. Thus, having access to integrated health care information is the fundamental requirement for clinicians to make the correct diagnoses [15]. In health care, achieving interoperability among health care information systems still has a long way to go. Existing systems are experiencing transition from integration of hospital information system into interoperability of health information systems [3,16]. Promoting Electronic Health Record (EHR) is one of the big steps forward for automating and streamlining the clinician's workflow [17]. Many standards of EHR have been developed for improving the level of interoperability.

Citizen Information Systems:

For achieving citizen empowerment and communication with various service providers and communities, an information management system which could help them to own, create, manage and share information with commonly available and easy to use formats and tools is vital. With the tools and approaches knows as Web 2.0, the user/citizen-generated content has become popular and the idea widely accepted. Service consumers have also become producers.

Similarly, in health care the focus is starting to shift from service providers' side to citizens' side [18]. Citizens need to have better information support in order to be more active in their own care. The counterpart of EHR in the citizen's world is the Personal Health Record (PHR) that is being promoted to help citizen to become more active in their own cares [19]. Some have used the term PHR 2.0 to refer to applying Web 2.0 into the PHR systems [20].

The third party

When the number of involved parties grows large, the benefits of having a third party acting as a hub or intermediary become obvious. For the service providers the third party provides a flexible integration mechanism with least amount of risks, provided they are experienced as trustworthy and providing value for money.

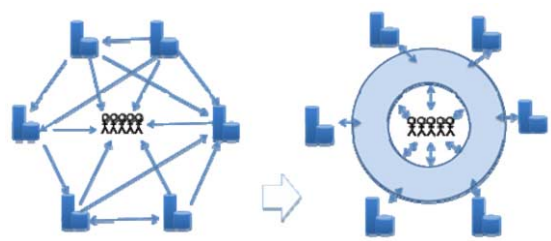

Figure 3- The third party minimizes the connections and builds a trusted and community platform

For the citizens, the third party can provide substantial help in a variety of activities and lowering the barrier of use. These include locating the relevant services and information sources, setting up explicit or implicit contracts with them for service use, integrating them, providing a single point for authentication, and also providing payment services both for providers and users.

In addition to the intermediary services it is also well positioned to provide the citizens an environment for storing, managing and sharing their own information.

The third party needs to follow two principles in order to build smooth communication and interactive collaboration between the service providers and citizens:

- Trusted environment: There are two key steps in creating a trusted environment. First, the service providers and citizens should be able to trust the third party. They need to consider it to be safe to transfer their data in the platform offered by the third party. Second, the third party should build the trusted relationship between the service providers and the citizens.
- Community environment: With the success of Web 2.0, people have experienced the power of social networks in enhancing collaboration and communication. This is also one of the ultimate goals of e-health. In CCA, the third party can take the responsibility of building community environment and enable social relationships among the professionals and the citizens. It has been already suggested that Web 2.0 approach and tools should be adopted into health systems [21].

Achieving growth by reinforcing feedback loop

Adequate volume and penetration in the population is vital to success, as in any other citizen service that requires network effect. Economically, only when the scale of integration is up to certain degree, the communication between citizens and service providers would benefit the society. Further, from dynamic point of view, a right solution for bridging the communication is needed to ensure the growth of the number of users over time. That is, the more citizens and service providers join in, the more benefit each party would achieve. That, again, would attract more citizens and service providers to join. While the motivation of the suggested CCA approach and dual model has been described above as enabler of citizen centric health services, we believe that the trusted third party is essential in creating the reinforcing feedback loop and such services to become reality in a large scale.

Discussion and Conclusion

The contribution of architecture research to health care service would have strategic significance on providing a high level solution for advancing the ICT revolution in healthcare sector. "It is increasingly difficult to practice modern medicine without information technologies [22]." While applying architecture frameworks and approaches for alignment of business and IT have been common in other sectors, it has not been much realized and discussed in the health care sector. Thus, this research may have deep implication for further development of e-health.

Realizing that solving the needs of citizens is the foundation of e-health development, the scope of the architecture need to be extended to integration of the citizens' information. In Dual Model, the role of citizens' and their information is given equally important position as that service providers'.

The benefits of CCA can be summarized into:

- Improving the two-way communication between citizens and service providers and providing an environment for service and information integration, management and sharing, facilitated by the trusted third party as a vital element of CCA.
- Stimulating and enabling necessary changes in service providers' current architecture at various layers. With CCA service providers can efficiently reach, utilize and mange the information generated by citizens and use it to improve the quality of service and reduce the costs.
- The third party can offer a secured platform for citizens to organize and manage their own information. In addition to being able to create their own content, more power and responsibility will be transferred from health care service providers to citizens' hands. They can collect information from different service providers conveniently, manage and distribute it as needed providing benefit to all parties.
- Enhance the citizens' capability to communicate with all relevant entities, including also other individuals and communities with common interests, in addition to the service providers. CCA is meant to facilitate processes, information, applications and infrastructure to be designed for citizens. This would help them to identify and locate the needed services, be empowered to manage the service process, and eventually to improve the quality of their own life.

Current Dual Model cannot yet provide explicit methodology of establishing an integrated platform among health service providers and citizens. At this early phase, Dual Model serves as the purpose of providing a high-level guidance in long term and encourages further research work in Citizen Centric Architecture, which can be generally applicable in any industry and service domain.

In last recent years, several PHR tools such as HealthVault by Microsoft, Google Health etc have launched to the market. However, the adoption of those applications was not smooth and fast as expected. Missing a comprehensive architectural approach would be a partial reason, as one single application solution is not enough to build an interactive communication among millions of service providers and citizens.

As stated, research works about architectural approach are not many in the domain of healthcare services. Possible future works related to CCA are plenty. What we would like continue is to conduct empirical investigations in order to better evaluate and validate CCA approach. As CCA changes both citizens and service providers' workflow, modeling and analyzing the process changes are necessary works in future study. Last but not least, to put CCA into real use, a feasible business model of CCA should also be further explored.

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Ensuring HL7-based information model requirements within an ontology framework

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Abstract

This paper describes the building of an HL7-based Information Model Ontology (IMO) that can be exploited by a domain ontology in order to distribute querying over different clinical data repositories. We employed the Open Medical Development Framework (OMDF) based on a model driven development methodology. OMDF provides model transformation features to build an HL7-based information model that covers the conceptual scope of a target project. The resulting IMO is used to mediate between ontologically queries and information retrieval from semantically less defined Hospital Information Systems (HIS). In the context of the DebugIT project - which scope corresponds to the control of infectious diseases and antimicrobial resistances – Information Model Ontology is integrated to the DebugIT domain ontology in order to express queries.

Keywords:

Information systems, Knowledge, Software design, Semantics, Information systems/methods.

Introduction

An important limit of most existing surveillance systems in healthcare is that they rely on local clinical data repositories based on proprietary data models without any semantic interoperability. The main objective of the DebugIT (Detecting and Eliminating Bacteria UsinG Information Technology) project [1], a 7th EU Framework Program, is to build an interoperability platform able to share heterogeneous clinical data sets from different European hospitals for the monitoring and control of infectious diseases and antimicrobial resistances. In this context, Semantic Web technologies are used to aggregate and query heterogeneous distributed clinical data in a unified view via ontologies. In particular, SPARQL[1] are Semantic Web services implemented to interface local clinical data repositories with ontologies.

A challenging issue is to ease the querying process between proprietary information models (IM) and domain ontologies. Indeed, it seems easier, as a first step, to map proprietary IMs to "mediator" ontologies that are instantiated by information entities. The binding of a domain ontology to an IM ontology has then to be done in a second step [2] in order to improve the coverage of the domain ontology.

This paper describes the methods and tools for building an HL7 IM based ontology that serves ensuring coverage of the conceptual scope within DebugIT by amending the DebugIT domain ontology (DCO)[2] with new "information entity" concepts. In this way the Information Model Ontology (IMO) ensures ontological coverage needed to query heterogeneous clinical data repositories while still largely complying to HL7.

Background

Healthcare standardization efforts

One major contribution of the standardization bodies in the health care domain (Health Level 7 (HL7)[3], CEN TC251, International Health Terminology Standards Development Organization (IHTSDO)[4], etc.) is to define the domain knowledge (reference business models, reference IMs, reference health care services and reference terminologies/ontologies) to enable semantic interoperability.

HL7 is an important standard for encoding clinical information. Its Reference Information Model (RIM) has been developed through a consensus process including harmonization activities. The RIM is the general structure that guarantees the coherence of the complex set of HL7 version 3 models that may be used in many contexts to describe particular administrative or clinical health care information. Besides IMs, HL7 also provides a controlled vocabulary that has been developed for coded properties of the HL7 IMs. Vocabulary specifications often refer to standard biomedical terminologies such as SNOMED CT.

[1] http://www.w3.org/TR/rdf-sparql-query/

[2] http://www.imbi.uni-freiburg.de/~schober/dco_owlDoc/

Model-Driven Architecture for ontology building

A new generation of Hospital Information Systems (HIS) integrate more and more standard IMs linked to biomedical terminologies, using state-of-the-art software development process methods, such as the Unified Process or Model-Driven Architecture (MDA) proposed by the Object Management Group (OMG)[3]. MDA defines a software development approach based on modeling and automated mapping of models [5]. Consequently, an increasing number of development frameworks are available allowing the use of MDA approaches into the HIS development process [6, 7, 8].

Only few of them provide the use of MDA associated to a healthcare standard into the HIS development process and investigate the use of ontologies mapped to information models [9, 10]. But, according to us, none of those development framework allow to build ontologies. Moreover, the use of the MDA approach for designing an ontology development platform is addressed by recent initiatives such as the OMG's one. Although ontologies and the Model-Driven Architecture (MDA) are approaches largely developed in parallel, many authors have attempted to bridge these modeling approaches [11, 12]. A software tool called DUET[4] enables the importing of DAML ontologies into IBM Rational Rose and ArgoUML and the exporting of UML models into the DAML ontology language. The tool is actually implemented as an add-in for IBM Rational Rose and as a plug-in for ArgoUML. It is freely available. XPetal[5] is a freely available tool implemented in Java that transforms mdl, the IBM Rational Rose model format, to the RDF and RDFS ontologies [13, 14].

In a previous work, we have developed the Open Medical Development Framework[6] (OMDF) that is a UML editor that supports adaptation of HL7 IMs according to local constraints. In this paper we present an additional extension that supports the building of an IM ontology.

Material

Conceptual scope of the DebugIT project

The objective of the DebugIT project is to aggregate clinical data, stored in different hospitals, in a unified system dedicated to the control of infectious diseases and antimicrobial resistances. The infection control scope of the stakeholders of the project is delineated via several queries. At the current stage, nine queries are being tested, e.g "percentage of patients with a given infection type (e.g urinary tract infection) by a given pathogen (e.g E.Coli) resistant to a given antibiotic (e.g trimethoprime (TMP)". The DebugIT data catalog includes 58 items covering the conceptual scope of the queries considered within the project. As a typical feature of IMs, it mixes information artifacts with references to real-world entities and is divided into four domains: microbiology lab results ("CULTURE") (11 items), antibiotherapy ("PATHOGEN TREATMENT") (7 items), patient data ("PATIENT DATA, PATIENT TREATMENT, PHYSIOLOGY & LAB FINDINGS") (31 items) and encounter ("EPISODE OF CARE") (9 items). Those items have been used as a resource in the development of DCO.

HL7 information models

We considered the January 2009 version of the HL7 ballot as the standard IMs source [3]. This ballot version includes 1285 IMs (e.g Administrable Medication or Result Event) that are available in the section Universal Domains, including 30 domain chapters (e.g. Clinical Statement, Laboratory, Medication, Orders, Pharmacy, etc.).

Open Medical Development Framework

The OMDF is a methodology and a platform dedicated to medical artifacts development. It uses the Model-Driven approach in the sense that it takes platform independent UML models and exports them into various output format. We have extended the functionalities of the UML editor Topcased[7] by integrating the following features: i) import of selected HL7 models, ii) model adaptation, iii) model transformation into various languages (html, sql, c#, etc.).

The "HL7 model import" functionality takes XML files provided by HL7 content information relating to the previously selected models to transform HL7 IM into UML [15]. The "models adaptation" function allows the designer to select the relevant classes to keep in the intended model. Only classes inheriting from "Entity", "Role" and "Act" of HL7 RIM are presented to the designer; other kinds of classes can be considered as structured relations. Relations are added automatically whenever two classes involved are part of the selection, thus simplifying specialization, aka model scope refinement, by the designer. The last feature, "model transformation" is the result of the integration of the Atlas Transformation language (ATL) engine[8]. This engine allows to implement a transformation (from one model to another) by describing the transformation process in an ATL file.

Method

We have extended OMDF in order to use the model-driven development methodology for designing an HL7-based ontology in the specific context of DebugIT. The ATL transformation engine of OMDF allowed the transformation of an IM in XMI syntax into an IM expressed in OWL syntax, which was then "ontologized" using Protégé and DCO. The Eclipse Modeling Framework for Semantic Web[9] was used to define the ATL syntax mapping file. For example, the UML classes will be mapped with OWL classes.

We followed a 3-steps methodology to derive the IMO from HL7 IMs.

[3] http://www.omg.org/
[4] http://marinemetadata.org/references/duet
[5] http://www.langdale.com.au/styler/xpetal/
[6] https://gforge.spim.jussieu.fr/projects/omdf/
[7] http://www.topcased.org
[8] http://www.eclipse.org/m2m/atl/
[9] http://code.google.com/p/eclipseuml2owl/

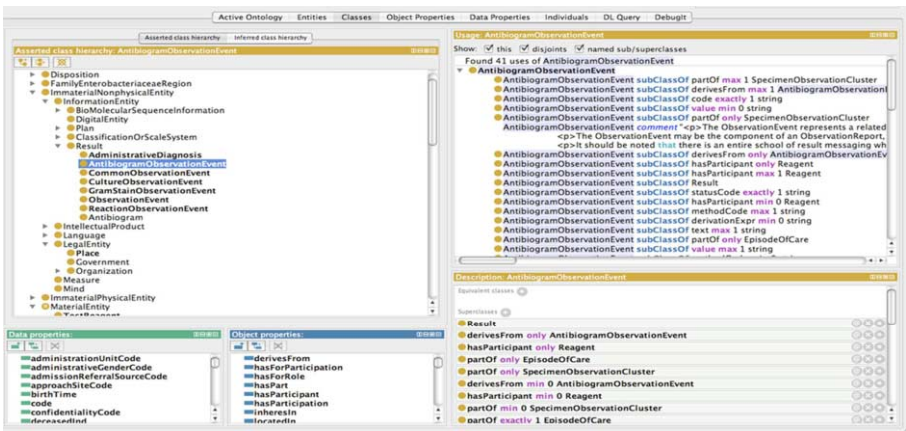

Figure 1- Protégé 4 GUI showing the classes and properties of IMO.owl file with DCO imported concepts (as "dco:InfomationEntity"). In this example, the right panel shows the usage of a highlighted "AntibiogramObservationEvent" class and below its auto converted formal definition

Identifying relevant sub-models

We investigated relevant standard IMs in the following HL7 Domains: Common Message Element Type, such as i) for encounter "EPISODE OF CARE", ii) for patient administrative data "PATIENT DATA", iii) for microbiology lab results "CULTURE", iv) for antibiotherapy orders "PATHOGEN TREATMENT", and v) for patient clinical data "PATIENT DATA & TREATMENT". We organized meetings with medical experts, business analysts and designers in order to browse the HL7 IMs of the chosen HL7 domains and select sub-models that covered the conceptual scope of the DebugIT domain.

Each HL7 domain is characterized by a representative model (Domain Information Model - DIM). We first compared the DebugIT catalog to each DIM to validate the choice of HL7 domains. Since the DIM frequently provides overly abstract information to be aligned directly with a data catalog, we then looked for more specific models within each domain. We evaluated the relevancy of a model according to the rate of mapping between the properties of the classes of the model and the items of the DebugIT data catalog.

Designing a DebugIT conceptual information model

The scope of DebugIT covers more than one HL7 domain (e.g. Laboratory, Order, etc.) and sometimes addresses more specific information. Therefore, we have been using OMDF to i) aggregate selected models into one model, ii) specialize this model to retain only the information relevant in the DebugIT conceptual scope.

Deriving IMO and completing DCO

We used OMDF in order to automatically transform the DebugIT conceptual IM into an OWL file. The problem with automatically generating OWL models from representational formalisms with different expressiveness is that the syntactical transformation may lead to semantically invalid statements. Therefore the target representation must be manually validated and if possible adapted aka "ontologized".

The initially exported OWL file is a semi-formal ontology in the sense that its semantics does not use DL expressiveness. The auto generated list of concepts, properties and attributes needs to be formalized manually.

The OWL file is edited into Protégé environment to add constraints on properties and classes. Then DCO is imported into the same OWL file to be completed with IMO's concepts by hand.

Experimenting queries using the ontology

Evaluating an ontology can be divided in two parts: verification and validation [16]. Verification refers to a technical process that aims at checking the correctness of the ontology. It deals with the formalization of the ontology and may be guaranteed by a reasoner. For instance to check the consistency of our ontology, we used a reasoner included into the Protégé editor (FaCT++[10]).

While the ontologization enabled us to use a classifier to check the logical consistency, the adequacy must be checked manually by a domain expert. An ontology is valid if it is useful to execute the task it has been built for.

The queries defined in the scope of the DebugIT project have to be expressed by IMO and DCO. As a matter of fact, the validation of IMO consists in testing the queries defined for the scope of the project.

10 http://owl.man.ac.uk/factplusplus/

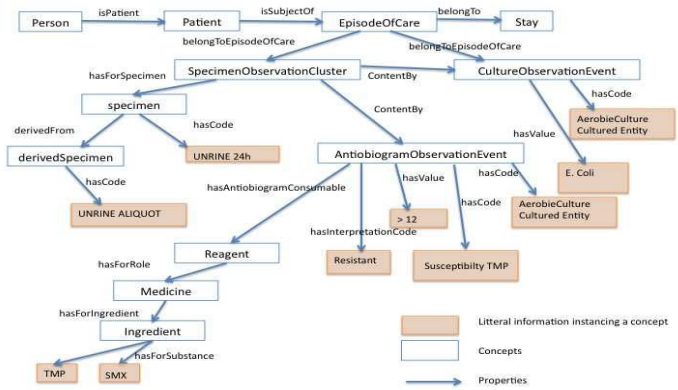

Figure 2- Instances of IMO concepts as needed within the scope of the query: "Percentage of patients with a given infection type (e.g. urinary tract infection) by a given pathogen (e.g. E.Coli) resistant to a given antibiotic"

Results

DebugIT HL7-based information model

OMDF enables us to design the conceptual model describing the information entities needed for the DebugIT project according to the HL7 standard. At this stage, this model is available as XML Metadata Interchange or HTML file. The six relevant HL7 IMs are: A_Encounter universal (COCT_RM010000UV01); Result Event (POLB_RM004000UV01); Composite Order (POOR_RM200999UV); Common Observation (POOB_RM410000UV); Adverse Reaction (REPC_RM000022UV) and A_BillableClinicalService Encounter (COCT_RM290004UV06). The IM includes 61 classes and 262 properties. The classes consist in Entity type classes (n=7) such as "Natural", "Person" or "Organization"; Act type classes (n=22) such as "ObservationEvent", "ObservationCluster", Role type classes (n=9) such as "Specimen", "Derived Specimen", "Patient", "Assigned Organization"; Participation type classes (n=10) and ActRelationship type classes (n=13). We have been able to express the totality of the DebugIT data catalog in the resulting HL7-based model. There is a one to one mapping with an HL7 property in 84% of cases. Seven per cent of the items were expressed using more than one HL7 property. For 4 items (9%), more than one item corresponded to one single HL7 property in the HL7 source IM. For example, EncounterStay.effectiveTime represents two items (admission date and discharge date).

The DebugIT HL7-based ontology

The OMDF extension enables us to get all the information we need about concepts and relations (cardinality, lexical information items as comments or definitions, domains and ranges for the properties) as shown in figure 1. The ontologization was done as follows : i) restructuring the concepts by adding subsumption properties between IMO concepts and concepts from DCO. So we imported and used classes as "clinical administration activity" "InformationEntity" "LegalEntity" or "PatientRole", ii) it is important to add constraints on the concepts and relations. "Admitter" and "Discharger" are both defined as linked to the concept "AssignedPerson" by a property. Nothing in the ontology states that a discharger is different from an admitter so that the reasoner defines both concepts as equivalents. So we have to create a disjointness axiom between those two concepts. The current version of the DebugIT HL7-based domain information includes 40 classes and 41 properties (10 Object properties and 31 Data properties). We used the reasoner (FaCT++) included into the Protégé editor. It took around twenty iterations the FaCT++ reasoner to obtain a consistent ontology. After each step, constraints were adjusted manually. Then, medical experts validated the completeness of IMO using the ontology to express the nine example questions defined in the DebugIT project. Figure 2 shows a sample of this validation process. It represents one of the queries expressed by IMO's concepts and properties.

Conclusion

Large-scale data integration efforts to support clinical and biological research are greatly facilitated by the adoption of standards for the representation and exchange of data. As part of the DebugIT project dedicated to multi-institutional sharing of disparate data on infectious diseases, we have explored the potential of the standard HL7 information models (IMs) for representing medical information entities and makes them usable through ontologies. We adopted state-of-the-art software development methods, such as the MDA approach proposed by OMG and have used the Open Medical Development Framework, developed in our laboratory, to support software designers and developers in adapting (importing and specializing) relevant HL7 IMs and transforming IMs into ontologies than can be mapped to domain ontologies.

We found that HL7 was a valuable source of artifacts and knowledge such as domain use cases, IMs and vocabularies. In our study, 100% of the DebugIT data catalog has been covered

by the standard IMs selected in the HL7 Ballot. We experienced that HL7 IMs, though available in a specific format not handled by the UML modeling tools, could be converted to UML and used to build an IM ontology. HL7 IMs include many explicit comments about the meaning of classes and/or properties that are carried on from conceptual models to an OWL file, across all the transformations performed with Open Medical Development Framework. We experienced that the syntactical transformation that occurs while automatically generating OWL models from other representational formalisms may lead to semantically invalid statements. Indeed, the IMO derived from HL7 IMs does only yield a semantic network like OWL file including both information entities and real-world entities. Manual adaptation and validation are required so that this IMO conforms to the ontological assumptions of OWL. A potential outcome of this effort is an example of how epistemological assertions, as occurring in information models, can be modeled within an ontological framework. Thus, using one single representation formalism, our proposal brings together HL7 information models and philosophically founded ontologies. At this first stage of the DebugIT project, we focused on integrating HL7 and not CEN TC251 artifacts to the MDA approach. CEN TC 251 also provides reference models (the openEHR Information Model [17]) and defines in additional constrained models how the general reference model is used to describe particular administrative or clinical health care information. Although, integrating specific plug-ins dedicated to the use of HL7 artifacts, the Open Medical Development Framework is not structurally dedicated to HL7 standards and we will develop specific extensions dedicated to support CEN TC251 IMs as long as these IMs conform to a meta-model conforming itself to the Meta Object Facility (MOF).

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Foundations for a Nursing Services Reference Model

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Abstract

The Nursing Services Reference Model (NSRM) is presented as a theoretical position and discussion paper. The aims are to describe the components of the NSRM concept, to explain why such a model needs to be developed and to explore methodological issues in the development of a NSRM. The concept is important to address as it may illuminate a most pressing problem faced by the Australian health care industry where the content and activity of nursing practice is not embedded as computer processable data in health information system structures. Digital documentation of nursing content and activity is urgently needed to enable reliable electronic processing of nursing services. However, it is necessary, prior to this, to develop a reference model that describes the range of nursing services in an unambiguous manner.

Keywords:

Nursing information systems, Health knowledge management, Reference models, Operations management, Acute health services.

Introduction

The content and activity of nursing practice in the Australian health care industry is not embedded as computer processable data in health information system structures. Two key conceptual matters must be addressed for this to occur. There is a need for standardisation of nursing service description at an abstract business level as well as standardisation of clinical nursing language in terms of computer processing of digital documentation. While these conceptual matters persist and remain unaddressed, the imbalance continues at a business level where nursing services have not made the same pace of development as other fields such as supply chain management which are advanced in terms of the standardisation of service models e.g. Supply Chain Operations Reference Model [1-3].

Reference models are proven methods for communicating business information to stakeholders, strategists, policy makers and business analysts. Two examples of such models include the SAP reference model [4] and Scheer's model for production planning and control systems [5]. The Service Reference Model of the Australian Government Architecture (AGA) contains seven service reference models, including, for example, Customer Services, Business Management, and Back Office Services [6]. It does not include a service reference model for nursing services, which is a critical part of the Australian health and social infrastructure. Nurses represent the largest health workforce in Australia. Conservative estimates suggest the acute services nursing workforce continue to represent greater than 30% of total inpatient costs [7]. In addition, public hospital unit/ward nursing costs alone constituted 24% of the national average case cost identified in round 12 of the National Hospital Cost Data Collection Round 12 (2007-08), and critical care, operating room and emergency services, where nursing costs are very significant, constituted a further 25.6% [8].

The concept we wish to develop is a Nursing Services Reference Model (NSRM) to fill the previously identified gap. The NSRM is separate to diagnostic taxonomies which also lack integration into clinical nursing practice in Australia. For example, the nursing taxonomy with most development is an outcome of two decades of research by the North American Nursing Diagnosis Association (NANDA) where more than 100 nursing diagnoses form a taxonomic structure that reflect patient responses to actual or potential health problems. A NSRM is a different concept and comprises a standard business structure which documents the business activity of nursing practice in a manner that will support management of nursing service delivery and represent nursing activity in business system structures. It forms the basis for knowledge resources, data types and structures.

The proposal for a NSRM is also in line with the IT Infrastructure Library (ITIL) Framework [9-10] in relation to the definition of a service catalogue. Based on ITIL, the service catalogue is used as a starting point for the implementation of the Service Level Management process. Carefully planned and documented IT Service Management (ITSM) processes are becoming an increasingly important component in the delivery of higher customer satisfaction.

At a consultation workshop titled "S*tudying the redesign of patient care*"[1] participants voiced powerful opinions about the current state of health knowledge management and indicated

[1] Hosted at Victoria University (VU), Melbourne, Australia on the 20th of July 2009. Attendees comprised 25 targeted participants including researchers from within VU, key policy advisors, regional health services officials, representatives of the Victorian Government Department of Health (DoH) , the Australian Nursing and Midwifery Council and executive nursing and information communictaoin technology members from Western and Melbourne Health service providers including their health service redesign teams.

that support would be received for several projects (for example, the NSRM project) by peak health professional bodies in nursing, health informatics and health service officials at many levels of industry and government.

This paper is based on a critical reflection upon the workshop results and what is needed to develop a NSRM. The NSRM we propose will be informed by an international standard: The International Standards Organization (ISO) 'Health informatics - integration of a reference terminology model for nursing' (ISO/FDIS 18104). This ISO standard helps researchers to recognize that nursing data cannot stand alone [9]. It requires integration within clinical records. Also, the NSRM model we propose will be developed within the Australian Government Reference Model of the Australian Government Architecture (AGA). If the model can be situated in this context, the language for nursing services has potential for recognition alongside other health agency services in Australia. This work follows related projects, especially, of health informatics standards development, health terminology and electronic health records including knowledge management and ontology documented in the following references [11-18].

No reference model exists for nursing services in Australia and we could only source very limited international literature on reference models to support nursing practice. Destrebecq et al [19] from Italy refer to an 'old reference model' to allow for classification of tasks performed by nurses in three areas-nursing activities without chances of delegation, nursing activities that could be assigned to aids, and activities beyond the competence of nurses. They made a comparison between data collected and the reference model. The study has limitations for international audiences as the detail on the reference model was not provided. An example of the application of reference model for heatlh services more generally is provided by Huber-Bloder et al [20] who report a reference model with comprehensive hierarchical specifications for the domain layer of a hospital information system and its enterprise functions.

The development of a reference model would form the basis for the further development of an ontology (containing links to terminologies and bindings) for the nursing domain of knowledge. The nursing activity domain is wide-ranging and diverse; nurses practice in settings ranging from acute to community care as well as private and public services. For this project, our research team will focus on clinical public hospital nursing. The proof of concept or theoretical work to be achieved is to fit the NSRM with the many information /workflow processes where each process is associated with a specific aspect of nursing care.

The Nursing Services Reference Model

As part of the e-Government Strategy (released in March 2006), the Australian Government Information Office (AGIMO) defined a vision for increasing the effectiveness of service delivery and established the requirement for a 'cross-agency services oriented architecture' [6]. A crucial part of this was the development of a set of high-level reference models that provide a common language and classification scheme for business and technology (see Figure 1).

Figure 1 - Business Management Services of the AGA [6]

The development of the NSRM concept was proposed with the recognition that service improvement efforts would be supported through the considered application of ICT. It has been recognised that ICT will play an increasing role in terms of patient care. In proposing the NRSM, we wanted to ensure that technology plays a subservient role to the needs of service provision and therefore, the establishment of the NRSM was proposed as a means to push the "nursing business architecture" in front of technology architecture.

The development of the NRSM concept was influenced by the Service Reference Models of the AGA, in terms of granularity and abstraction of the service types. Development of the model will be informed by the AGA to enable the eventual acceptance of the NRSM as part of the Service Reference Models of the AGA. National adoption would be a longer process and would depend upon funding to support further development and application of the NSRM. The proof of concept NSRM model will be developed and tested as a valid model that fits with international standards (through the ISO) and Australian Government standards (through the AGRM and AGA). Methodologies will be developed during the development for testing validity. Generally, the model of validation will be based on consultaion and feedback incorporating elements developed by others who have adopted this approach. See, for example, Mohpatrea et al [21]; Colton and Hatcher [22]; and Tracey et al [23].

In parallel to this, the study of service management practice in the industry brought forward the ITIL Framework. The official definition of an ITIL Service Catalogue is: "A database or structured Document with information about all Live IT Services, including those available for Deployment. The Service Catalogue is the only part of the ITIL Service Portfolio published to Customers, and is used to support the sale and delivery of IT Services. The Service Catalogue includes information about deliverables, prices, contact points, ordering and request Processes" [24].

The initial NRSM concept was developed on this basis as the foundation for service management in the nursing sector in Australia. As an applied discipline, nursing uses knowledge in the service of solving problems of human health and caring. Nursing care also has complex management dimensions.

Integration within the AGRM and AGA will establish a national consistent approach with reference models of other clinical domains such as medicine and allied health. Hence, relevant entities of the Australian Commonwealth Government will benefit through improved understanding of ICT investment via access to repositories of standards, principles and templates derived from reference models. Improved design and delivery of nursing infrastructure ICT capability will improve business services to Australian citizens.

A high level start point for the clinical component of the NSRM is shown in Figure 2. The basis for this is that effective nursing is always organized and systematic, that prioritizes patient assessment and management.

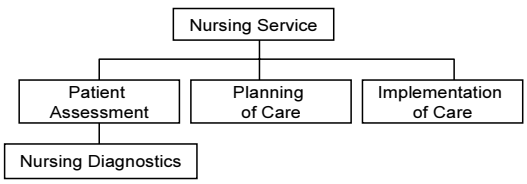

Figure 2 - High level classification of nursing services

The fundamental elements of the model are as follows:

- ***Assessment.*** An integral and ongoing aspect of the nursing service.
- ***Planning and Implementation.*** The formulation and implemention the care.
- ***Evaluation***. Determining whether the action taken has met the identified needs.

A challenge immediately emerged, where the nursing service includes more entities beyond procedures/techniques necessary for care and actually includes day to day personnel management and training/mentoring activities. Furthermore, delivery of the nursing services also includes significant multidisciplinary interactions with doctors, consultants and other specialists, going beyond the administrative domain (see Kelley et al [25].

It emerged from the workshop that there are other categories, for example in "Implementation of Care", the category of "Respite services" was put forward, which tends to be provided on a short-term basis because of the emergency absence or need for routine or periodic relief of the primary caregiver. They are provided in an individual's home, other community residence or in other community sites. Examples include assistance with activities of daily living such as: bathing or showering, toileting, and routine personal hygiene skills.

Further, in developing the NSRM, consideration must be given to other relevant areas of work to reflect the interdependency with behavioral sciences to allow room for the inevitable expansion of nursing practice.

It was clear to the participants of the initial consultations that the NSRM would have to capture monitoring health status and physical condition, assistance with medication and other medical needs. This also included assistance with preparation and eating of meals.

The NRSM must also include the holistic and effective nursing care, including health promotion and health screening. It must also include service descriptors relating to "housebound" care, where for reason of their diagnosis patients are best supported in their own environment by the skills and expertise of the nurses.

Another issue that emerged was the level of abstraction in describing aspects of services that were generic across the entities described in Figure 2. This is shown in Figure 3.

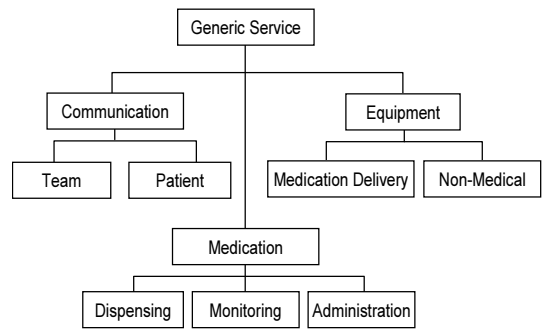

Figure 3 - Generic service descriptions

Communication

Communication (team) is generic, related to the exchange of information among the patient care team about a patient and patient care issues. Communication (patient) relates to the exchange of information from the patient care team or the health care facility to patients. This aspect will be common across assessment, planning and implantation of care.

Equipment

This relates to the physical infrastructure and may be categorized into medication or non-medical. Examples of non-medical include hospital lighting, privacy, physical safety and noise abatement. Medication delivery equipment identifies the services provided in terms of ensuring availability, reporting of malfunctions, maintenance, design, training and operations.

Medication

This category is related to a patient medication that originates in the dispensing process. Administration is related to patient medication that originates with administration of medication to a patient. Monitoring is related to a patient medication that originates after a drug is administered to a patient.

Future application of a NSRM with a common nursing data structure will enable formal recognition of nursing services from which an evidence base can be built to inform understandings of the nursing infrastructure including funding and provision of nursing services, and for the connection and integration of nursing care services across the health system.

Discussions

Given the importance of the nursing domain of care provision, the lack of a reference model at a national level in Australia has a major impact on research and development of health service systems including using source data to monitor, measure and evaluate nursing performance. Also nursing data cannot be shared within and between healthcare agencies.

Nursing work is complex and has many interconnections with medicine, allied health and community services. Nurses must increasingly deal with information and share their information with multi-disciplinary teams. Nursing services are largely documented upon paper-based records. Nurses have multiple files and documents to deal with for specific nursing aspects of patient care. For example, these files might be paper-based documents related to assessments of neurological observations, input of figures related to fluid balance management which forms part of managing an intravenous infusion, and pain management records.

Systemic change is necessary to accommodate the content of nursing records within information systems to fulfill interdisciplinary needs. Interdisciplinary professionals must access nursing files and records daily to make decisions about patient care. Design of digital systems will be enhanced by a sound description of nursing services in the form of a NSRM. Effective digital nursing data flow within and between healthcare agencies enables the use of these data both as contributions to electronic patient records and for the purpose of managing nursing workflow efficiency, nursing workload allocation, costing, and effective nursing service and performance management.

These different areas of work should be underpinned by a standardized and widely accepted structure or framework for describing nursing services. The Australian Government has recently announced its intention to fund hospitals federally based on activity (casemix) data. This means there must be a mechanism to consistently identify the nursing service contribution to ensure that these services are adequately funded to achieve desired outcomes. The NRSM should be sufficiently mature and embody the goals and descriptions of nursing services and can then be looked at as a reference for the various purposes discussed above.

Conclusions

The development of the NSRM is in the infancy stage, but it is in the opinion of the authors that this forms the first critical step to achieving the same degree of maturity in definition which will be comparable, eventually, to SCOR or the Service Reference Models of the AGA.

A Nursing Services Reference Model (NSRM) concept will be developed within the context of Australian government ICT architecture frameworks and international standards development organization (ISO TC125) as a research endeavour towards achieving a sustainable health care system.

This paper arises from dialogue between senior health care officials, health care managers and academics interested in the complex health knowledge management needs of contemporary health care organization. These discussions have continually underscored the importance of dialogue between the service and academic sectors. Such collaboration is necessary if the evidence from studies on reference models are to be effectively linked to initiatives in practice that to enhance the quality and safety of patient care. Development of a NSRM will involve key nursing stakeholders to build consensus on requirement analysis. The methodology when formally developed will include critical inputs from stakeholders and a project reference group. We will work with peak groups in nursing, health informatics and relevant government entities supporting the AGA to achieve levels of rigor acceptable to these groups.

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The Health Service Bus: An Architecture and Case Study in Achieving Interoperability in Healthcare

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Abstract

Interoperability in healthcare is a requirement for effective communication between entities, to ensure timely access to up-to-date patient information and medical knowledge, and thus facilitate consistent patient care. An interoperability framework called the Health Service Bus (HSB), based on the Enterprise Service Bus (ESB) middleware software architecture is presented here as a solution to all three levels of interoperability as defined by the HL7 EHR Interoperability Work Group in their definitive white paper "Coming to Terms". A prototype HSB system was implemented based on the Mule Open-Source ESB and is outlined and discussed, followed by a clinically-based example.

Keywords:

Interoperability, Systems integration, HL7, SNOMED CT.

Introduction

A main challenge in the field of health informatics is to enable shareable and computable information [1]. Taylor defines three "grand challenges" for health informatics: reading and writing patient records; creation of medical knowledge; and access to medical knowledge [2]. The key to all these challenges is interoperability, which is defined in the next section.

In [3], a conceptual framework for interoperability in healthcare was outlined based on the Java-based Jini Architecture. Following that work, due to some limitations of the Jini Architecture, an improved framework called the *Health Service Bus* based solely on Enterprise Service Bus technology but following the same principles was developed and is presented here.

Definition of Interoperability

The definition of interoperability in healthcare was the focus of research conducted by the HL7 Interoperability Work Group, a part of the Electronic Health Record Technical Committee. The result of this study was the observation that there are in fact three definitions of interoperability in the e-health industry [4]. In practice, these definitions correspond to three hierarchic levels of interoperability.

The first is *technical* interoperability, which involves communicating data between different applications and systems over a network. Messaging is the best solution to this type of communication problem [5], and is the approach taken here, as the Health Service Bus is built on a messaging core.

The second level, and the most difficult to achieve, is *semantic* interoperability. This pertains to messages not just being received, but that meaning can be transmitted from the sender to the receiver and be understood in the same way by both. Semantic interoperability is about the meaningful exchange of information in association with its context. It evolves beyond communicating message structure into also communicating the intent or meaning of data, so that the information will be understood in precisely the same way by both the sender and recipient [6].

The third level is *process* interoperability, which refers to social or workflow engineering aspects of interoperability.

The ESB-based solution to interoperability in healthcare proposed addresses all three levels of interoperability as defined in [4], as will be shown.

Methods

The methods employed in this work follow the paradigm of *design science*. Design science is a method of information systems research which seeks to extend the boundaries of human and organisational capabilities by creating new and innovative artefacts, which fall into four product-types: *constructs*, *models*, *methods* and *implementations* [7,8].

The work presented here as a solution to interoperability in healthcare is a model of an implementation, using distributed methods from the field of enterprise integration. The main method from that field employed here is that of the *Enterprise Service Bus*.

Enterprise Service Bus

Enterprise Service Bus (ESB) is a term coined at Stanford University to describe a specific middleware software architecture. An ESB provides a loosely-coupled, highly distributed approach to enterprise integration.

An ESB has a standards-based messaging engine, which is event-driven and provides foundational services for more complex software systems [9].

Standards-based integration is a fundamental concept of ESB and thus makes a fitting solution in the standards-filled realm of health informatics. ESB solutions can also be implemented incrementally, so there is no need for downtime to completely

swap over to a new architecture – it can be done one department at a time as it is deemed necessary or convenient.

The Health Service Bus (HSB) presented here is essentially an ESB using health standards within its messaging formats.

Service Containers and Endpoints

In an ESB, all applications and services that are connected to the bus are considered abstract endpoints. The underlying implementations of these endpoints can be diverse, but the abstraction of treating them as the same provides a powerful paradigm for higher-level tools to assemble endpoints into process flows – a part of process interoperability.

A service container is a physical implementation of an endpoint and provides the service interface to the ESB. The traits of service containers lead to the distributed nature of ESB [9]. Figure 1 shows a generic endpoint.

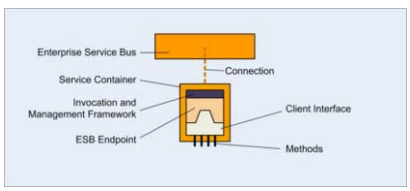

Figure 1 – A Generic ESB endpoint

Service containers should handle configuration, fault handling and management data – called the "Invocation and Management Framework". As Figure 1 shows, the endpoint connects to the client via an interface, which should be separate from the actual methods in the service connecting to the bus. This means that services can be changed over time, as long as their interface to the bus remains the same.

Mule Open-Source ESB

Mule, owned by MuleSoft, is the world's most widely used Open-Source ESB [10]. Like Jini, Mule is Java-based and provides a messaging framework which can use a variety of message formats. In Mule, application functionality is wrapped as a service, which includes a service component (business logic), routers (where to send the message), and configuration settings. This is consistent with the standard for ESB service containers and endpoints, and also provides process interoperability.

Results

HSB Prototype Implementation

A prototype HSB implementation was set up using the Mule Open-Source ESB, and making use of various services connected to the bus.

A client application for entering patient observations was developed for testing the prototype HSB. A SNOMED CT XML database, developed during a previous project was given a Web Services front-end and hooked into the HSB, allowing the Observations Application timely access to the SNOMED CT terminology.

Translation Services were also developed based on XSLT transforms to translate HL7 V3 messages to HL7 V2 and OpenEHR. The structure and content of these messages provides the level of semantic interoperability in the HSB. The actual XSLT transforms are discussed in [11].

The translation service was also set up with a Web Services front-end for connecting to the HSB. Figure 2 shows the components of the Mule HSB prototype.

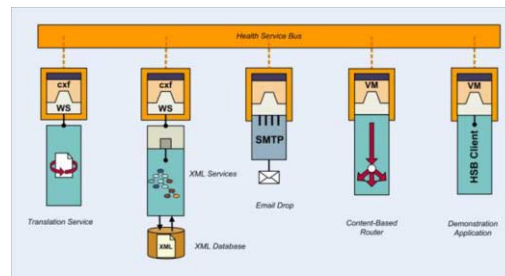

Figure 2 – Components of the Mule HSB prototype

As well as the services discussed, a content-based router is also included, and an email drop for reporting errors. The "HSB Client" shown in Figure 2 refers to the Observation Application, and the "XML Services" and "XML Database" combined make up the SNOMED CT XML Service.

Translation Service

Ontology mapping between different health standards (HL7 V2, HL7 V3 and OpenEHR) led to the development of XSLT stylesheets for translations between these standards in the instance of patient observations messages, as discussed in [11]. These XSLT stylesheets form the basis of the translation service connected to the HSB.

The functionality provided by the translation service allows for direct translation between HL7 V3 and HL7 V2, and from HL7 V3 and OpenEHR. Translation between HL7 V2 and OpenEHR may also be achieved within 2 steps – from V2 to V3 and then V3 to OpenEHR or vice versa.

SNOMED CT Terminology Service

The "XML Services" and "XML Database" in Figure 1 together refer to the SNOMED CT terminology service.

A subset of the SNOMED CT terminology was converted to XML for use as the basis of a terminology service which was connected to the HSB, based around the concept of *Vital Signs*. This encompasses Observations data, which is the example data used the HSB prototype.

SNOMED CT is distributed as data delimited into fields, with each record on a new line. To convert the SNOMED CT concepts to XML, each concept is converted to an XML node called "concept", with each field of the concept represented as one of its child nodes. For example, compare Table 1, which shows the concept "Sensation of blocked ears", to its XML representation, below.

Table 1 – Example SNOMED CT Concept

Concept ID	Status	Fully Specified Name	CTV3 ID	SNOMED ID	Primitive
103281005	0	Sensation of blocked ears (finding)	XU0sM	F-F5612	1

```
<concept>
    <conceptId>103281005</conceptId>
    <status>0</status>
    <fullySpecifiedName>
            Sensation of blocked ears (finding)
    </fullySpecifiedName>
    <CTV3Id>XU0sM</CTV3Id>
    <SnomedId>F-F5612</SnomedId>
    <isPrimitive>1</isPrimitive>
</concept>
```

The SNOMED CT relationships and descriptions pertaining to the concepts in the subset were also converted to XML in a similar manner. These XML records were then stored in a native-XML database, which provides a richer data model than a traditional database and makes the data self-describing, by way of the XML tag names [9]. The XML database can be queried over the bus by sending messages to its Web Services front-end.

Email Drop Service in the HSB

The purpose of the email-drop service is for automatically sending emails to a designated address when errors occur on the HSB. A service container is configured containing an endpoint which simply connects to an SMTP server and sends an email with a given subject and message to a defined address. The other services on the HSB are then configured to automatically use this service whenever an error occurs.

Content-Based Router

A *content-based router* examines the contents of a message and then routes it based on information contained in the message [5]. In the HSB, messages are routed based on who the messages are addressed to. HSB clients register their names with the router when they first connect to the bus. Messages between HSB clients are then sent through the router, which will pass them on to the appropriate party. The end-to-end example at the end of this section will demonstrate the router.

Patient Records in the HSB

Continuous patient records are stored in an XML database connected to the HSB. The format of the records is OpenEHR.

The format of most messages transmitted on the HSB is HL7 V3, so the translation service is used here to translate messages from the HSB into OpenEHR for storage in the database. The observation structures in HL7 V3 and OpenEHR are similar, making this translation simpler than expected. The "observation" sections of HL7 messages are translated to OpenEHR observations and then stored in the relevant patient's record.

Figure 3 shows the process of storing the observations in the patient's record. The setup of the EHR XML database is the same as the SNOMED CT database – the "XML Parser" in Figure 3 corresponds to "XML Services" in Figure 2, XML databases are shown in both Figures 2 and 3.

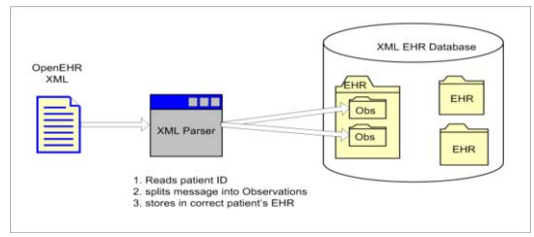

Figure 3 – Patient records stored in an XML database on the HSB. Observation Entries are stored in a patient's EHR.

Total Interoperability in the HSB

All three levels of interoperability (based on the definition in [4]) are achieved in the HSB.

Technical Interoperability

Technical interoperability is achieved in the HSB by the central HSB structure, specifically the messaging bus core. The messages sent "over the wire" are actually XML based on health standards, which brings us to semantic interoperability.

Semantic Interoperability

Semantic interoperability is achieved in the HSB by the content of the message sent within the framework and how they are processed. The messages are XML based on HL7 V3 models, which are themselves based on SNOMED CT constructs. The mapping from SNOMED CT to HL7 to obtain these models is covered in [12] and [13].

Process Interoperability

The level of process interoperability is achieved by the inherent nature of the HSB. Features such as intelligent routing and monitoring facilities which are part of ESBs contribute largely to process interoperability.

End-to-End Example

Figure 4 shows an end-to-end messaging example from the Mule HSB implementation. The HSB client wishes to send a message on the bus to another HSB client.

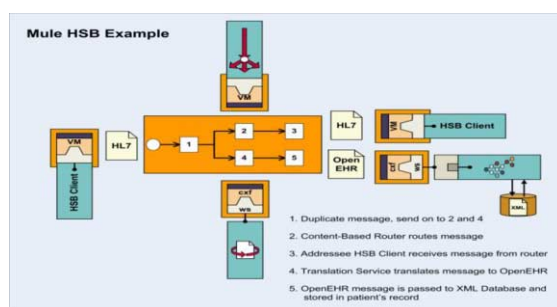

Figure 4 – End-to-end example of the Mule HSB implementation.

Step 1 is to duplicate the message and send it on to both the content-based router and the translation service. All observations messages sent from the HSB client Observations Applications are recorded in the OpenEHR database in the respective patient record.

Step 2 is the content-based router, which routes the message as described previously and sends it on to the receiver (Step 3).

Step 4 is the translation service, which translates the HL7 message into OpenEHR and passes it on to the EHR database (Step 5), where it is stored in the database as described previously.

Discussion

The prototype HSB demonstrates how ESB concepts can be applied to healthcare and is useful as a proof-of-concept. However, a large scale health information system is more complicated than this.

The HSB is scalable in that ESB is a highly distributed enterprise integration solution in that services that can work together are actually separated due to loose coupling principles and can be scaled independently from one another.

In terms of vertical scalability, a service container may manage multiple instances of a service; and in terms of horizontal scalability, several service containers may be distributed across multiple machines for the purpose of handling increased message volume [9].

Figure 5 shows an industry-level example between several healthcare facilities. Each entity has its own set-up and can communicate within itself and also to all other entities in the network through the HSB. For example, the Aged Care Facility has three desktops with a packaged patient administration application installed on each. The three computers can communicate with each other, and the Aged Care Facility as a whole can also communicate with other entities in the care network.

Previous Work

Bicer et al's *Artemis Message Exchange Framework* (AMEF) aims to mediate between healthcare information systems with differing messaging standards using Web Services and OWL[14].

A prototype demonstration mapping HL7 V2 to HL7 V3 is shown by the authors in [14]. This involves ontology mapping of the HL7 V2 and V3 XML schemas to each other using a mapping tool the authors have developed called *OWLmt*. Existing applications are then wrapped as Web Services and the messages they exchange are mediated through OWLmt

The HSB is different to AMEF in that it is a complete integration solution, encompassing message mediation, terminology services, patient records, management and monitoring and whatever else is required to be plugged into it; whereas AMEF concentrates solely on message mediation with some Web Services.

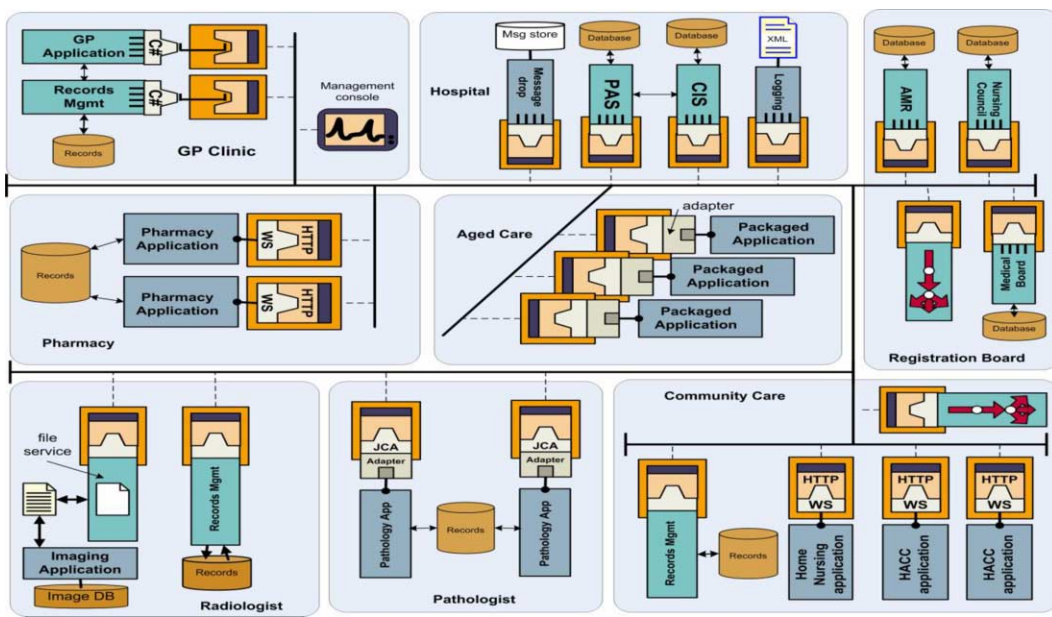

Figure 5 – Industry-based example HSB, covering eight different entities in a healthcare network.

Conclusion

ESB is a powerful technology for standards-based integration, which provides am excellent solution for communication in healthcare. The HSB solution achieves all three levels of interoperability, as defined by the HL7 Interoperability Work Group – technical, semantic and process – thus providing an architecture for a complete interoperability solution.

The small proof-of-concept HSB using Mule ESB Open-Source software shows that the solution has potential to be adapted to a larger industry-based solution.

Acknowledgments

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Applying a User Centered Design Methodology in a Clinical Context

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Abstract

A clinical decision support system (CDSS) is an interactive application that is used to facilitate the process of decision-making in a clinical context. Developing a usable CDSS is a challenging process; mostly because of the complex nature of domain knowledge and the context of use of those systems. This paper describes how a user centered design (UCD) approach can be used in a clinical context for developing a CDSS. In our effort, a design-based research methodology has been used. The outcomes of this work are as follow; a customized UCD approach is suggested that combines UCD and openEHR. Moreover, the GUI developed in the design phase and the result of the GUI evaluation is briefly presented.

Keywords:

Clinical decision support system, User centered design, Usability, UCD, Prototype, Design and development process, Iterative design, *open*EHR.

Introduction

Errors that occur in a clinical process are mostly due to cognitive limitations of humans, the potential to forget knowledge in the health care flow. Information systems have the ability to decrease such errors by supporting clinicians in this process e.g. by reminding them of important factors to be considered for the current case or to alert them of adverse drug-drug interactions [1]. A Decision Support System (DSS) is an interactive application that is supposed to facilitate the process of decision making for decision makers. This support is done by mapping or compiling existing data to useful information that can be used as a clue for making the best decision [2]. Clinical Decision Support Systems are those DSS:s that are used in the clinical domain. CDSS:s are intended to help clinicians in the process of decision making. Services supported by CDSS:s include diagnosis, alerting, reminding, treatment suggestions, and patient education. Based on a thorough literature review done on around 140 papers about CDSS, it is clear that CDSS:s have the potential to improve care [3].

Usability of CDSS

ISO 9421 [4] defines usability as the "Extent to which a product can be used by specified users to achieve specified goals with effectiveness, efficiency and satisfaction in a specified context of use." Poor usability is the one of the reasons for why CDSS:s have not yet gained a broad acceptance. While there have been many efforts in developing CDSS:s, very few of those systems have been accepted in real clinical environments. Studies show that user interfaces have an impact on acceptability of CDSS:s in a clinical context. The success of a CDSS has a direct relation to the way its graphic user interface (GUI) has been designed [5].

CDSS:s are meant to reduce clinical errors, nevertheless, because of improper design of those systems, other kinds of errors may occur by using them [1,6]. Studies reveal that clinical information systems with low usability not only do not improve patient care and reduce clinical errors, but also may have the opposite effect [7, 8].

Involving Clinicians in the Design Process of CDSS:s

Not just in the clinical domain, but in every other domain experiences show that by involving users in the design and development process of a system, the system will be more usable for the intended users [9-12].The design approach which emphasizes on involving users in the design is called User Centered Design process(UCD) [9, 10]. Accordingly, one can not develop a CDSS which addresses clinicians' needs in a clinical context without a design process in which end users, clinicians, are involved actively [13]. To make a CDSS a usable product, we should consider not only user needs that reveal functional requirements of the system, but also non-functional or usability requirements as well as characteristics of the clinical environment in which the system will finally be applied.

In this paper, we present issues related to user-centered design of a CDSS for Dry Mouth, an oral disease. The main reason for selecting Dry Mouth is that our end users expressed a need for a CDSS for this disease.

Methods

The research method we applied in our work is a design-based research method [14]. For this purpose, our collaborators in Sahlgrenska Academy[1] suggested the design and development of a CDSS for an oral disease named Dry Mouth. "Dry mouth or Xerostomia is the abnormal reduction of saliva and can be a

[1] http://www.sahlgrenska.gu.se/english

symptom of certain diseases or be an adverse effect of certain medications"[15]. Treatment of Xerostomia is related to finding its cause(s). There are five main categories for Xerostomia: Drug-induced, Disease-induced, Radiation-induced, Chemotherapy-Induced, and cGVHD-induced [15].

The reason for suggesting Dry Mouth was that the dentists and dental hygienists are commonly the first clinicians to face the complaints by patients regarding this disease; hence, they should be aware of it and its problems to prevent the deleterious consequences of this disorder. However, according to our expert panel, finding cause(s) of Dry Mouth is a challenge for dentist and dental hygienists, and needs to be supported by a clinical application. The decision support process we aim for includes these two main steps (1) finding the cause(s) of disease based on the patient's medical records (2) suggesting related materials and treatment options, based on results from the first step. Since this system is intended to be used integrated with an existing Clinical Data Entry application [16], data entry forms are not part of the Graphical User Interface (GUI), however we have to provide users with options to edit existing data. Finally, users need to be able to enter their own comments; including diagnosis or treatments to the system.

The Design Process

The approach we use in this design process is UCD. UCD focuses on the end users, their needs and the context in which the system will be used. The main goal in this method is user satisfaction. UCD has an iterative nature. It means that during the design and development process, at several points, prototypes are delivered to users for evaluation and improvement.

As depicted in Figure 1, the idea of UCD is a circular design process including analysis, design, prototyping and getting user feedback. End users are in the heart of this design process and should be involved in all steps. Users are asked about what they expect the application to do for them and what priorities they have in doing their tasks using the intended application. Users have the chance to specify their needs as detailed as possible e.g. which colors do they prefer or what are their time limits running a specific task using the application.

On the other hand, informaticians can communicate with users to extract vital information about their current situation and their future needs e.g. what users like about the way they are currently doing their tasks or what would they like to be changed [11]. Finally, *task analysis* and *evaluation* [9-10] should be done based on the gathered information.

The Importance of Involving Clinicians in the design

Domain knowledge plays the main role in complexity of clinical applications. Clinical tasks may not be complex by themselves but what makes the clinical application development so complicated is that most of the clinical processes are unstructured. They are done in clinicians' mind and based on their expertise. Moreover, clinical knowledge is ever-changing.

Hundreds of data items are involved in a clinical decision making process. After all, concepts in clinical domain are not easy to understand for informaticians and they face difficulties communicating with clinicians or studying literature to get enough domain knowledge to be able to model it and to develop an application.

Extracting domain knowledge in the clinical domain has always been a bottleneck in the development process of such systems and a challenge for informaticians. Therefore, in the clinical domain, we need to involve clinicians in designing the Information model or more precisely domain concept models to be used for information modeling. One of the recent approaches that focuses on involving users in domain concept modeling is *open*EHR [17].

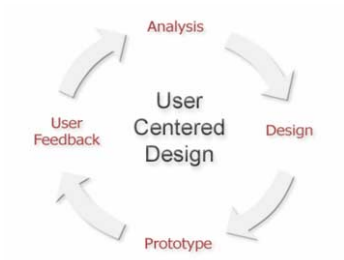

Figure 1- User Centered Design Process[2]

The openEHR Approach

*open*EHR is an open standard specification that emphasizes on the role of clinicians in organizing domain knowledge in form of different clinical concepts such as observation, evaluation, instruction and action [17].

In the *open*EHR approach, clinicians are in charge of defining the specification of clinical knowledge to be used in information modeling. This approach suggests a two level architecture for clinical applications to separate knowledge and information levels in order to overcome the problems caused by the ever-changing nature of clinical knowledge.

While the main emphasis of *open*EHR is on semantic interoperability of medical records, we found the approach highly compatible with UCD. Therefore, we applied *open*EHR to facilitate involving clinicians in the design and to ease domain concept modeling and communicating with our end users.

From an UCD point of view, *open*EHR is very helpful. This approach recommends the utilization of expert knowledge not only just by consulting clinicians but also by letting them design concept models based on what they have in mind. By applying *open*EHR, we can communicate better with our end users since clinical concepts recommended by *open*EHR are understandable for clinicians.

UCD Principles Applied in The Project

There are number of principles that are recommended in UCD [18]: *Multidisciplinary design team, Understanding users and context, Active user participation, Early prototyping, Continuous evaluation,* and *Holistic design*. Besides Holistic de-

[2] Copyright 2009, Kevin Bury Design

sign, we have been concerned about the other principles, as explained below.

Project Team

Our development team is a multidisciplinary team consisting of an interaction design expert, two computer scientists with different backgrounds (AI, Software Engineering), a domain expert (specialist in dentistry), a programmer, and a nurse. However, more end users and experts are involved in different steps in various time periods.

Intended Users, Tasks and Context of Use

One of the main principles in UCD is to define users and the context of use [10].

Users: In this project, direct users are dentists who work in an oral medicine clinic. We used narrative explanation of some typical end users, *personas,* [7] to find more about our end users' characteristics. Since the output of the CDSS will be a treatment decision, patients are our indirect users. Nonetheless, patients will not use the system directly.

Tasks: Based on literature review and interviews with end users and domain experts, we defined the tasks listed below as the main tasks that dentists carry out with regard to Dry Mouth: (1) Information Overview (2) Information manipulation, (3) Requesting related actions like laboratory tests, (4) Diagnosis, (5) Referring to guidelines and other clinical evidence, (6) Recording the results.

Context of use: Dentists will use the application while they are visiting a patient in the clinic. They will use it in presence of the patient, at the same time they are communicating with the patient and in a setting with a limited amount of time.

Users' priorities/Usability goals: The goal is to develop a system, which fits to the dentists' workflow as much as possible; experiences show that clinicians should not need to change their clinical workflow while using a CDSS [18]. It is also important to consider that not all clinicians are experienced in using information systems. On the other hand, because of their occupations, they do not manage to spend much time on learning a new application. Based on this information, we set up our usability goals such as: Effectiveness, Efficiency, Safety, Learnability, etc.

Iterative GUI Design and Evaluation

During the design, we have been using both low fidelity and high fidelity prototypes. From those, we can name sketches designed and improved during brain storming sessions for collecting functional requirements and usability requirements together with our expert panel. In this step, conceptual design of the application was done. These sketches were later translated to some power point prototypes. Afterwards, low fidelity prototyping tools were used to visualize the design solutions. Finally, a Java based GUI has been developed to make the final usability tests more realistic and reliable.

Iterative Domain Concept Model Design

The domain concept modeling started with brain storming sessions in which our expert panel (experts in Dry Mouth) were asked to think about Dry Mouth and its related concepts based on this question: *What do you want to know about a patient who visits you because he/she suffers from Dry Mouth?;* and to put as much information as possible on a paper. Later, our expert panel has been asked to prepare a questionnaire based on this question: *What do you ask from a patient who visits you because he/she suffers from Dry Mouth?*

Questions on the questionnaire were then categorized based on *open*EHR concepts; in other words, their logical relation e.g. is the question related to patient history or is it a lab result? In the next step, simple diagrams were created based on the questionnaire. For this purpose, a mind-map application[3] was used to make it possible for our expert panel to simply understand and edit the created diagrams.

GUI and Domain Concept Model Evaluation

For the GUI evaluation, we used the evaluation methods applicable in early stages of the project. Two main methods we have been utilizing so far are *Heuristic Evaluation* and *Usability Tests* [9]. Based on the results from the evaluations we improved the GUI in several stages. One of the resulting GUI screens is showed in Figure 2.

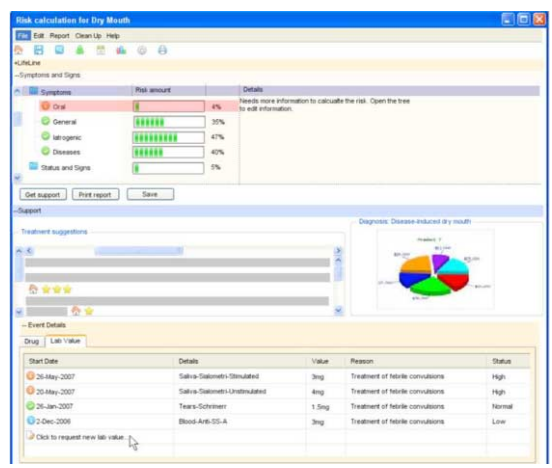

Figure 2- GUI Prototype

Iterative design of the domain concept model includes evaluations of the current model based on the literature and experts' opinions, and story-based assessment. Information modeling diagrams were improved several times based on the experts' opinions. Several experts were involved in this process to minimize the subjectivity of the design and to be as broad as possible in collecting knowledge. A sample mind map is depicted in Figure 3.

[3] http://www.xmind.net/

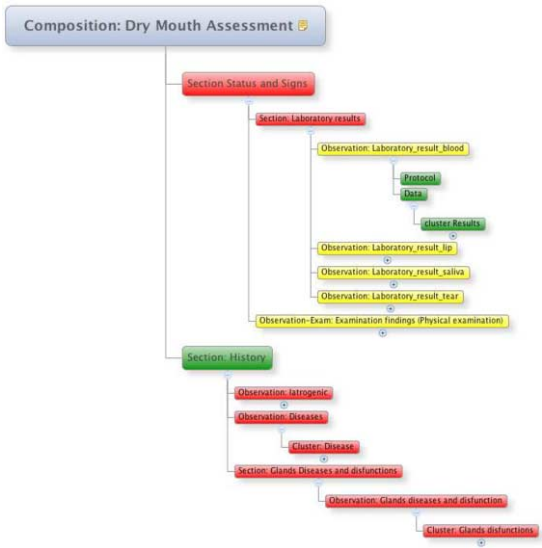

Figure 3- Information modeling

Results and Discussion

UCD emphasizes that users' needs should be reflected in the GUI design and that the GUI design should influence the design of the rest of the system [12]. On the other hand, *open*EHR emphasizes the domain concept modeling as the starting point. But how much does the domain model reflect the end users' needs? By using the *open*EHR approach without considering other aspects like usability issues, we may end up developing highly adaptable systems with comprehensive information models, which are not usable.

In this project, we tried to benefit from the strengths of the two of approaches and to introduce an adaptation of UCD in a clinical concept keeping an eye on the *open*EHR approach.

The Customized UCD Approach for *open*EHR Based CDSS Development

As references suggest "The actual contents of the UCD process, the methods used, the order of activities, etc, must be customized and adapted to the particular organization and project based on their particular needs" [19]. So it was not a surprise to see that we need to apply a customized version of UCD in this project.

As shown in Figure 4, the main idea of UCD is used in the process but in three different cycles. One is a general cycle to develop the whole application. This main cycle contains a cycle to develop the Domain Concept Model; and a cycle to develop the GUI. So the process includes two main steps in parallel (1) Iterative development of the domain concept model (2) Iterative development of the GUI. For the first step, several specialists in dentistry (expert panel) and for the second step, both domain experts and general dentists (end user panel) were involved.

GUI vs. Domain Concept Model

During the iterative design process we noticed that the impact of the domain concept model on the GUI is inevitable. Decision about the components to be shown on the GUI is directly related to the output from the domain concept modeling. Any changes in the domain concept model should be checked from the GUI point of view. Therefore, as depicted in Figure 3, in each iteration, there should be an input from the left hand side process (domain concept model) to the right hand one (GUI). In other words, after each domain concept modeling iteration, the necessity of a new iteration for GUI design should be checked.

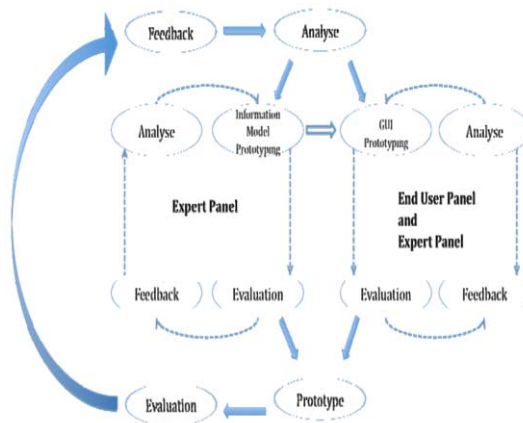

Figure 4- Customized User Centered Design Process

Characteristics of the Customized Approach and prblems

The recommended approach has several characteristics:

- This approach considers active involvement of the end users and domain experts in designing and evaluating the domain concept model and the GUI
- In the suggested approach new GUI and Domain Concept modeling iterations will be performed until the end users are satisfied with the results.
- In this approach, the effect of the domain concept model on the GUI has been considered as explained before.
- The approach helps overcoming the knowledge extraction bottleneck by applying clinical concepts suggested by *open*EHR for communicating with clinicians and providing an opportunity for them to model domain knowledge based on their expertise.
- This approach inherits the idea of the knowledge and the information level separation suggested by *open*EHR in order to make developed applications highly adaptable.
- Finally, the approach is applicable for developing not only *open*EHR-based applications but also all kinds of

clinical applications e.g. OWL based ones. Important issues to be considered while applying the approach are (I) the parallel iterative UCD of the domain concept model and the GUI, and (II) the effect of the domain concept models on the GUI.

We also faced some problems during the design phase. In design and implementation of CDSS:s a big challenge is choosing a knowledge representation and reasoning. Our experience showed that, selecting the representation and reasoning method have to be done in parallel with the information modeling and the GUI design, otherwise, the changes forced by this selection causes modifications in the GUI design which is more cost effective to be known in the early stages of the GUI design. Secondary, the classical bottleneck of knowledge acquisition in clinical domain still exists. While applying the suggested methodology decreases difficulties in mutual understanding of clinicians and designers, it cannot eliminate the bottleneck problem totally, especially for the cases that reasoning should be done by applying knowledge intensive methods.

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Bridging the HL7 Template – 13606 Archetype gap with Detailed Clinical Models

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Abstract

The idea of two level modeling has been taken up in healthcare information systems development. There is ongoing debate which approach should be taken. From the premise that there is a lack of clinician's time available, and the need for semantic interoperability, harmonization efforts are important. The question this paper addresses is whether Detailed Clinical Models (DCM) can bridge the gap between existing approaches. As methodology, a bottom up approach in multilevel comparison of existing content and modeling is used. Results indicate that it is feasible to compare and reuse DCM with clinical content from one approach to the other, when specific limitations are taken into account and precise analysis of each data-item is carried out. In particular the HL7 templates, the ISO/CEN 13606 and OpenEHR archetypes reveal more commonalties than differences. The linkage of DCM to terminologies suggests that data-items can be linked to concepts present in multiple terminologies. This work concludes that it is feasible to model a multitude of precise items of clinical information in the format of DCM and that transformations between different approaches are possible without loss of meaning. However, a set of single or combined clinical items and assessment scales have been tested. Larger groupings of clinical information might bring up more challenges.

Keywords:

Archetypes, Templates, Information modeling, Detailed clinical models, Concept representation

Introduction

Huge efforts are ongoing in the specification of clinical data elements. In particular clinicians, regulatory agencies, health statisticians, institutions for quality control, among others, invest in clinical data standards [1-4]. The idea of two level modeling has been taken up in healthcare information systems development [5]. Two level modeling is in particular of interest for the electronic health record, the electronic exchange of patient data for continuity of care, and aggregation purposes.

There is ongoing debate whether one approach should be taken, or that alternatives are equivalent. Most efforts consist of data item specification, definitions of each element, and unique coding to determine the semantics. In particular the interaction between the information model and the terminology model is of interest because several standards that model information, such as the Health Level Seven (HL7) [6] and the ISO 13606 [7] apply external terminologies like Snomed CT [8], LOINC [9] or others. These clinical information models, templates, archetypes, clinical data elements, and Detailed Clinical Models (DCM) aim at three parts [10]:

1. Formalizing, organizing, structuring or standardizing clinical data elements to allow semantic interoperability,
2. Modeling these data elements independently of the technical implementation itself, and
3. Applying these data elements and models in different technical implementations [11], such as electronic health records, electronic messages, data warehouses / data repositories, and clinical decision support systems [12].

A fourth area of concern of such models is quality control and governance. The latter is not content oriented, but establishes what quality measures are necessary and how the ongoing maintenance is guaranteed for current and future use.

The question this paper addresses is whether Detailed Clinical Models (DCM) can bridge the gap between HL7 templates and 13606 archetypes and allow specification of concepts for use in both HL7 and 13606 standards.

Methods

In existing comparisons between HL7 templates (TM) and 13606 archetypes object model (AOM), the comparison is based on the 'whole' approach, including the full extent of the reference information models used [13, 14]. We discuss the information view only. Bointner and Duftschmid compare the TM and AOM models and find many differences e.g. in inheritance of characteristics, definition of semantics of reference model instances rendering them incompatible [14]. Their findings are consistent with earlier discussions in the standards organizations themselves. However, we see this as the effect of object modeling using a top down approach that is based on the whole standard, and starts with the Reference Information Model downwards.

When the starting point is the clinical relevant concept such as represented in the scientific literature and/or in clinical practice documentation, records and guidelines, the comparability can be improved. This however, requires a bottom up approach on the conceptual level. One example of such compari-

son is presented by Cuggia et al, where they compare the Apgar score representations in both HL7 v3 and OpenEHR archetype [15].

In the CEN/ISO mirror panel of NEN, the Netherlands, the two approaches HL7 v3 and 13606 have been part of ongoing debate for many years. Based on a bottom up approach we were able to further disentangle the clinical concept modeling from the technical modeling and to identify adequate levels of equivalence [16]. This allows comparing data element – by data element based on review of medical knowledge on the specific topic. The underlying assumption is that data elements that medically must be similar for safe patient care should remain the same despite the applied modeling and despite their technical representation.

In other words: if a patient has a coronary heart disease, a receiver of information should not see diabetes type 2 in the problem list. Or, if a Glasgow Coma Scale (GCS) is assessed, or a body temperature is measured, then the results of such observations must be exchanged without loss of meaning, leading to appropriate care by the receiver of information.

In order to bypass all technical constraints that might block a full comparison, the Detailed Clinical Modeling approach [10] has been taken to model a Top 10 of frequently used clinical concepts (height, length, temperature, pulse, respiration, blood pressure, Apgar score, Barthel index, Braden scale and Glasgow Coma Scale). Six are variable based; four are assessment scales with a well established meaning.

We identified these levels of comparison as appropriate:

1. Data types; that is the use of different types of data such as free text, (coded) value sets and physical quantities, [17] including their units of measurements [18].
2. Encoding; that is the manner in which each approach refers to external terminologies [8, 9] for the semantics of each data element.
3. Concepts; that is the level of the clinical concept, the unit of thought.
4. Meaning is created by combining concepts, including component data elements and linking this with the context and knowledge for use in health care.
5. Electronic communication, i.e. the exchange of clinical data between systems, which is a technical level.
6. Cooperation, which discusses expectations based on exchange of information, which is an organizational level.
7. Workflow around the data elements and concepts.
8. Agreements between stakeholders.
9. Maintenance and management of the instances of models.

For this comparative analysis the Top 10 of frequently used clinical concepts where modeled in Unified Modeling Language, are represented in HL7 v3 via a mapping to the Clinical Statement Pattern, and are also modeled into an archetype using an archetype editor.

In the analysis, the search is for equivalence on the level of information modeling, applying rules from data element standards, terminology standards and information model standards. In addition, where appropriate, we applied specific knowledge about the content. E.g. when a scale is represented, the psychometric measures of reliability and validity require that scientific rules are applied as well.

Materials

Results indicate that it is feasible to compare and reuse information models for single or combined clinical data elements and for assessment scale from one approach to the other. This works when specific limitations are taken into account and precise analysis of each data-item is carried out. In particular the HL7 template approach and the ISO/CEN 13606 and OpenEHR archetypes reveal more commonalties than differences. When compared against DCMs, it becomes even easier to transform from one to the other formalism.

In the area of data types, level 1 comparison, DCM, HL7 v3 and ISO/CEN 13606 use the ISO 21090 standard for data types. All examples show that the data types as expressed in the DCM could be expressed in both the HL7 v3 Clinical Statement Pattern (CSP), TM and in the AOM (Table 1).

Table 1- Data type level: example blood pressure

Clinical knowledge	Clear understanding is clinically important, e.g. 120 80 37 68 only make sense as 120 / 80 mm Hg 37 OC, and 68 /min
DCM	Data type PQ, unit mm Hg
HL7 v3 message using ISO 21090	<value xsi:type="PQ" value="165" unit="mm[Hg]"/>
OpenEHR archetype Partly ISO 21090	value matches { C_DV_QUANTITY < property = … units = <"mm[Hg]"> > }

For encoding data elements, level 2, DCM, HL7 v3 and archetypes can refer to external terminologies, or use internal coding. In order to achieve interoperability however, only the external codes offer equivalence. E.g. HL7 internal vocabulary deals with the mechanics of the messaging, where an archetype uses an internal numerical order for each element, called ontology. Latter has no reference to external ontologies in the medical domain. The linkage of DCM to terminologies suggests that to some extent data-items can be linked to terms present in multiple terminologies. Table 2 gives some examples of data element coding from the Top 10 of items, represented in DCM and mapping to TM and AOM.

Table 2- Coding level: blood pressure

Clinical knowledge	Systolic Blood Pressure: The maximum pressure that is build in the aorta when the left ventricle contracts.
DCM	Blood pressure as Observable Entity, using both Snomed CT and LOINC codes as presented above.
HL7 v3 message using	SNOMED CT <code code="271649006" codeSystem="2.16.840.1.113883.6.96" displayName=" systolic blood pressure"/> LOINC: <code code="8480-6" codeSystem="2.16.840.1.113883.6.1" displayName=" BP Systolic "/>
OpenEHR archetype	ontology > ["at0004"] = < text = <"systolic"> description = <"the systemic arterial blood pressure in systolic phase"> term_binding = < ["SNOMED-CT"] = < items = < ["at0004"] = <[SNOMED-CT(2003)::163030003]>

On the concept level 3, Cuggia et al (2009) [15] illustrated that the Apgar Score can be expressed in both the TM and AOM formats. Similarly, the Glasgow Coma Sale (GCS) can be modeled. The GCS consists of three categories: eye opening, best motor response and best verbal response. The GCS is scored by documenting the number representing the best response that could be observed with the patient. Here DCM, in which concepts can be represented by one or multiple individual data elements, potentially ensure uniformity across standards concerning composition, format and structure. See Table 3 for the concept level comparison of the Glasgow Coma Scale.

Table 3- Concept level: example Glasgow Coma Scale

Clinical knowledge	This scale is used to measure the level of consciousness of a patient with respect to verbal, motor and eye movement reactions. It has a total score summated from the three underlying observations.
DCM	Each data element is described as is the relationship between data elements. The derivation into the total score is expressed and class models can be drawn, including defining the hierarchical relationships.
HL7 v3 message using	Class representation for each of the score items and component relationships to identify hierarchical relationship with total score. Each class represented for instance by a LOINC and/or Snomed CT code: LOINC 9269-2 Glasgow Score Total, SNOMED CT 281395000: GCS eye opening sub score.
OpenEHR archetype	Node representation does allow identifying the three observations as a single data item and the total score. Also the fact that the total score is derived is defined. Each can be linked to an external code system as illustrated in table 2.

Level 4 Meaning. Figure 1 illustrates HL7 v3 classes forming the context for GCS, including the total score and the underlying components of Eye Opening, Motor and Verbal. In the code attribute the codes from external code systems can be specified. In the example LOINC codes are used, but also other codes can be included as synonyms. Figure 2 similarly represents (excerpts from) the GCS in AOM formalism.

Meaning is about the interaction between the (often intrinsic) knowledge model of clinical concepts, the information model representing it in technology, and the terminology model revealing its semantics. Both Standards do have a generic structure where concepts fit. In HL7 v3 this is the so called Clinical Statement Pattern (CSP). This is a RIM derived choice box pattern allowing 1 – n data elements to be represented and linked together with the component relationship. Figure 1 is in fact a roll out of that CSP. Similarly, the 13606 standard has the Entry component (Figure 3). DCM examples for e.g. blood pressure and GCS apply a full class diagram in which the concept is modeled, each component is represented in a class, each value is represented as a class diagram and the set of values and the code bindings are both represented in classes. An example is presented in Figure 4. This full modeling allows a full mapping to either a HL7 CSP / TM and to an Entry in AOM.

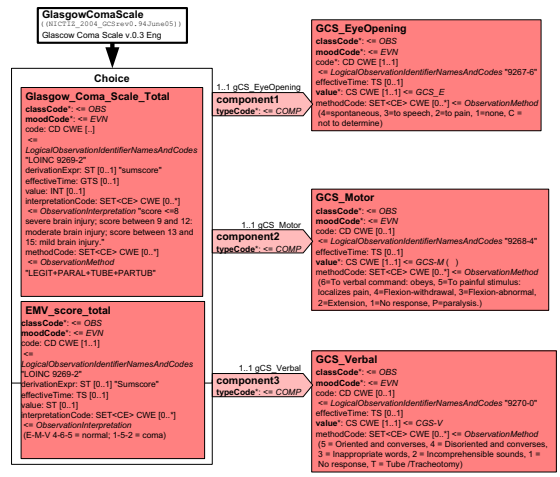

Figure 1- HL7 v3 representation of Glasgow Coma Scale.

```
ELEMENT[at0034] matches {-- E= Opening of Eyes
        value matches {
        1|[local::at0036], -- No  reaction (etc.)
ELEMENT[at0041] matches {-- M=Best motor reaction
        value matches {
        1|[local::at0043],    -- none (etc. enumeration)
ELEMENT[at0049] matches {-- V= Best verbal reaction
        value matches {
        3|[local::at0053],    -- Inadequate
ELEMENT[at0033] occurrences matches {0..1} matches {-- To-
tal score
        value matches {
DV_COUNT matches {magnitude matches {|3..15|}
```

Figure 2- Glasgow Coma Scale concepts as in AOM.

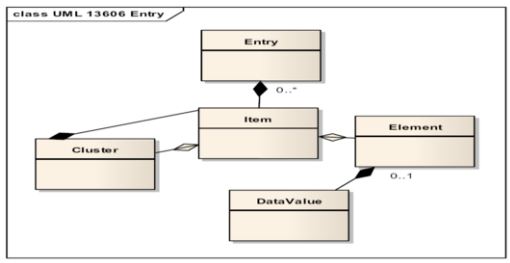

Figure 3- Entry part of 13606 RIM.

The entry level in 13606 RIM seems to equal the CSP function in HL7 v3 Models. Comparing this reveals a difference of the Reference Models between 13606 RIM and HL7 RIM. The first is, although generic, representing the 'whole' picture, where the HL7 v3 RIM requires a second step to create a so called Domain Message Information Model, of which the CSP is an example. Thus if we are to compare how a concept fits in the overall model, the 13606 Entry is the equivalent level to deal with a single data element or a concept (e.g. one (set of) observation(s) as CSP in HL7 v3 or one (or more) item(s) in 13606). This way the same level of comparison is achieved between TM and AOM. Concepts partly get their meaning from the structure they are embedded, which cannot lead to full 100% comparability of the reference models differ.

In HL7 v3 it is possible to represent the step in workflow (level 7) for each data element via the HL7 moodCode attribute that is inherited in each instance from the HL7 v3 RIM Act class. For instance, it is possible to order a blood pressure measurement (HL7 RQO or request mood), plan it (HL7 INT or intent mood) and document it (HL7 EVN or Event mood). In AOM such a workflow definition or modeling of a care process is absent. In DCM, the actual use of data elements, e.g. their creation, the phase in a care process and where relevant more aspects of workflow are expressed. Also general guidelines for the correct interpretation of values are included, offering the option for appropriate follow up.

Levels 5, 6, 8 and 9 would require a technical, organizational and managerial discussion, which is out of scope for this study. It is a more human and organizational issue to discuss the technical tools to be used, the cooperation between care professionals, getting agreement on formalisms and maintenance issues. However, on level 7 of comparing TM and AOM, it is possible to model processes and determine workflow support. For instance in health care it is quite common that particular observations are requested, planned and carried out. For observations this can lead to entering a value (score, text, value from list) into the EHR and exchange that.

Discussion and Conclusion

This work proves that it is feasible to model items of clinical information in the format of DCM and that transformations between different approaches are possible without loss of meaning. In particular, DCM expresses clinical concepts that can be represented in TM and AOM. However, the sample of data elements that has been tested includes single data elements or small scale groupings of elements and assessment scales. Larger data sets and groupings of clinical information might bring up more challenges, and perhaps reveal potential conflicts between the terminology model and information model.

The comparison from a bottom up approach following the levels indicated reveals many commonalties. At the first level of data type specification we find no differences, as long as the standards themselves adhere to ISO 21090. When the standards create additional data types, they will render semantic interoperability hard to achieve.

At the second level of coding, we see agreement between TM and AOM in the option to bind individual clinical data elements to codes from external terminologies. In Table 2 we see a difference in the Snomed CT code applied for blood pressure systolic. However, this is partly a matter of choice. In the HL7

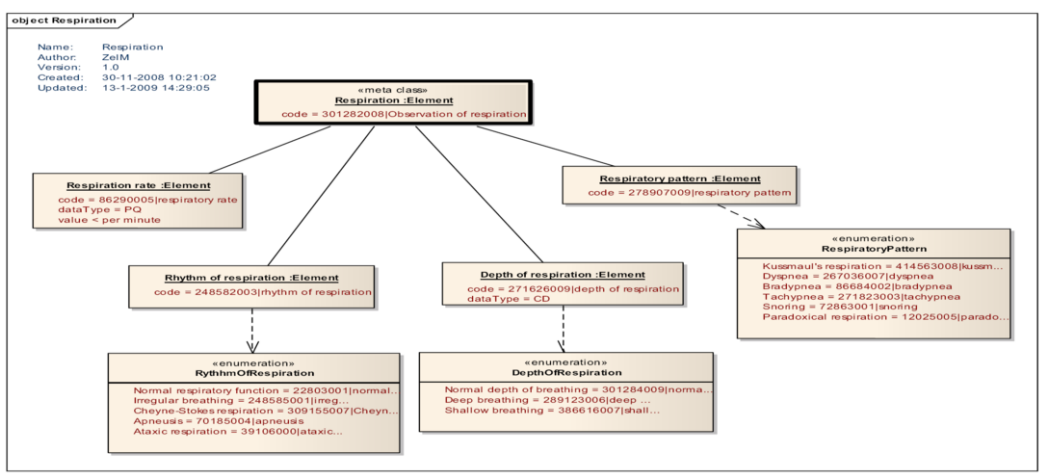

Figure 4- DCM model of respiration

example, which is similar to the DCM, the Snomed code for Observable Entity is used, referring to a field name in EHR. In the archetype example the clinical finding code is used, pointing to the actual finding on examination and the value entered. This illustrates the depth of knowledge necessary to model clinical information and to options that have to be set for actual implementation. It can be argued here that the AOM is more accurate in using the clinical finding, compared to the HL7 example. However, DCM, TM and AOM allow any choice. It can be recommended to use guidelines for code use such as Terminfo in HL7 [6] to sort this out. A difference between TM and DCM and AOM is that the latter currently does not support multiple external code systems as synonyms in the definition.

At the third level of concept, TM, AOM and DCM can define all relevant data elements, their relationships, their binding to coding, and the derivation of results. Although the representation formalism does look different, and obviously is handled different in an EHR system or an HL7 v3 XML message, the concept representation in DCM, TM and AOM remains intact for the clinical concept aspects. Only the hierarchical aspect cannot be defined in AOM itself, and needs some external mechanism. Class models applied in DCM would serve as such.

Meaning, level four of our comparison, is often discussed from the viewpoint of the reference information model of 13606 and/or HL7 v3. In fact HL7 v3 RIM is a generic structure with building blocks requiring a domain specific modeling exercise before it becomes meaningful. One format in HL7 is the CSP [6] that is used in several HL7 domain message information models or D-MIMs and message models derived from that. In the 13606, the RIM does represent the whole model used for the EHR communication [7]. The exercise with DCM examples Glasgow Coma Scale en blood pressure illustrate that these can be modeled against either the CSP in HL7 v3 and the Entry class in 13606. From this bottom up approach the commonalties become apparent, although it is not a 100% fit. Differences still remain in the hierarchical representation of concepts and in the workflow options that are both present in HL7 v3 and currently not in the AOM.

Comparisons of standards work can have different approaches, depending on the focus of the researcher carrying this out. With the bottom up approach is it feasible to stay very close to the original clinical concepts and relate these to terminologies, and different information models. Criteria from terminology use, information models, and the clinical knowledge need attention in order to get the necessary quality on the details. Use of DCM seems to bridge the gap to some extent at the very granular level indeed. However, transforming DCM into HL7 v3 TM and 13606 AOM does require transformations and careful attention for adequate concept representation and prevention of loss of meaning on the clinical side and appropriate application of the formalisms on the technical side. The overall approach is very promising; it reveals proof for the validity and the core asset of DCM: allowing specification of semantics and reuse of investments, independent of technology or standard.

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Chapter 14.

Data Mining and Information Extraction

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Data mining techniques for analyzing stroke care processes

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Abstract

Controlled randomized clinical trials and meta-analyses show that stroke patients benefit from access to specialized Stroke Units, in terms of mortality, disability and dependency. However, many issues relating to stroke diagnosis and therapy and to the organization of stroke care remain to be solved and little is known about what interventions make Stroke Units more effective. It is also agreed that compliance with clinical practice guidelines improves health outcomes for these patients, but little is known about the relative weight of the different guideline recommendations. Over the last decade, many hospital- or population-based stroke registers have been set up with the aim of identifying specific key indicators able to monitor the quality and adequacy of acute stroke care. Registers seem to be adequate tools for collecting the data needed to analyze care processes, providing data useful for both national healthcare planning and scientific research. In this paper we applied data mining techniques to data collected within the stroke register of the Lombardia region in Italy. From our analyses both expected and unexpected results have been found: not always compliance to recommendations is related to a good patients' outcome.

Keywords:
Data mining, Stroke care, Clinical practice guidelines.

Introduction

Stroke is a leading cause of disability and death in developed countries. Since many years, national scientific communities work to support specialists with the most appropriate approach to stroke care. In Italy, the Stroke Prevention and Educational Awareness Diffusion (SPREAD, www.spread.it) collaboration, active since 1998, involves multidisciplinary experts coming from 36 different organizations together with representatives of patients' associations. The goal of SPREAD is to make available clinical practice guidelines (GLs) for stroke management, from prevention to acute and post-acute phase. These GLs are a set of practical recommendations periodically revised (we are now currently at 5th edition) and based as much as possible on the best available scientific evidence: according to the strength of the supporting evidence, recommendations are labelled with decreasing degrees from A to D.

In previous works, we described how these GL recommendations have been translated in logical (IF-THEN) rules and integrated within an existing electronic patient record (EPR) through a careflow management system [1]. The result has been a real-time decision-support system based on clinical evidence, which has been implemented in our hospital. Moreover, a module has been implemented, called RoMA (Reasoning on Medical Actions) [2], able to detect non-compliances with GLs. In principle non-compliances could be weighted with the recommendations degree. RoMA is a flexible tool that can be integrated with different databases, such as different EPRs. It has been used on about 500 cases to evaluate adherence to SPREAD GL before and after the implementation of the decision support system [1], showing its effectiveness.

In order to obtain more significant statistics with respect to the analysis of a single EPR, RoMA has then been used to analyze the bigger amount of data collected in the Stroke Unit Network (SUN) register, still with the aim of verifying GL compliance and its correlation with patients' outcome. The results so far obtained show that good compliance improves the clinical outcome. However, this is an *overall* result, correlating the outcome with the total number of non-compliances, while no result exists about the influence of every single recommendation, or set of similar recommendations, on the outcomes.

Therefore, there are several open questions:

1. Which are the recommendations more related to a good/poor outcome? Is it possible to make some inference on the importance of the recommendations with low scientific evidence degree?
2. Which is the most effective organisational setting for a Stroke Unit? Which facilities, among those distinguishing a Stroke Unit from a regular ward, are more influential on the outcome?
3. Which are the major patterns of non-compliance, i.e. is it possible to individuate predictors of non-compliance for the different SPREAD recommendations?

4. Are these patterns more related to clinical or organisational factors?

As shown in [3], data mining techniques can be profitably used in this area. Thus we used decision trees and rule extraction methods on the SUN register data to try answering some of the above questions.

The paper organisation is the following: the next section illustrates the data available in the register; then the GL recommendations are illustrated together with data necessary for testing the compliance; then we describe the data mining techniques used; eventually, analyses and results are shown.

The Stroke Unit Network Register

The SUN register is part of a web-based network connecting 36 Stroke Units and Neurological Departments in the Lombardia region, Italy, with the aim at improving the quality of stroke care in the acute and post-acute phase. The SUN website facilitates storing homogeneous data, debating among specialists and sharing research projects and results.

The data collected within the SUN register can be split into different categories as shown in Table 1.

First, there are general information about patient's demographics, admission modalities, stroke type and severity scales.

In the second category there are patient's clinical data such as risk factors for cerebro-cardiovascular diseases and medical complications that arise during the hospital stay.

In the third category there are indicators of the care process. Some of them describe diagnostic patterns: whether or not ECG, neuroimaging and other basic tests have been performed in the emergency room, and all the instrumental tests performed during the hospital stay. Timing of each performed test is also recorded. Others are indicators of good medical assistance: again, both type and timing of every assistance procedure are stored. Finally there are indicators of therapeutic procedures, both for the acute phase and for the early clinical phase, treatment for comorbidities (diabetes, hypertension, etc.) and counselling for healthy lifestyle.

The fourth category is composed by outcome indicators, among which the Rankin scale, collected both at discharge and at three months follow-up.

Moreover, each clinical centre is provided with a description of the hospital to which it belongs (e.g. rural or not, university-related or not), of its organisation (e.g. human resources), and diagnostic facilities (e.g. presence and 24h availability of a service).

The register is provided with procedures for data quality control both in real time and in batch.

The register and its database have been designed and implemented during 2006, while the patients' recruitment started in January 2007. At January 2009, the register contained 5079 cases of ischemic strokes, which represent our study population.

Table 1 – Data collected within the Stroke Registry

<table>
<tr><th colspan="3">General information</th></tr>
<tr><td>Demographics</td><td colspan="2">Stroke onset</td></tr>
<tr><td>Birth date
Gender
Race</td><td colspan="2">Time
Rankin and NIHSS scales (higher values indicate higher severity)
Diagnosis (TOAST Classification)</td></tr>
<tr><th colspan="3">Clinical data</th></tr>
<tr><td colspan="2">Risk factors</td><td>Medical complications</td></tr>
<tr><td colspan="2">Smoking; Previous stroke Atrial fibrillation; Hypertension; Dementia; Diabetes; …</td><td>Hypertension; Hyperglycaemia; Myocardial Infarction; Hypertermia; Endocranial Hypertension; Seizures; …</td></tr>
<tr><th colspan="3">Process data</th></tr>
<tr><td>Diagnostic work-up</td><td>Medical assistance</td><td>Therapeutic patterns</td></tr>
<tr><td>ECG; Coagulation screening, carotid, vertebral, peripheral duplex, scan, transcranial Doppler; Echocardiography; Brain image; Cerebral angiography.</td><td>Neurological evaluation; Monitor of vital signs; Dysphagia screening; Early mobilization; Positioning of gastric probe and bladder catheter; Deep venous thrombosis prophylaxis.</td><td>Thrombolisis; Antiplatelets; Anticoagulants; Surgical procedures; Additional drugs for complications treatment; counselling.</td></tr>
<tr><th colspan="3">Outcome indicators</th></tr>
<tr><td colspan="3">Mortality, Recurrence; Disability (Rankin).</td></tr>
</table>

The guideline recommendations

As we are dealing with a disease register, we must point out that it contains less data, for an individual patient, with respect to a clinical chart, which reports much more detail. That means that we have fewer data fields available for testing GL compliance. On the other hand, a register allows a quick collection of a high number of patients, from a high number of clinical centers, thus allowing sounder statistics.

The information needed to assess the GL compliance has been matched with the data model of the SUN register in order to obtain IF-THEN rules as a formal representation of recommendations. The IF part of a rule is called *eligibility condition*, while the THEN part is the *action*. Three examples of this matching procedure are reported in Table 2. We remark that such a matching is not a trivial task, and it requires the collaboration of physicians in order to interpret the text, often ambiguous, of the GL, and to include some "hidden" knowledge that is not explicitly written in the GL, because part of the cultural background of any physician (e.g. which tests belong to a given diagnostic work-up, which diseases belong to a certain category, etc) or simply because obvious (e.g. the patient must be alive at a certain time for being evaluated).

Table 2 – Examples of matching the Register data with GL recommendations, in order to assess compliance

Recommendation	GL section	Register data used
5.5(D) - After a TIA or a stroke, transthoracic echocardiography (TTE) is recommended only when a heart disease is clinically suspected.	Diagnostic work-up	Alive at 3 days, TTE execution, myocardial infarction, atrial fibrillation, coronaropathy, heart failure, arrhythmias, prosthesis
9.7(D) - A non-contrast CT scan is recommended as soon as possible in the emergency care: to allow the differential diagnosis between ischaemic and haemorrhagic stroke, and with non-cerebrovascular lesions; to detect possible early signs of infarct.	Acute stroke:hospital admission (diagnostic procedures)	Time of stroke onset, time of hospital admission, time and setting of the neuroimaging execution
12.6a (B) - After stroke or TIA, lowering of high blood pressure is recommended, preferably using agents active on the renin-angiotensin system, calcium channel blockers and diuretics.	Secondary prevention	Alive at discharge, hypertension as risk factor or complication, antihypertensive therapy at discharge

The overall procedure result was that compliance can be verified for 12 recommendations of the acute phase and 4 of the secondary prevention phase, subdivided according to their scientific degree as follow: 2 with grade A, 4 with grade B, 1 with grade C, 8 with grade D and 1 only supported by experts consensus. While, in general, a guideline can contain recommendations that either suggest or advise against an action, all the 12 recommendations are of the first type and the non-compliance is defined as a case where the eligibility condition is satisfied and the action has not been performed.

The rules obtained have been used within the RoMA tool to assign every patient with a 1/0/null flag for any recommendation, representing non-compliance/compliance/no-eligibility respectively.

Data mining techniques

To analyze the impact of non-compliance to clinical GL on patients' outcome, we herein chose to exploit Data Mining (DM) techniques besides the classical statistical analysis that is the most frequent approach in these cases. The reason why DM can be useful is that it provides some tools to model the possible paths that lead to the outcome in a way that can be easily visualized and interpreted also by clinicians. These motivations led us to the choice of a specific DM algorithm, i.e. Classification Trees.

Classification Trees are a classification algorithm that works by recursively partitioning the examples space on the base of the most discriminant feature to predict the outcome (also known as class variable). Besides providing a method for class prediction, classification trees can be also a useful instrument for data exploration and understanding. Each branch of the extracted classification tree not only leads to the class prediction (in the leaves), but also identifies a clinical path that can be usefully considered for results interpretation. Each branch of the tree can be in fact seen as a classification rule where the body of the rule is represented by the conditions that characterize the patients belonging to that branch, while the head of the rule is the outcome. Such a representation is very suitable to identify the patterns that can lead patients to a particular outcome.

For Classification Trees construction we used the algorithm that is implemented in the Orange Data Mining Suite [4], choosing Gain Ratio as attribute selection criterion. Moreover, we set a minimum number of 100 patients in the leaves in order to avoid an excessive expansion of the tree obtaining too small and not significant patients sets. As we will see in the following paragraphs, we herein exploit classification trees mainly to analyze and discuss with our clinical partners about the clinical paths that lead to a certain outcome. For these reason the Orange widget "Classification Tree Graph" was very useful for results visualization and presentation.

Besides Orange, also S-Plus (Tibco Software Inc., Palo Alto, CA) was used for more classical statistical analysis such as logistic regression.

Analyses and Results

In order to produce results easily interpretable, different types of analyses have been performed using subsets of variables instead of using all the variables together, and continuous/ordinal variables have been discretized as follows:

Age: <=45years, 46-79, >=80

NIHSS scale: 0-7, 8-14, >14

Rankin pre-stroke scale: 0-1, 2-3, 4-5

Rankin scale at discharge/follow-up: good (0-2), bad (>2, including death). This binary value has been chosen as the main patients' outcome.

Delay between stroke onset and hospital admission: <=3 hours, 3-6, 6-24, >24.

The analysis has been performed using 5079 cases. The outcome at discharge was good for 2737 patients and bad for 2342, while the outcome at follow-up, where 2739 patients were available, was good for 1826 patients and bad for 913 (*good* and *bad* defined as illustrated above). On the average 3760 patients were eligible for each recommendation (range: 109 to 5079) and the average non-compliance rate was 36% (range: 0% to 80%).

The compliance flags, produced by the RoMA tool for the above mentioned 16 recommendations, have been used as explanatory variables for the health outcome, the discretized Rankin scale both at discharge and at 3-months follow-up. Age, gender, and severity at admission, that are known to be correlated with health outcomes, have been included in all the analyses as correction factors.

In the next paragraphs we show some results from different types of analyses. For sake of space, only the most significant results are shown.

Non-compliance vs outcome

In principle, GL compliance should be correlated to a good outcome, mainly when recommendations are based on scientific evidence deriving from clinical trials. This is not guaranteed in the real-world setting indeed, because the clinical routine can be very different from the *ideal* conditions in which trials are conducted. As an example, about short-term outcome, we obtained the classification tree in Figure 1. The tree has been derived considering the *Rankin scale at discharge* (good/bad) as outcome and the *non-compliance/compliance* to the set of recommendations of the acute phase as features. Figure 1 suggests that, after considering stroke severity represented by NIHSS and Rankin scales, that resulted the most discriminant variables, and age and gender (not appearing in the tree because not discriminant), the non-compliance to the recommendation 5.15 (namely *Transcranial Doppler is a complementary examination in patients with a recent TIA or stroke. It may provide additional information on patency of cerebral vessels, recanalization and collateral pathways; grade D*) is the most important to determine poor outcome in patients with less severe initial status. This is in agreement with the current physicians' feeling that this examination is very important to drive the subsequent diagnostic work-up, despite its low degree of scientific evidence.

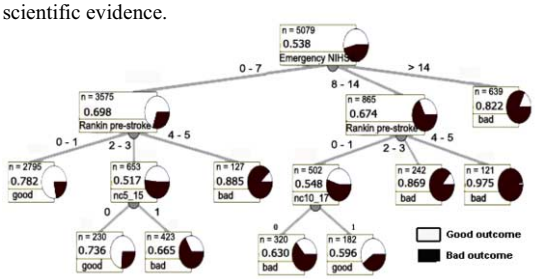

Figure 1 – The classification tree for the identification of the recommendations that are most related to the health outcome. "nc X" means "non-compliance with recommendation X". Bottom lines in the leaves indicate the majority class of the outcome (dichotomized Rankin scale), and the numbers represent the sample size (top) and the proportion of cases belonging to the majority class (middle).

On the contrary, in patients with a slightly more severe initial status (NIHSS 8-14), compliance to recommendation 10.17 (namely *Early mobilisation and hydration are always indicated to prevent Deep Venous Thrombosis. Graded compression stockings as well as intermittent pneumatic compression are recommended in combination with anticoagulation or as an alternative when anticoagulation is contra-indicate; grade D*) seems to be not as beneficial as expected (see Figure 1 again, bad outcome in 63% of compliance cases, and good outcome in about 60% of non-compliance cases) . The result is in agreement with a recent publication [5] that raised some doubts among such prevention procedures, which mainly consist in using graduated compression stockings. This is a very interesting exploitation of data mining, showing that a continuous monitoring of the collected data can anticipate and support some literature results, providing early indications for both GL developers and users.

The results shown in Figure 1, both for recommendation 5.15 and 10.17, are confirmed considering long-term outcome (Rankin scale at three-months follow-up). Among the 4 questions mentionned in the Introduction, the analyses just described are related to question #1.

Another type of analysis, still related to question #1, has been performed using every single recommendation, with the usual correction factors, as predictor of the health outcome. This analysis has been run through logistic regression, using age as a continuous variable. The rationale for this investigation is that some clinical trials enroll only a subset of the entire population (only males, only less than 80years, etc.) and the results are then extended to the entire population. Otherwise, a trial may involve unselected population, but lack of the so-called "subgroup analysis" may hide important distinctions about the treatment effect in different patients subsets. Therefore, we investigated whether some recommendations do not hold for the whole sample of our patients.

An interesting result has been obtained running logistic regression with recommendation 12.6a (hypertension treatment, see text in Table 2) as explanatory variable. In particular, the presence of a non-compliance to this recommendation resulted to have a negative correlation with the outcome (i.e. patients with non-compliance had better outcome). In order to gain a deeper insight into this result and since also the age variable turned out to be significantly correlated with the outcome in the logistic regression, we tried to stratify the patients sample on the base of their age. The main goal of this step was to see whether there exists a group of patients where this behavior is stronger. We created two age groups relying on the median of the age distribution (75 years) and we obtained a significant negative correlation between non-compliance and outcome with an odds ratio of 0.25 for the population of older patients with mild/severe impairment. Results on the younger patients group were instead not statistically significant.

After discussing this result with medical partners, they realised that it could be sensible, because the antihypertension treatment may induce a too high reduction of blood pressure, thus compromising the cerebral autoregulation mechanisms and causing secondary damage from cerebral hypoperfusion. This can be even more possible for elderly people living alone. For these people it is in fact difficult to monitor drug assumption and provide for prompt dosage correction if needed. The bad effect of lack of blood pressure response (and thus hypoperfu-

sion) in stroke was already described in [6], but the study was limited to the acute phase. After finding the result described above, a literature search was performed and our finding has been strengthened [7,8].

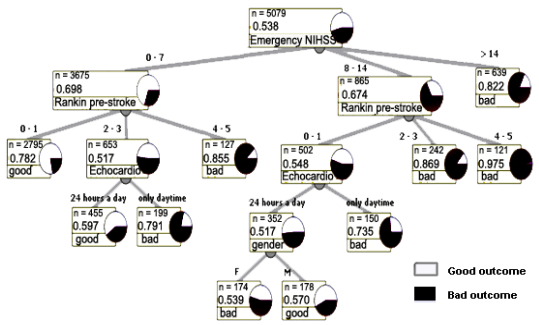

Figure 2 – The classification tree for the identification of the organizational variables that are most related to the health outcome.

Organizational setting vs outcome

To answer question #2 of the Introduction, an analysis has been performed using organisational variables, again besides considering severity, age and gender. Among the resources that characterize the medical units in terms of diagnostic facilities, only the possibility of performing echocardiography over the 24 hours was found to be related to the health outcome, as shown in Figure 2. Note that the result holds only for a subset of patients with moderate impairment.

Conclusion

Our study demonstrates that data mining techniques are a useful tool for (a) continuous monitoring of GL recommendations when implemented in the real-world clinical routine, (b) promoting discussion among GL developers and users and (c) suggesting priorities for equipping stroke units with diagnostic and treatment facilities. In particular, the results obtained in this work stimulated useful discussion among clinical experts, rising doubts on the general applicability of GLs and providing a feedback to the SPREAD GL developers themselves. Interestingly, the debate fostered a deeper literature search, that eventually strengthened our findings. From another point of view, when data-mining techniques show unexpected results, these can suggest further clinical research. It must be stressed, in fact, that data mining cannot replace clinical trials, but only give suggestions for their planning.

About the support to organisational issues, we observed that transcranial doppler examination leads to a better outcome, both at short and long-term. This suggests this equipment, still rare, should be highly recommended: its initial cost will be very likely justified by long-term cost-saving. Similarly, enough personnel to ensure 24h echocardiography should be provided in every hospital that treats stroke patients.

In a near future further analyses will be performed in order to answer also questions #3 and #4 enumerated in the Introduction. In particular, individuating predictors of non-compliance and organisational pitfalls could allow to enact the opportune correction actions to modify the incorrect behaviours and to enhance clinical settings.

Acknowledgments

We are grateful to all the participants of the SUN project for providing data in the stroke register.

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Automatically Detecting Medications and the Reason for their Prescription in Clinical Narrative Text Documents

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Abstract

An important proportion of the information about the medications a patient is taking is mentioned only in narrative text in the electronic health record. Automated information extraction can make this information accessible for decision-support, research, or any other automated processing. In the context of the "i2b2 medication extraction challenge," we have developed a new NLP application called Textractor to automatically extract medications and details about them (e.g., dosage, frequency, reason for their prescription). This application and its evaluation with part of the reference standard for this "challenge" are presented here, along with an analysis of the development of this reference standard. During this evaluation, Textractor reached a system-level overall F_1-measure, the reference metric for this challenge, of about 77% for exact matches. The best performance was measured with medication routes (F_1-measure 86.4%), and the worst with prescription reasons (F_1-measure 29%). These results are consistent with the agreement observed between human annotators when developing the reference standard, and with other published research.

Keywords:

Pharmaceutical preparations, Drug prescriptions, Natural language processing, Program evaluation, Knowledge bases.

Introduction

Computerized physician order-entry (CPOE) and E-Prescribing systems are becoming widely available in the healthcare system [1], and provide detailed information about the medications prescribed and managed with these systems, but a substantial proportion of the medications actually taken by the patient are still only mentioned in narrative clinical text documents in the patient electronic health record. These medications were prescribed in another institution or private practice, were bought over-the-counter, or were prescribed before the introduction of CPOE. Their mention in narrative text format makes them inaccessible for decision-support, research, or any other automated processing. These functionalities require coded data, and as a possible answer to this issue, Natural Language Processing (NLP) can convert narrative text into coded data. Techniques for automatically encoding textual documents from the electronic health record have been evaluated by several groups, as described in Meystre et al. [2]. Examples are the Linguistic String Project [3] and MedLEE (Medical Language Extraction and Encoding system) [4]. Other systems automatically mapping clinical text concepts to standardized vocabularies have been reported, such as MetaMap [5]. MetaMap and its Java™ version called MMTx (MetaMap Transfer) were developed by the U.S. National Library of Medicine. MetaMap has been shown to identify most concepts present in MEDLINE titles [6] and has been used for Information Retrieval [7] and Information Extraction [8].

When extracting information from narrative clinical text documents, the context of the extracted concepts plays a critical role. Important contextual information includes negation (e.g., "denies any chest pain"), temporality (e.g., "...fracture of the tibia 2 years ago..."), and the event subject identification (e.g., "his mother has diabetes"). NLP systems such as the LSP [3] or MedLEE [4] include negation analysis in their processing, but research focused explicitly on negation detection started only a few years ago with algorithms like NegEx [9].

The automated extraction of information from clinical text documents has been the focus of several competitions — called "challenges" — these last few years. Prominent ones were organized by the i2b2 (Informatics for Integrating Biology and the Bedside) National Center for Biomedical Computing. These "challenges" took the recent application of NLP to clinical research a step further by providing a de-identified corpus of clinical narrative text documents and by stimulating new developments in this domain. The i2b2 "challenges" started in 2006, with an automated de-identification challenge [10], and a smoking status detection challenge [11]. The obesity challenge was organized in 2008 [12]. The latest "i2b2 challenge" was organized in 2009 and focused on the extraction of medications, details about these medications, and reasons for their prescription. A corpus of 1249 clinical text documents (discharge summaries from Partners Healthcare in Boston, MA) has been semi-automatically de-identified and re-identified with realistic surrogates, and then split into a training corpus of 696 documents, and a test corpus of 553 documents. Only 17 documents in the training corpus were annotated by the organizing team for medications and prescription details; all other documents in the training corpus were not annotated.

For this challenge, we built a new NLP application based on the UIMA (Unstructured Information Management Architecture) framework [13]. This new application, called Textractor, and its evaluation using the first part of the reference standard are presented here.

Materials and Methods

Architecture and development process

Text analysis functionalities developed for Textractor are implemented as modules organized in a pipeline, as depicted in Fig. 1. The whole analysis pipeline is implemented in the UIMA framework. UIMA provides a development model that enforces the use of XML description files for maintainability and interoperability, as well as tools to test and visualize the text annotations realized by the system.

The pre-processing phase starts with the analysis of the document structure. Each document is broken into sections using regular expressions to match section titles or subtitles. Some sections that typically contain mentions of medications that should not be extracted by our system are filtered out (e.g., "Family history" sections mention drugs taken by family members, "Allergies" sections mention drug allergies that should not be extracted for this i2b2 challenge). For each section of interest, the text is split in sentences using an OpenNLP [14] module based on the maximum entropy principle. The whole text is then tokenized, and a part-of-speech (POS) tagger is applied to the set of tokens. The POS tagger is also based on an OpenNLP module, with a supplementary logic to treat sections where the end of the sentence cannot be inferred without knowledge of the section content structure.

During the second phase, medications and details about them (dosage, duration, frequency, route, reason for prescription) are extracted. We use MMTx to extract medications and possible reasons for their prescription. MMTx was developed to extract data from MEDLINE abstracts, and acronyms are less common in paper abstracts than in clinical documents, and are the principal source of ambiguity for our system. Examples of acronyms ambiguous to MMTx are "Dr." (detected as diabetic retinopathy), "Mr." (mitral regurgitation), "M.D." (mental depression), etc. For disambiguation, we expand abbreviations and acronyms before feeding MMTx with each sentence of the document to parse. A list of abbreviations and acronyms and corresponding full terms from the APL system [15] was expanded for this purpose. MMTx (version 2.4.C) is used to extract UMLS Metathesaurus [16] concepts related to drugs and health conditions. More specifically, the system implements the MMTxAPILite class and uses the default dataset (complete 2006 UMLS Metathesaurus) and settings. The following semantic types were used to extract medications: Amino Acid, Peptide, or Protein (aapp), Antibiotic (antb), Biologically Active Substance (bacs), Carbohydrate (carb), Hormone (horm), Organic Chemical (orch), Pharmacologic Substance (phsu), Steroid (strd), Vitamin (vita), and the following semantic types for possible prescription reasons: Disease or Syndrome (dsyn), Congenital Abnormality (cgab), Finding (fndg), Pathologic Function (patf), Sign or Symptom (sosy), Therapeutic or Preventive Procedure (topp). Since MMTx lacks context analysis (e.g., Insulin will be extracted in "…glucose management didn't require insulin …"), a context analysis step is also required after the extraction. Context analysis is based on an improved version of NegEx. This algorithm uses regular expressions and lists of terms to analyze negation (a concept can be affirmed, negated, or possible). Our implementation uses a variable window to analyze the context of each concept (instead of the 5 tokens fixed window originally used in NegEx) and infers the context from a larger set of base phrases. Finally, medication attributes (dose, frequency, duration, and route) are extracted with a set of regular expressions.

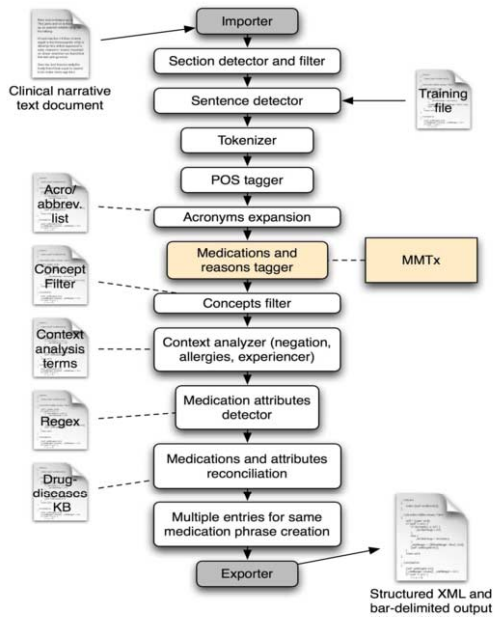

Figure 1- Components of Textractor for medications extraction

During the last phase, extracted medications are combined with medication attributes to build the prescription annotations. Each medication is combined with attributes that follow (or sometimes precede) it according to a set of rules. For example, in "Rheumatology suggested starting colchicine 0.6 mg b.i.d. for two days"…, the medication *colchicine* is followed by a *0.6 mg* dose, a *b.i.d.* frequency, and a *for two days* duration that are combined with the medication. Reason for prescription annotations are more complicated. As mentioned earlier, possible reasons are extracted with MMTx. They are then linked with the corresponding medication using a few rules and regular expressions that recognize possible reasons preceded by expressions like "because of …", "due to …", "… was treated with", etc. For the prescription annotations that do not have any reason attribute after applying this logic, we complement the search with the use of a drug-disease knowledge base. This knowledge base was built from existing databases that include the Pharmacogenomics Knowledge Base

(PharmGKB; available at www.pharmgkb.org), the Comparative Toxicogenomics Database (CTD; available at ctd.mdibl.org), and the UMLS Metathesaurus. The final knowledge base contains about 750 paired relationships of medication and disease, with their CUIs, and their relationship type. If a possible reason is found in a window of ± 2 lines of a medication (as defined for the i2b2 challenge) and is related to this medication according to the knowledge base, then it is added as the reason attribute for this prescription.

Finally, multiple prescription annotations are created for a single medication if the associated attributes describe multiple values or reasons (e.g., "Tylenol 650 mg p.r.n. pain or headache" becomes two *Tylenol – 650 mg – p.r.n.* annotations, one with the reason *pain*, and the other with the reason *headache*).

Reference standard creation

As mentioned previously, part of the reference standard (251 documents) was built by all teams participating in the challenge. Each document was annotated by one member of two different teams participating in the challenge with a member of a third team adjudicating disagreements in a second step. This process produced a final reference standard created by the challenge teams that could be used for evaluation purposes. Assigning annotation tasks to challenge participants is one of the novel approaches for this i2b2 challenge.

For our own annotations, we created an annotation schema using an open source annotation tool called Knowtator [17] and based on the annotation guideline provided by the i2b2 challenge team. Knowtator is a Protégé [18] plugin tool that uses the unique knowledge representation capabilities of Protégé to develop complex annotation schemas. Our annotation schema treats medication as the parent class and all other related information as child subclasses. Each medication class has an associated slot attribute describing whether the annotated mention was found in a list or in narrative text, and a complex slot attribute used to link annotated subclass information with the parent medication class. Using the Knowtator tool and this annotation schema, the span of medication mentions can easily be annotated and linked with associated spanned mentions of dose, route, frequency, duration, and reason.

Our team was assigned 40 reference standard documents for annotation. From these documents, each member of our team was assigned 10 documents to annotate using the guideline and the Knowtator annotation schema (10 documents were annotated by two of us, for subsequent agreement analysis, as described below). The logic for annotation tasks for each mention of medication in the clinical texts was as follows: a) identify the parent class medication; b) determine if the identified mention is in the context of a list or narrative test; c) identify associated subclass mentions of dose, route frequency, duration, and/or reason; d) link the subclass mentions with the parent class medication; e) identify the next medication mention (Figure 2).

Due to the complexity of this challenge, we felt it was necessary to evaluate the performance of human beings on annotation tasks related to this challenge. We evaluated reliability (task consistency) of the team annotation task using a subset of 10 documents from the assigned document set. Two team members annotated each of these documents. Logical pairings were created so that each annotator was evaluated against every other annotator on our team. Task consistency was evaluated using inter-annotator agreement, as published by Roberts [19], using the formula for the Inter Annotator Agreement (IAA): IAA = matches / (matches + non-matches).

We report IAA for class, subclass and slot attribute agreement for instances where class matched with an overlapping span, or where class and span matched exactly.

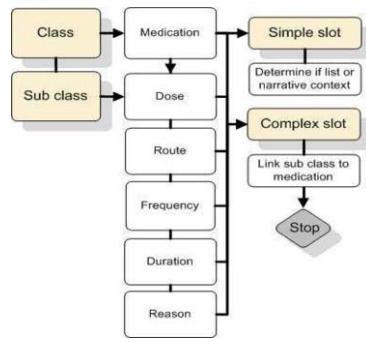

Figure 2- Annotation task logic process flow diagram

Medication extraction evaluation

Evaluation for this "i2b2 medication extraction challenge" is realized with exact matches (i.e. the extracted phrase corresponds exactly to the reference standard) and with inexact matches (i.e. the extracted phrase overlaps with the reference standard) separately.

Exact matches evaluation is done at the instance level, and metrics are recall (number of correct distinct instances extracted / all instances in the reference standard), precision (number of correct distinct instances extracted / all instances extracted), and the F1-measure (a harmonic mean of recall and precision, with a weight of 1 [20]). Instances that are not mentioned are ignored.

Inexact matches evaluation is realized at the token level (i.e. words or character groups separated by a white space). Metrics are also recall, precision, and F1-measure, but recall and precision are calculated differently (recall = number of correct tokens extracted / all tokens on the reference standard; precision = number of correct tokens extracted / all tokens extracted).

Exact and inexact matches evaluations are done separately for each class (e.g., all doses or all medications) and also for each full prescription annotation (i.e. medication, prescription details, and reason for the prescription if present), and then averaged at the document level or at the system level (i.e. over all medications extracted). For the example in Table 1, these metrics would be: exact recall = 3/5 (3 correct instances extracted and 5 instances in the reference standard); exact precision = 3/5 (3 correct instances extracted and 5 instances extracted); inexact recall = 5/8 (5 correct tokens extracted: toprol, 50, mg,

p.o., b.i.d.; 8 tokens in the reference standard); inexact precision = 5/6 (5 correct tokens extracted: toprol, 50, mg, p.o., b.i.d.; 6 tokens extracted).

Table 1- Medication extraction example

Medication instance extracted					
Medication	Dose	Route	Frequency	Duration	Reason
toprol	50 mg	p.o.	b.i.d.	Nm	Asthma
Reference standard					
Medication	Dose	Route	Frequency	Duration	Reason
toprol xl	50 mg	p.o.	b.i.d.	3 weeks	Nm

nm = not mentioned

Results

The testing corpus of 553 documents was made available for three days in August 2009, and each participating team could submit up to three runs. We analyzed this corpus with three slightly different configurations of Textractor: the first included the 15 UMLS semantic types cited above, the second had fewer prescription reason semantic types (aapp, antb, carb, horm, orch, phsu, strd, bacs, vita and dsyn, patf, sosy), and the third fewer medication and prescription reason types (antb, phsu, vita and dsyn, patf, sosy).

Local evaluation details and results

The results of our first configuration of Textractor, with the part of the reference standard annotated by the participating teams, are presented here in Tables 2 and 3. System-level results were averaged over all medications extracted by the system; patient-level results were averaged at the level of documents (since we had one document per patient).

Table 2-Results of the exact match evaluation

Information	**N**	**Syst R**	**Syst P**	**Syst F**	**Pat F**
Medication	8882	0.752	0.769	0.761	0.759
Dose	4432	0.758	0.910	0.827	0.811
Route	3417	0.813	0.921	0.864	0.842
Frequency	4074	0.781	0.890	0.832	0.824
Duration	545	0.329	0.395	0.359	0.347
Reason	1529	0.185	0.679	0.290	0.259
OVERALL	22879	0.720	0.830	0.771	0.760

Syst = system-level results; Pat = patient-level results;
R = recall; P = precision; F = F1-measure
N = number of instances of each class in the reference standard

Table 3- Results of the inexact match evaluation

Information	**N**	**Syst R**	**Syst P**	**Syst F**	**Pat F**
Medication	8882	0.766	0.782	0.774	0.784
Dose	4432	0.785	0.921	0.848	0.830
Route	3417	0.798	0.927	0.858	0.837
Frequency	4074	0.736	0.924	0.820	0.817
Duration	545	0.326	0.481	0.388	0.398
Reason	1529	0.145	0.697	0.240	0.244
OVERALL	22879	0.693	0.837	0.758	0.750

This corpus included 251 documents and took Textractor an average of about 24 seconds to analyze each document. Most of the time was spent extracting concepts with MMTx, and even when limiting the semantic types and skipping sections of the document for MMTx analysis, the concept extraction phase represented most of the execution time.

Annotation task reliability evaluation

For the 10 documents we used to evaluate task consistency, overall inter-annotator agreement for class and span exact matches (or with matching using overlapping span) was the highest for identification of mentions of medication 85.9% (92.4% partial match), and the lowest for identification of duration 16% (29.3%) (Table 4). Slot attribute agreement for overall exact match to determine if the medication was mentioned in a list or in narrative text was 62%, and 63% for linking subclass attributes with the parent medication class.

Table 4- Inter-annotator agreement (all values are percentages)

Annotation class/subclass	**N**	**Exact match IAA (class match, Span match)**	**Partial match IAA (class match, span overlap)**
Medication	303	85.9	92.4
Dosage	109	88.4	88.4
Route	119	76.5	81.0
Frequency	88	73.3	89.9
Duration	16	16.0	29.3
Reason	59	31.3	73.1
OVERALL	694	78.5	86.6

N = number of annotated instances of each class

Discussion

This evaluation showed that the NLP application we developed for this task – Textractor – performed satisfactorily. The reference metric for this challenge, the system-level overall F_1-measure, reached about 77% for exact matches. Performance was good for medication attributes like dose, route, and frequency, with recalls around 80% and precisions around 90%. Results were not as good for durations, with recall and precision between 30% and 40%, and for reasons, with a recall below 20%, and a precision below 70%. These two attributes are very difficult to define precisely and also resulted in low agreement when analyzing our own manual annotations. The exact match IAA is equivalent to the F_1-measure when scoring one annotator against the other (i.e., treating one annotation as reference and the other as test), and in our case, this agreement only reached 16% with durations and 31.3% with reasons for prescription, in similar ranges than the measured performance of Textractor.

Our results are also consistent with other published similar research, such as the MERKI system [21] with measured precisions of 83.7% for dose, 88% for route, and 83.2% for frequency. What distinguishes our work from MERKI is its foundation on an open-source pipeline, a more comprehensive test set, and broader multi-reviewer evaluation scheme.

The adoption of UIMA as a firm ground for our developments gave us several advantages: efficient development tools to test and visualize the results of the system, good integration with

Eclipse [22], use of standard XML description files for maintainability and interoperability, and easier integration of existing developments (e.g., OpenNLP tools). We also integrated MMTx in UIMA, and benefited from its good UMLS Metathesaurus concepts indexing. However, the significant pre- and post-processing required to use this application with clinical text, its relatively slow performance, the impossibility to adapt it for multi-processing, its planned phase-out by the NLM, and its lack of an API will lead us into the development of a new concept extraction tool integrated in UIMA.

For our annotations, considering the complexity of this annotation task, we were not surprised to see that exact span matching had much lower agreement compared with overlapping span matching for all classes of annotated information. Prevalence of annotated classes varied widely across the 10 documents used to assess annotator agreement at the class and subclass level. The high variability in the observed agreement could be partly explained by this small sample. A more formal evaluation of both reliability and validity of annotation tasks across the challenge in general would show interesting results and would help define how to deal with some of these issues.

The automated extraction of information from biomedical text is still a relatively new field of research, and the extraction of information from clinical text is even newer [2]. The potential uses of information extracted from clinical text are numerous and far-reaching. In the same way the Message Understanding Conferences have fostered the development of information extraction in the general domain, similar competitive challenges for information extraction from clinical text, such as the "i2b2 medications extraction challenge," will undoubtedly stimulate advances in the biomedical field.

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Extracting Medication Information from French Clinical Texts

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Abstract

Much more Natural Language Processing (NLP) work has been performed on the English language than on any other. This general observation is also true of medical NLP, although clinical language processing needs are as strong in other languages as they are in English. In specific subdomains, such as drug prescription, the expression of information can be closely related across different languages, which should help transfer systems from English to other languages. We report here the implementation of a medication extraction system which extracts drugs and related information from French clinical texts, on the basis of an approach initially designed for English within the framework of the i2b2 2009 challenge. The system relies on specialized lexicons and a set of extraction rules. A first evaluation on 50 annotated texts obtains 86.7% F-measure, a level higher than the original English system and close to related work. This shows that the same rule-based approach can be applied to English and French languages, with a similar level of performance. We further discuss directions for improving both systems.

Keywords:

Natural language processing, Information extraction, Drug prescriptions, Computerized medical records systems, Information storage and retrieval/methods

Introduction

The information contained in Electronic Health Records (EHRs) may take the form of coded data or may be written in free text. Free text is indeed the easiest and most natural way for physicians to convey information [1]. It cannot, however, be used as is by health information systems [1,2]. It is also time-consuming for clinicians to read narrative sections in order to find relevant information. Natural Language Processing (NLP) techniques — more specifically information extraction methods — have therefore been proposed to gain easier access to this information [3]. Among the useful types of information to extract from narrative reports is information related to treatment such as medications [4–9].

Within the framework of the i2b2 NLP2009 challenge[1], we developed a medication extraction system for English narrative patient records. This system extracts and links medications with related information such as dosage, mode of administration, frequency, duration and reason for treatment. According to Harris [10], "The structure of each science language is found to conform to the information in that science rather than to the grammar of the whole language". This was exemplified further by Borst *et al.* [11] when they designed a system for analyzing French discharge summaries starting from Sager's [12] original system designed for English. In contrast, Friedman *et al.* [13] highlight the differences found when developing systems for two distinct domains (clinical and biomolecular), although both in English. Closeness or distance of information structure is thus stronger than closeness or distance in languages. If the same principle applies to the language of medications, it should then be possible to transfer our initial English medication extraction system to one for French medications with limited modifications. In this paper, we test this hypothesis and report the implementation of a similar system to deal with medications in French medical records.

This work is part of the AKENATON project which addresses information extraction in the domain of telecardiology. In this context, extracting information from clinical texts would allow physicians to link more easily automatic alerts to patient data, including coded data obtained from electronic health records and that obtained from free text. Medications are one type of useful information to be extracted in this regard.

This paper is structured as follows. We begin by a review of existing work. We then describe our corpora of clinical texts and detail the implementation of our system. We finally present its evaluation and discuss the results.

Related work

A few approaches, all dedicated to English, have addressed medication extraction from free text.

Some approaches focus on extracting a specific type of medication information, such as drug names or dosage. Levin *et al.* [4] developed a system based on lexicons (drug names and medical abbreviations) and regular expressions to extract drug names (generic or trade names). In order to deal with misspelled drug names, the authors used a phonetically based matching module, thus allowing them to increase the extraction by 7%. Also centering on drug name recognition, Sirohi *et al.* [5] studied the importance of determining the best lexi-

[1]https://www.i2b2.org/NLP/Medication/

con list to use in order to improve the quality of drug name extraction. They used the commercial software FreePharma and experimented with filtering criteria to refine drug lexicons, more specifically to eliminate ambiguous entries or to take into account abbreviated forms. Shah and Martinez [6] focused on recognizing dosage from the free-text field of a database of patient records specifying dosage instructions. The extracted information is then classified according to an existing format, which includes daily dose, frequency, units, duration. This system does not detect drug names, as they are contained in a structured field of the database.

Other approaches aim at extracting a more complete set of information elements related to medications. The first system specifically designed to extract drug and dosage information was that of Evans *et al.* [7]. The authors defined a model of the drug-dosage information to be extracted that included drug name, dose level, route, frequency and necessity. They detected this information using a set of extraction rules relying on lexicons (both general and specialized) and NLP steps including stemming, part-of-speech tagging and semantic category assignment. In their system, a drug name was extracted only if associated with at least one related piece of information (*e.g.* dose, frequency, duration, etc). More recently, Gold *et al.* [8] built Merki, a parser for extracting a similar set of information. The process consists in identifying drug names using a lexicon as a first step, and in applying regular expressions to detect associated elements as a second step. Xu et al. [9] used a more detailed drug model and detected medication information performing semantic tagging and parsing.

Materials and Methods

Development and test corpora

The corpora used in this experiment consist of a total of 17,412 French EHRs from the cardiology unit of a French University Hospital, written between 2004 and 2006. They include discharge summaries, consultation reports and surgical reports. This set is divided into two corpora: a development corpus of 17,362 documents which we used to implement our system and a test corpus of 50 documents which we manually annotated to use as a gold standard. The test corpus contained 253 medications, plus the associated information elements.

A rule-based approach to medication extraction

Our approach to medication extraction is rule-based, as is often the case in information extraction. A set of lexicons define the relevant vocabulary, and a set of extraction rules encode the grammar of medication expressions.

Lexicons

Lexicons associate linguistic information to words. Here, each lexicon entry is associated to a semantic category which corresponds to one of the target information types: drug, dosage, mode of administration, frequency, duration, and sign or symptom which is the reason for prescription. We group these entries into three lexicons according to the sources of information used to compile them. The first two are acquired from external sources, while the third is mostly obtained from a development corpus: a *drug lexicon*, used to recognize drug names; a *list of signs and symptoms*, to detect reasons; a *list of abbreviations and expressions*, which is used by the extraction rules to identify information related to medications: dosage, mode of administration, frequency, and duration.

System outline

The system first segments the text into sentences based on typographical clues, *i.e.* certain types of punctuation (here we considered only full stops). We use these punctuations to determine sentence boundaries, while also taking care of exceptions, mainly periods which occur in abbreviations ("etc.") or within numbers ("1.5").

Then, the first stage of our extraction algorithm iterates over the sentences to recognize drug names. The process consists in a lexicon look-up. A drug is extracted when an exact match is found between the text and an entry of the drug lexicon. This stage terminates when the text has been completely scanned.

The second stage starts by dividing each sentence into subparts according to the detected drug names. That is, each resulting text span is composed of a medication name and the text which follows that name. We call this process drug span segmentation. The underlying assumption is that most information associated to a drug occurs in the text span which follows the drug name.

The second stage of the algorithm thus consists in looking for information related to medications within each of these text spans. If needed, we also extend the search to other parts of the sentence in which a drug name occurs, especially to the text closely preceding the drug name, in order to deal with cases where a piece of information does not follow a drug name. This second stage relies on lexicons and on a set of extraction rules implemented by regular expressions.

French implementation of the system

The system was originally designed for English in the context of the i2b2 challenge. The above-described principles and outline apply to both the English and French versions of the system. We do not detail the specificities of the English system any further and we focus on the French implementation from now on. This version was modified and extended to take into account the specificities of the language and the corpus.

Corpus study

A first study of the corpus highlighted structural similarity between French and English EHRs. At the document level, information is generally structured as follows: illness and social history, allergies, medications on admission, examinations, and discharge medications. At the local level, drug names are often followed by related information (dosage, frequency, mode of administration, etc.) in the same sentence. These shared patterns point to the same direction as previously observed by Harris [10] and Borst *et al.* [11]. They give positive signs that our hypothesis could be valid, and that it might thus be possible to obtain a localization from English to French with limited modifications.

Lexicons

Three French lexicons were constituted according to the three previously defined types. The *drug lexicon* was compiled from the Internet using drug lists provided by three different sources: Vidal[2], Eureka Santé[3] and Doctissimo[4]. We also completed these lists with drug names not found in these sources, namely drug name abbreviations ("*avk"* for "*anti-vitamine K"*, *i.e. oral anticoagulants* in English), common orthographic and grammatical variations of names ("*bétabloquant"*, "*bêtabloquants"*, *i.e. beta-blockers* in English), and drug names mentioned in the records but absent from the Internet sources since they are not used anymore nowadays. Finally, we added substance names from the Biam database[5]. The resulting lexicon is composed of 33,371 drug names.

The *list of signs and symptoms* was obtained by querying the UMLS (version 2008AA) for French terms with the *Sign or Symptom* semantic type. It contains 3,988 entries.

The *list of abbreviations and expressions* was adapted from the English list, by translating existing entries and adding new ones when necessary. This list includes 68 abbreviations and expressions for 4 types of elements: dosage, mode of administration, frequency, and duration (see Table 1).

Table 1 – Excerpt of the list of abbreviations and expressions

Entry	Attribute
mg	DOSE
iv	MODE
h	FREQUENCY
heure (*hour*)	FREQUENCY
semaine (*week*)	DURATION

Since we can easily access such kind of information for French, there was no problem in creating these lexicons. Nevertheless, a small amount of post-processing of the lists was performed to remove entries that were ambiguous (for instance, *eau* (*water)* was listed as a pharmacologic substance) or too general (e.g. *"mal": pain*, *illness, disease,* in the signs and symptoms list); this should allow us to reduce over-extraction and thus increase precision.

Extraction rules

The extraction rules were designed using both the initial English rules and examples from the development corpus. For each item to be extracted (*i.e.* dosage, mode, frequency, duration and reason), regular expressions are applied in combination with a lexicon look-up. The list of abbreviations and expressions is used to detect dosage, mode, frequency and duration, while the purpose of the lexicon of signs and symptoms is to identify reasons. Examples of extraction rules are given in Table 2, where uppercase words represent semantic categories as obtained through lexicon lookup.

Table 2 – Example extraction rules (FREQ = frequency)

Rule	Sample matched phrase
[0-9]+[.,0-9]* DOSE	2,5mg
[0-9]+ DOSE [0-9]/[0-9]	2 cp 1/2 (*2 tabs 1/2*)
[0-9]+ FREQ / FREQ	3 fois / j (*3 times a day*)
[0-9]+ FREQ / [0-9]+	5 jours / 7 (*5 days out of 7*)
Pendant [0-9]+ DURATION	pendant 3 semaines (*for 3 weeks*)

These rules were either adapted from the English ones or rewritten based on the corpus study. The adaptation of the rules was often almost direct. For instance, the first rule of table 2 corresponds to the English rule *[0-9]+[.0-9]* DOSE*. In this case, a comma has simply been inserted in the expression since figures such as 2.5 are usually written as 2,5 in French. The last rule of Table 2 also shows a basic modification of the initial English rule *for [0-9]+ DURATION*: here, the English word *for* has been translated by the French word *pendant.*

The implementation of this French system was performed in a relatively short period of time: about 10 hours, of which approximately 1/3 was devoted to lexicon compilation and 2/3 to the adaptation and development of rules. Preparing the gold standard was comparatively a more time-consuming task (approximately 10 hours to annotate the 50 documents).

Evaluation

We evaluated our system against the test corpus, in terms of recall (the ratio between the number of correct extractions and the number of expected extractions), precision (the ratio between the number of correct extractions and the total number of extractions), and F-measure (the weighted harmonic mean of recall and precision, with a weight set to 1 to give recall and precision the same importance) computed at different levels: an horizontal level which assesses all information as a whole (drug names and their associated information) and specific levels (referred to as the vertical level) which evaluate each item separately (medication, dosage, frequency, mode, duration, reason), as per the i2b2 medication extraction guidelines.

Results

Table 3 shows that the F-measure is high on the horizontal level, as well as on the levels of medication, dosage, frequency and duration, but rather low for mode and reason.

[2]http://www.vidal.fr/fiches-medicaments
[3]http://www.eurekasante.fr/medicaments.html
[4]http://www.doctissimo.fr/html/medicaments/articles/medicaments_loupe.htm
[5]http://www.biam2.org/ (last update: May 2001).

Table 3 – Evaluation of French medication extraction (n = number of instances to be extracted, R = recall, P = precision, F = F-measure)

	n	R	P	F
Horizontal	257	0.839	0.896	0.867
Medication	257	0.887	0.934	0.910
Dosage	110	0.891	0.907	0.899
Mode	6	0.500	0.750	0.600
Frequency	122	0.795	0.858	0.825
Duration	4	0.750	0.750	0.750
Reason	23	0.391	0.563	0.462

Table 4 – Example extracted medications (an "nm" label is used when the information item is not mentioned in the text)

Original text	Extracted medication
nous conseillons donc la mise en place d'un traitement par Durogésic et débutons ce jour les patch de 25 µg/72 h *we thus advise treatment with Durogesic and start today patches of 25 µg/72h*	medication="durogésic" dose="25 µg" mode="patch" frequency="/72 h" duration="nm" reason="nm"
Paracétamol 1 g = x 4/j si douleur *Paracetamol 1g = x 4 a day if pain*	medication="paracétamol" dose="1 g" mode="nm" frequency="x 4/j" duration="nm" reason="douleur"

The results obtained by our localized French medication information extraction system are higher than those of the original English system[6]: at the horizontal level, we obtained an F-measure of 0.867 in French and of 0.773 in English. At the vertical level, medication name extraction yielded the best results for French (0.910) while it was only average for English (0.798). Dosage extraction also yielded much better results in French: 0.899 against 0.804 in English. Frequency detection was equally good for both systems (0.825 and 0.827). Reason extraction produced the worst results also for both systems: 0.462 in French and 0.299 in English (this was a common feature to all systems participating to the i2b2 challenge as well). There is a high difference in favour of the English system, however, regarding the extraction of the mode of administration: while it is the best type of information we extracted in English (F-measure of 0.836), we obtained a low F-measure in French (0.600). This difference is essentially due to the fact that there are very few occurrences of modes in the French corpus (only 6 occurrences over a total of 257 medication sets of information to extract).

Table 4 gives examples of medication information extracted by our system.

Discussion

Our system achieved good results for French, even higher than those of our initial English version. It should be noted, however, that this cannot constitute a fully accurate comparison between the two systems, mainly because we evaluate the French system on a much smaller reference corpus (annotating records is indeed time-consuming) than that used in the i2b2 challenge. It gives a fair indication, though, as to the quality of the system. Results are also close to existing systems working on English. Gold *et al.* [8], for instance, obtained a precision of 94.1% and a recall of 82.5%, and Xu *et al.* [9] reported F-measures over 93% for drug names, strengths, routes and frequencies. Our system is most comparable to these two works because we identify similar types of information. They do not extract, however, reasons for administration.

There is room for improvement, especially for the extraction of reasons. We mainly relied on proximity to associate signs and symptoms to prescriptions. However, more sophisticated Natural Language Processing modules, such as a part-of-speech tagger or a syntactic parser, could also be applied to the texts. Syntactically parsing the text is an interesting direction to investigate, as it would allow us, for instance, to identify prepositional and noun phrases and grammatical relations, which would be useful to link reasons to prescriptions more accurately. Another way to improve reason identification would be to rely on a knowledge base associating drug names with the symptoms they treat (*e.g. simvastatine* and *Zocor* for *hypercholestérolémie*). Based on this known association, if the reason *hypercholestérolémie* (or other signs or symptoms related to this one) is found in the neighborhood of *Zocor* or *simvastatine*, we could give it a more important weight: this might help improve the precision of reason detection.

Originally, the program was designed within the framework of the 2009 i2b2 challenge. Therefore, the pieces of information to extract are those defined in the challenge. We transposed our program from English to French using the same definition of the items to be extracted, namely the following six types of information: drug name, dosage, mode, frequency, duration and reason. However, when processing the corpus, we were confronted with the ambiguity of some types of information. *Dosage* refers both to the drug dose the patient has to take ("Previscan **1 cp** par jour": *Previscan **1 tab** a day*) and to the drug concentration ("Plavix **75 mg**"). Sometimes dose and concentration are both mentioned (e.g. "Levothyrox **150 µg 1 cp**": *Levothyrox **150 µg 1 tab***), in which case both pieces of information were extracted as dosage. It might be interesting, however, to separate them. Another ambiguity due to the chosen representation of information concerned *Frequency*: it can refer to the frequency with which the patient has to take the medicine ("Coversyl 8 mg**/jour**": *Coversyl 8*

[6]The English system was evaluated against a set of 256 annotated records. Those are the official results of the i2b2 challenge.

*mg **a day***) as well as to the time of day when the drug should be taken ("Symbicort 1 bouffée **matin et soir**": *Symbicort 1 puff **in the morning and in the evening***). In this last example, we can deduce the frequency from the time (2 times a day), but we cannot deduce the time from the frequency. Grouping information into one type makes identification easier, but it would also make sense to represent each type of information separately.

It could also be interesting to extract additional information related to medications. Useful information would be, for instance, *temporal markers (i.e.* is the time of medication administration in the past, in the present, or in the future?*), events* (*i.e.* is the medication being started, stopped, or continued?), and *certainty (i.e.* is the medication suggested or compulsory?). These were considered by the i2b2 challenge at first, but later dropped to simplify the task. An interesting direction for future work would be to process such information.

Finally, the current output representation is the exact strings of words found in the input texts. Further work will address normalizing these strings into canonical forms: *e.g.* unique identifier for each drug, unique preferred form for *tab* and *tablet*, etc.; a task similar to that described in [14]. This will enable us to merge them with coded data obtained from EHRs.

Conclusion

In this paper, we presented our experiments to localize an existing medication information extraction system from English to the French language. This localization kept the same target information items and semantic categories. It was based upon the compilation of French lexicons and the adaptation to French of the regular expressions used to extract the different items. This last part represents most of the work, since it implies re-writing a certain number of rules. Nevertheless, the work done for English gave us pointers to the types of rules to define, so that we believe our approach saved time compared to creating a system from scratch. Also, the French medical texts exhibited some similarity to the English texts, which made the transposition of some of the rules almost direct.

An evaluation of this localization over a corpus of 50 French EHRs provided better results than those obtained by the English systems at the i2b2 challenge.

This work shows that in the case of a specific sublanguage, that of prescriptions, the same approach can be successfully applied to two different languages, English and French.

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Text Mining approaches for Automated Literature Knowledge Extraction and Representation

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Abstract

Due to the overwhelming volume of published scientific papers, information tools for automated literature analysis are essential to support current biomedical research. We have developed a knowledge extraction tool to help researcher in discovering useful information which can support their reasoning process. The tool is composed of a search engine based on Text Mining and Natural Language Processing techniques, and an analysis module which process the search results in order to build annotation similarity networks. We tested our approach on the available knowledge about the genetic mechanism of cardiac diseases, where the target is to find both known and possible hypothetical relations between specific candidate genes and the trait of interest. We show that the system i) is able to effectively retrieve medical concepts and genes and ii) plays a relevant role assisting researchers in the formulation and evaluation of novel literature-based hypotheses.

Keywords:

Text Mining, Annotation networks, Gene ranking, Candidate gene study

Introduction

Current biomedical research is starting to increasingly rely on automated literature analysis. Text Mining (TM) and Natural Language Processing (NLP) provide algorithms and techniques for automated summarization and analysis of textual content, so that it is possible to extract and interpret the information contained in literature databases and repositories. This task is particularly important in the early stage of any study, when gathering the available knowledge about the problem of interest is crucial in formulation of initial hypotheses and planning of the next research tasks. Several TM systems exists which can help us expose relevant biomedical literature [1] in order to retrieve available knowledge which is relevant to user's interest, like finding all publications about a disease candidate gene. The challenge is to broaden and deepen this search to expose possible other useful information for proposal of novel hypotheses [1 - 3]. For instance, an added value could be the suggestion that the candidate gene is often related to another gene, which has not been previously considered.

We describe the tools that we are developing to provide such kind of support. In particular, we focused on genetic studies, in which a set of initial hypotheses of genes-disease association is made on some candidate genes, so that the first step is to explore the recent literature to confirm their possible role in the disease mechanism. We extracted the concepts of interest (genes and medical terms, like pathologies) using a structured knowledge base like Unified Medical Language System (UMLS), by which we derived genes/disease annotation. Then we implemented a similarity metric that is based on a relevance measure of the terms for each gene. In this way the approach identifies which terms are shared between genes. The results of such analysis can be summarized as a graph in which the proximity of the nodes reflect how tightly related are these terms according to the available literature.

We tested our tools for the INHERITANCE research project, which aims to translate basic knowledge of the aetiology and pathophysiology of genetic dilated cardiomyopathies (DCM) into routine clinical practice and to identify novel therapeutic strategies. We show how our automated literature analysis strategy was able to both correctly reconstruct the available knowledge and support researcher's new hypotheses formulation and evaluation.

Materials and Methods

The analysis method we propose aims at derive a literature-based gene annotation by extracting UMLS terms related to diseases from the abstracts of the publications referencing each gene. The overall analysis consists of 3 main steps:

- querying PubMed via Web Services to retrieve the most recent literature about specific genes/diseases
- automated extraction of concepts (genes/disease) from PubMed abstracts based on NLP techniques
- construction of annotation/co-citation networks to interpret available knowledge and suggest new hypotheses that can be tested.

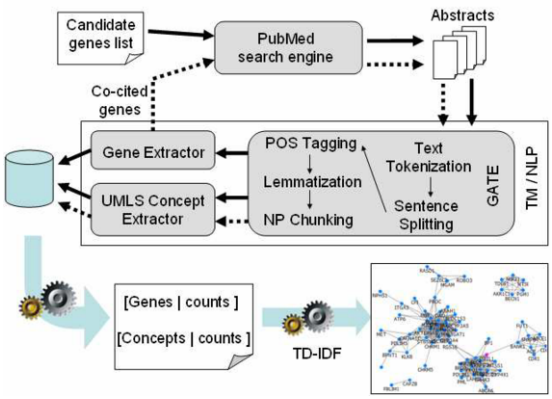

Figure 1 – Schematic representation of the analysis pipeline

The literature searching engine

The first module we developed is a searching engine which exploits the NCBI Web Service implementation of the Entrez Programming Utilities (EUtils) [4]. EUtils are software tools that provide access to Entrez data outside of the regular web query interface, in order to retrieve search results in another environments. In particular, the Web Service implementation, which enables developers to access Entrez Utilities via the Simple Object Access Protocol (SOAP). The modules query PubMed to retrieve scientific papers dealing with the genes of interest in XML format, so that their title and abstracts can be automatically processed and analyzed .

Abstracts text mining

The system is aimed at extracting both medical concepts (diseases, in particular) and genes, from titles and abstracts of articles obtained from PubMed databases. To work out this task, we have implemented a text extraction system that relies on a language processing environment called GATE [5]. The text analysis is handled through seven different steps, scheduled in a pipeline-like architecture. The first five steps are typical of many text mining systems and are in order: Text Tokenization, Sentence Splitting, Part Of Speech (POS) Tagging, Lemmatization and Noun-Phrase (NP) Chunking. The last two modules of the pipeline, i.e. the UMLS Concept Extractor and the Gene Extractor, have been designed specifically for our purposes.

The *Text Tokenizer* operates in two stages: the simple identification of parts of text separated by blank spaces and the management of the language-dependent exception to the basic rule.

The *Sentence Splitter* separates the sentences within the text. The so-called "ANNIE POS *Tagger*" module assigns each previously identified token to the grammatical class (POS) that it belongs to. The *Lemmatizer* derives the lemma belonging to every token. The *Noun-Phrase-Chunker* is aimed at identifying noun phrases (NP) within the text. The NP identification has proven its usefulness in many text mining tasks, because most searched concepts are contained in NPs [6].

The *UMLS Concept Extractor* module accomplishes the task of extracting medical concepts from the text. It relies on the resources available within the Unified Medical Language System (UMLS) [8], one of the National Library of Medicine (NLM) projects. In particular we exploited the UMLS Metathesaurus, a large database containing health-related concepts coming from many different source vocabularies. Among the different sources, our systems relies on the main ones: MTH (the official vocabulary of the Metathesaurus) and MSH (Medical Subject Headings), both provided by the NLM [9]. The module starts its analysis generating a set with all the possible substrings of each noun phrase in the document. For each token contained in the noun phrase those substrings are generated considering the token itself and its lemma. At this point the module sends a query to the database storing the concepts for each string. When a positive matching arises, the system makes another query aimed at identifying the official name of the found concept and creates a new annotation on the document.

Finally, the *Gene Extractor* finds the genes names present in the analyzed text. The identification is related to the whole abstract document, as the exact position of the name in the phrase is not what we are seeking. As well as the UMLS Concept Extractor, also the Gene Extractor relies on a database, which is directly derived from the Entrez Gene NCBI's database [10] (we consider human genes only). The module starts evaluating each token found by the Text Tokenizer in order to discard strings which do not fit with a standard gene representation (for example a string candidate to represent a gene must have almost one capitalized letter and can't be composed only by digits). Once the set of candidate strings is defined the Gene Extractor sends a first query to the database for each string, trying to find the string between all official genes names and their synonyms. When a match with an entry is found, a second query is sent in order to find out the official name of the gene previously identified.

Once that articles titles and abstracts have been retrieved for each candidate gene contained in the initial set (11 and 18 genes for Hypertrophic Cardiomyopathy and Dilated Cardiomyopathy respectively, see Results section for more details), these textual resources pass through the text mining pipeline just described. The analysis is therefore the same for titles and abstracts, but the results are kept separate in order to preserve the possibility of a further separate management of the results. From the first set of abstracts analysis, the system exploits the output of the Gene Extractor in order to build a new, larger, set of co-cited genes which are cited together with the first candidate ones. Then, for each gene of this augmented set, we retrieve articles titles and abstract from PubMed; all of these textual resources pass again through the analysis pipeline, now

ending with the UMLS Concept Extractor. By now the system is able to associate an array to each gene belonging to the larger set. The array contains the name of the diseases cited in the articles titles and abstract relative to the gene and, for every disease, the number of citation occurrences. At this point all the arrays are passed to the annotation measure and analysis module described in the next section.

Annotation networks

Our final aim is to derive a literature-based gene annotation by extracting UMLS terms related to diseases from the abstracts and the titles of the publications referencing each gene. Information about each gene in our study can be therefore represented by a gene annotation profile *A*, composed by a set of UMLS terms indicating diseases or symptoms and the counts of their occurrences in PubMed entries.

Formally, for the g^{th} gene, A_g is a feature vector which contains a set of tuples $a_{gj} = \{t_{gj}, f_{gj}\}$, with t_{gj} being the annotation term (i.e., a UMLS term) and f_{gj} the frequency the term appears in the annotation (i.e., the total number of times that the UMLS term t_{gj} is included in the papers citing gene *g*, with *j* ranging from 1 to the number of annotation terms found to be relevant for gene *g*). To expose the important terms for each gene, we applied a TF-IDF (Term-Frequency Inverse Document Frequency) transformation. TF-IDF is a popular technique used in Vector Space Model approaches [11] for the preprocessing of textual documents. Within this model, documents are represented by vector of features where each term is weighted according to its importance in the document. For a term *t* found in a document *d* of a document corpus *D*, the TF-IDF weight is computed as:

$$TF - IDF(t,d) = TF(t,d) * IDF(t) \tag{1}$$

where TF(*t*,*d*) is the term frequency in the document *d*, and IDF(*t*) is defined as:

$$IDF(t) = \log\left(\frac{|D|}{DF(t)}\right) \tag{2}$$

where |*D*| is the number of documents in the document corpus and DF(*t*) the number of times a term *t* appears in all documents.

Since we represent a gene by a vector of UMLS terms, the documents correspond in our case to genes and |*D*| is the total number of genes. As a result of this weighting scheme, a term indicating a disease is considered as an important annotation for a gene if it occurs frequently in the publications related to that gene. On the other hand, terms about diseases or symptoms that are not specific for a gene are rated as less important due to their low IDF. The weighted annotation profiles were then normalized.

One of our purposes was to test if the proposed gene annotation method is able to find groups of similarly annotated genes that are in fact known to be similar as they play an important role in the same disease. In addition, we aimed to find other genes related to cardiomyopathies. For these reasons, we needed a similarity measure that reflected the degree of gene similarity in terms of their feature terms and weights. To compute the similarity between the annotation profiles of two genes *g1* and *g2*, we resorted to the cosine similarity between the TF-IDF vectors W_g as follows:

$$sim(g_1, g_2) = \frac{W_{g1} \cdot W_{g2}}{\|W_{g1}\| * \|W_{g2}\|} \tag{3}$$

A similarity of 1 means that g1 and g2 have exactly the same terms and weights, while a cosine value of zero means that the two annotation vectors are orthogonal and had no match. To have a graphical visualization of the groups of similarly annotated genes we created gene association networks, where the genes are the nodes of a network and they are linked if their similarity is greater then a threshold (in our case set to 0.7).

The information coming from our literature-based annotation was used to build three types of gene annotation profiles: i) *Titles*, including for each gene only the terms extracted from the titles of the gene-related PubMed entries; ii) *Abstracts*, including only the terms extracted from the abstracts of the publications. iii) *Titles+Abstracts*, obtained by including all the terms from Titles and Abstracts and for each of them adding the corresponding weights resulting from TF-IDF.

Finally, we developed a Python procedure to process the gene annotation profiles, to evaluate the pair wise similarities and to create network files in a standard format. A network has been created for each of the annotations (Titles, Abstracts, Titles+Abstracts). The networks were visualized using an interactive network exploration module provided by the software Orange [12]. Giving information about gene names and attributes to this software, it is possible to show gene symbols next to each node, underline the genes of interest and make a zoom on a specific region. The software allows the selection of some nodes of interest (in our case the genes related to cardiomyopathies and their annotation-similar genes) in order to visualize their attributes. Giving as input data the weighted annotation vectors to Orange, we were also able to visualize in a table (see Figure 2 in Results section) the terms rated by TF-IDF scheme as the most important terms for our genes of interest and for their annotation-neighbors.

Results

We tested the strategy and tools described above to analyze data concerning Hypertrophic Cardiomiopathy (HCM) and Dilated Cardiomiopathy (DCM), which are the pathologies being studied in the Inheritance Project. HCM and inherited DCM are most commonly transmitted as an autosomal dominant traits is and they have been associated to mutations in a number of genes that encode for one of the sarcomere proteins. 11 loci (relative to genes *TNNT2*, *TTN*, *MYBPC3*, *ACTC*, *TPM1*, *MYH7*, *MYH6*, *MYL2*, *MYL3*, *TNNC1*, *TNNI3*) are known to be associated to HCM and 18 associated to DCM (*TNNT2*, *TTN*, *MYBPC3*, *ACTC*, *TPM1*, *MYH7*, which are the same as for HCM, together with *ABCC9*, *CLP*, *CTF1*, *DES*, *DMD*, *DSP*, *LDB3*, *LMNA*, *MVCL*, *PLN*, *SGCD*, *TAZ*) [13]. We used the two lists as starting set of candidate genes that we

want to investigate[1]. Through the search engine and the extractors modules we retrieved 1409 concepts and 866 other genes that are co-cited in the 30 most recent abstracts dealing with each of those initial genes and the 15 most recent abstracts for each of the other genes. For brevity, here we present and discuss the results of the Titles+Abstracts analysis, as it is the more informative combination we obtained[2]. The computed networks involve a great number of genes and other medical terms which are cited together with the initial ones, as well as all genes/medical terms related to the derived genes. Thus, we identified the spatial distribution of the initial sets, which have been highlighted in different colors: blue nodes are the six common associated genes, the orange ones are HMC related genes, the pink ones are the DCM related genes and the green filled ones are genes not mentioned in the known list but with an high co-citation index with the term "cardiomyopathy" (Figure 2).

TNNT2	**Hypertrophic Cardiomyopathy** - Hyperostosis, Diffuse Idiopathic Skeletal - **Cardiomyopathy, Dilated**
TTN	Respiratory Distress Syndrome - **Hypertrophic Cardiomyopathy** - **Cardiomyopathy, Dilated**
MYBPC3	**Hypertrophic Cardiomyopathy** - **Cardiomyopathies** - Heart failure
ACTC	**Hypertrophic Cardiomyopathy** - **Cardiomyopathies** - **Cardiomyopathy, Dilated**
TPM1	**Hypertrophic Cardiomyopathy** - **Cardiomyopathy, Dilated** - Exanthema
MYH7	**Hypertrophic Cardiomyopathy** - Myopathy – **Cardiomyopathy, Hypertrophic, Familial**
PRKAG2	**Cardiomyopathies** - Ischemia - **Hypertrophic Cardiomyopathy**
ANKRD1	Myopathy - Muscular Dystrophy - **Cardiomyopathy, Dilated**
TCAP	Muscular Dystrophy – Myocarditis - **Cardiomyopathy, Dilated**
PPIF	Muscular Dystrophy – Swelling - **Cardiomyopathy, Dilated**
...	...

Figure 2 – Most important terms for some of the genes of interest and for their annotation-neighbors

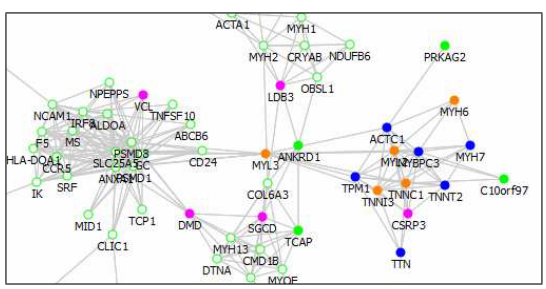

Figure 3 – Zoom on the HCM network . Blue nodes are the six common associated genes, orange nodes are HMC-related genes, pink-nodes are DCM related genes and the green-filled nodes are genes highly co-cited with the term cardiomyopathy

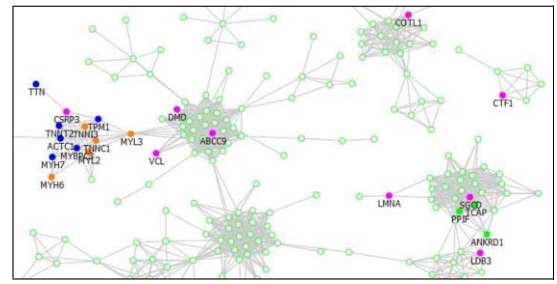

Figure 4 - Zoom on the DCM network

Figure 3 shows a snapshot of the region including the labeled genes for the network computed starting from the HCM related genes, while Figure 4 shows labeled genes for the network computed starting from the DCM related genes. Both of them are discussed in the next session.

Discussion

In this study we exploited the available knowledge about the genes which are known to be associated with the trait i) in order to perform an internal validation of the knowledge extraction capability of our tools, and ii) as a "background" to which new hypotheses of association can be compared.

In the first case, the results shown in the previous section confirm that the annotation networks built with our approach are able to reconstruct the existing knowledge, as the genes involved in cardiomyopathy are always clustered together. In particular, the six core genes (labeled with blue nodes in the figures) are always tightly connected, and the other genes related to HCM (highlighted in orange) always belong to the same clusters. This result gives a sufficient confidence that the algorithms have been properly set up to be able to extract evidence that we already know to be true. Similarly, networks show how the genes specifically related to DCM are on the contrary not so strictly linked to the HMC genes cluster, but they tend to be more scattered away from it. This also reflects the fact that current knowledge does not allow differentiating treatments on the basis of the different subtypes of DCM. Medical and interventional treatment strategies for DCM coincide with those optimised and indicated in the guidelines of scientific societies for HCM, congestive heart failure and atrial or ventricular arrhythmias or conduction disease. On the other end, the spatial distribution confirms the researcher hypotheses that DCM genetic mechanisms should be quite different from HCM ones.

Finally there are also some genes (green-labeled in figures) which are closely connected to the other known genes. Then, as the consideration made above gives us a good confidence

[1] Our elaboration took into account also synonyms of the gene names reported in [13]. In particular, our figures use ACTC1 for ACTC, COTL1 for CLP and VCL for MVCL.

[2] Titles are too shorts, and lead to very low connected network; however we kept the importance of the presence of a gene name or medical term in the title to strengthen Abstract-only results

that the literature analysis can properly extract knowledge, the new genes (green-filled nodes) related to the known ones may be interpreted as new candidate genes which could be further investigated.

Conclusion

In this paper we described a method for automated analysis of scientific literature. The tool is based on presentation of concepts in the association network, where concepts are related with respect to their similarity manuscript annotations in the most recent publications. We show how we can effectively retrieve medical concepts and a list of problem-related genes using this tool, which can play a substantial role in assisting researchers in the formulation and evaluation of literature-based novel hypotheses.

Our analysis investigates the data on the most recent published manuscripts, because the main interest is on the new findings, which have not yet been included in secondary databases that keep track of validated biological associations (e.g. OMIM, GAD, etc). The results depend on the abstracts content specificity. Our case study showed that the graphical representation can greatly facilitate results inspection, and the network tool is completely integrated with a data mining suite which provide a variety of other modules that can be used for further investigation of the subset of interesting genes.

The text mining process is comparable with the many already available tools, and a performance evaluation and comparison in term of precision and recall over a significant dataset is still ongoing. Nevertheless, our systems presents some peculiarities: i) the knowledge base on which the term recognition relies consists in whole terminological databases, while in general other systems use ad-hoc and manually cured collection of terms (moreover, this gives the system a greater modularity and scalability); ii) the similarity networks are based on a *weighted* measure of term's importance for a gene, and iii) the networks are able both to represent the current knowledge and to guide the hypothesis generation process.

The main assumption underlying the interpretation of the annotation similarity networks is that they associate concepts that are often referred to in the same manuscript and for this reason may have similar manuscript-based annotations. Notice that this does not (necessarily) correspond to a statistical or biological association between genes and diseases, but may nevertheless suggest a possible relation.

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Performance Analysis of a POS Tagger applied to Discharge Summaries in Portuguese

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Abstract

Part of speech taggers need a considerable amount of data to train their models. Such data is not readily available for medical texts in Portuguese. We evaluated the accuracy of a morphological tagger against a gold standard when trained with corpora of different sizes and domains. Accuracy was the highest with a medical corpus during the complete training process, achieving 91.5%. Training on a newswire corpus achieved 75.3% only. Furthermore, an active learning technique has been adapted to the POS tagging task. The algorithm uses a POS tagger committee to isolate the sentences with the highest disagreement indexes for manual correction. However, the method was not able to reduce training and tagging times when compared to a random selection strategy. We encourage that future works employ some effort in order to annotate a small amount of random data in the domain of study, which should be enough for higher accuracy rates.

Keywords:

Medical records, Natural language processing, Part of speech tagging.

Introduction

Natural language processing (NLP) has been studied and applied on a broad range of domains and languages across the world. An important use case is the automatic mapping of narrative EHR content to biomedical terminologies such as SNOMED CT [1], which provides the basis of clinical decision support systems. NLP tools are used for sentence and token boundary detection, acronym recognition and expansion and syntactical analysis of sentences. POS tagging is essential in this process to identify each token part of speech class and to assign the corresponding tag (e.g., V for verb, ADJ for adjective, etc.) to the term. This task can easily be addressed by a set of language-independent tools publicly available via the internet. These tools need only to be trained on a previously tagged corpus in order to build a language-dependent model.

English medical corpora are widely available, but Portuguese corpora are less common. Although pilot projects (like the one conducted by the Interinstitutional Center for Research and Development in Computational Linguistics in São Paulo University [2]) built tagged newswire corpora, the usage viability of these models on different domain, e.g. medicine, is still under discussion.

Hahn and Wermter [3] assessed the performance of POS taggers trained on the NEGRA corpus of German newspaper texts when applied on a German database of medical documents called FRAMED. They concluded, "POS taggers cannot only be immediately reused for medical NLP, but they also — when trained on medical corpora — achieve a higher performance level than for the newspaper genre".

However, they also cite the work of Campbell and Johnson [4], which came to an opposite conclusion: POS taggers trained on newspaper data cannot be used on the medical domain without a new training process on a medical corpus.

In this paper, we want to give our own answer to this question, focusing on discharge summaries written in Portuguese, which is the focus of our main project. We also evaluated an active learning approach to accelerate the construction of a gold standard for the medical domain.

Materials and Methods

Newspaper and Medical Corpora

We used both a newspaper and a medical corpus in order to study this question. The newspaper corpus, named *MAC-Morpho*, is a compilation of 1,167,183 texts published in the *Folha de São Paulo* newspaper during the year of 1994. The corpus was compiled by the *Lácio-Web* [2] project from NILC-USP.

The medical corpus contains two collections of discharge summaries from the Clinical Hospital of Porto Alegre, Brazil. 2,453 discharge summaries cover the whole range of clinical specialties during one month (June 2007) and 5,617 discharge summaries were taken from the cardiologic department, covering a time span between June 2002 and May 2007. The corpus has been obtained from a partnership program between the Pontifical Catholic University of Paraná and the Federal University of Porto Alegre and has not been made publicly available due to privacy concerns.

In order to minimize efforts and keep compatibility between the corpora, we used only a fraction of the entire corpus. Lezius [5] argued that many German taggers were successfully

trained on corpora variable from 20,000 (more common) to 200,000 (rarer) tokens. Based on that, we used a fraction of randomly acquired 120,000 tokens from each corpus.

We then extracted one out of ten sentences available in the corpora to produce a gold standard for each domain. After that, we collected some statistics from the final corpora, which we show on Table 1.

Table 1 - Corpora sizes

Corpus	Corpus Fraction	Sentences	Tokens
Newspaper	Gold	495	13,810
	Training	4,533	123,019
Medical	Gold	595	12,451
	Training	5,964	123,018

In the next step, we evaluated the newspaper and medical models on the medical gold standard over a set of iterations where training corpus size was continually increased.

Active Learning Strategy

We further analyzed an active learning strategy proposed by [6] to build a tagged medical corpus in Portuguese. The active learning approach, commonly applied during the training process of syntactical classifiers, is used there as a method for corpus construction. In our work, we employed a *committee-based* approach, which uses a committee of POS taggers to select the sentences with the highest disagreement indexes and thus indicate priority in manual correction.

In order to accomplish that goal, we first calculated the *sentence disagreement index* $D_{sent}(s)$ for each sentence without manual correction on a given iteration. That index equals to the average of the *token disagreement indexes* $D_{tok}(t)$ seen on a sentence. Ranged 0 to 1, those indexes show how inconsistent are the results of a tagger committee on a token or on a sentence view. Equations 1 and 2 were proposed by [7] and show those relations mathematically using a measure called *vote entropy*. Here, $\frac{V(l_i,t)}{k}$ is the ratio of k taggers that gave the tag l_i to a token t and $|s|$ is the sentence size.

$$D_{tok}(t) := -\frac{1}{\log k}\sum_{l_i}\frac{V(l_i,k)}{k}\log\frac{V(l_i,k)}{k} \quad (1)$$

$$D_{sent}(s) := \sum_{j=1}^{|s|}\frac{D_{tok}(t_j)}{|s|} \quad (2)$$

We created an *OpenNLP* [8] model for each training iteration and evaluated it on a gold standard that has been previously tagged, revised by domain specialists and isolated from the training corpus. We stored the measured accuracy and an average of $D_{sent}(s)$ indexes observed on the non-revised sentences in a relational database. We also stored the number of tokens that had been manually corrected for graphical analysis.

We ran the entire procedure three times, one for each methodological direction: (a) heterogeneous tagger committee, (b) homogeneous committee, and (c) homogeneous committee with optimal initial set. The use of different approaches aims at reducing errors due to a set of distinct taggers (approach b) and a non-optimal initial set of sentences (approach c).

In the first approach (a), we used a heterogeneous committee that combines a rule-based tagger (*Brill Tagger*) with four statistical taggers (*OpenNLP*, *MXPOST*, *TreeTagger* and *QTag*). Performance has been evaluated based on the model created for *OpenNLP*, which is the tool used in our other projects. We chose the initial collection of sentences randomly.

In the second approach (b), we applied a homogeneous committee composed of *OpenNLP* tagger trained on five different subsets of data. Nevertheless, we measured accuracy based on a model trained on all data available per iteration. The initial set was randomly chosen as in the first approach.

Finally, in the third approach (c) we also employed selection by homogeneous committee, but with an optimal non-real initial set. We chose the best sentences for training based on a model trained on data available on the entire corpus. The aim of this approach is to test the hypothesis that the initial set of sentences influences all subsequent iterations.

Results

Newspaper and Medical Corpora

Figure 1 shows *OpenNLP* accuracy evaluated on the medical gold standard according to the number of tokens used in the training process. The red and the blue lines express the results for the medical and the newspaper corpus used for training, respectively.

Active Learning Strategy

Similarly, Figure 2 shows *OpenNLP* accuracy for different training set sizes. Now, however, we compare active learning strategy (red line) with a simple strategy, like random selection (blue line). In both cases, the gold standard and the training corpus belong to the medical corpora.

Figure 3 shows the $D_{sent}(s)$ average observed in the subset of non-trained sentences for the heterogeneous committee-based approach. As in Figure 2, blue and red lines express, respectively, the active learning and random selection strategies. Flattening seen on the line beginning convey the need of a minimal amount of data to correctly train the taggers. Additionally, the abrupt dip in the end indicates process conclusion, when there were no more sentences available for training.

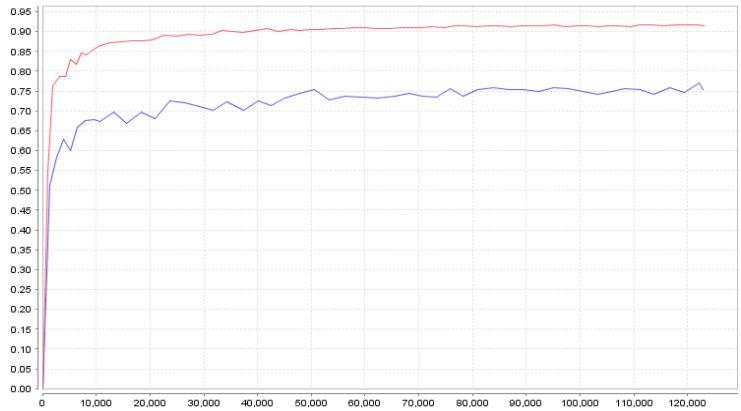

Figure 1 - Learning curves on the newspaper corpus (blue line) and on the medical corpus (red line), evaluated on medical data.

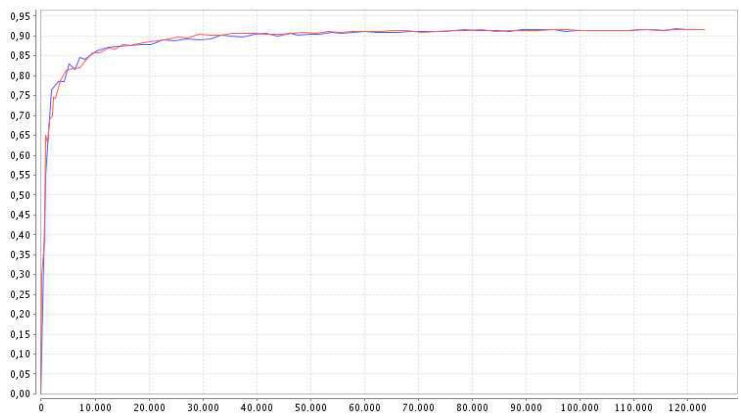

Figure 2 – Learning curves of active learning-based selection (red line) and random selection (blue line), trained and evaluated on medical data.

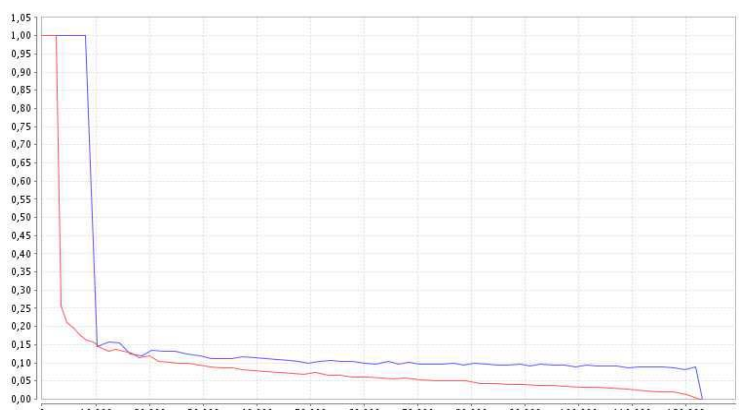

Figure 3 - Sentence disagreement index for active learning-based selection (red line) and random selection (blue line).

Discussion

When testing different approaches for active learning as proposed above (see "Materials and Methods"), we found similar results to those presented before. We then realized that active learning strategy should be adapted for POS tagging task in order to significantly reduce the manual tagging effort.

However, our results lack some statistical rigor. For example, a more precise result would have been found if we had run the random selection process at least three times. Nevertheless, our experience shows that data would have been similar and would not have affected conclusions presented here.

Despite that, a rigorous study would require the same initial set for random and active learning selections. The initial set influence was tested as described in the third approach presented above. We found that even an optimal initial set did not produce better active learning results.

Nonetheless, we could have tested other methodological approaches. The first one would be plotting learning curves as a function of number of sentences, not tokens. The second one would use 3/4 of the data available per iteration for the training process of each tagger, as proposed by [9]. Anyway, based on our experiments, we are certain that those variations would not considerably affect the conclusions of our work.

Conclusion

Our work confirm Campbell and Johnson [4] results: taggers trained on newspaper data cannot be readily used to tag medical data. At least in Portuguese, an *OpenNLP* model trained on a collection of 4,533 sentences (123,019 tokens), randomly chosen from the *MAC-Morpho* corpus of Brazilian newspaper, tags correctly only 75,3% of tokens from a collection of 595 sentences (12,451 tokens) arbitrarily chosen from a corpus of discharge summaries in Portuguese.

Comparing *OpenNLP* learning curves in the newspaper and in the medical corpus, we noted that newspaper data is more heterogeneous and more grammatically complex than medical data. Not only is the learning process in newspaper data slower and more sinuous than on medical data, but also the sentences are longer on that domain.

Considering that accuracy rates around 96.4% are expected [10], we encourage a domain-specific corpus to be build. However, our implementation of the active learning strategy for corpus construction [6] reached different results. We could not reduce manual correction effort by means of active learning when compared to a simple strategy like random selection.

Settles and Craven [11] reported similar results on a larger study with eight corpora from different domains. They realized that *vote entropy* is biased toward querying shorter sentences, which in our work showed as little or no value.

Our work showed additionally that manual tagging of around 30,000 tokens is enough to build a probabilistic POS tagger that accounts for an accuracy of 90% in the medical domain in Portuguese. Using a four times bigger sample, the tagger reached an accuracy index of 91.5%, which assures *OpenNLP*'s feasibility to annotate Brazilian hospital discharge summaries with POS tags.

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Identification of relations between risk factors and their pathologies or health conditions by mining scientific literature

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Abstract

Risk factors discovery and prevention is an active research field within the biomedical domain. Despite abundant existing information on risk factors, as found in bibliographical databases or on several websites, accessing this information may be difficult. Methods from Natural Language Processing and Information Extraction can be helpful to access it more easily. Specifically, we show a procedure for analyzing massive amounts of scientific literature and for detecting linguistically marked associations between pathologies and risk factors. This approach allowed us to extract over 22,000 risk factors and associated pathologies. The performed evaluations pointed out that (1) over 88% of risk factors for coronary heart disease are correct, (2) associated pathologies, when they could be compared to MeSH indexing, are correct in about 70%, and (3) in existing terminologies links between risk factors and their pathologies are seldom recorded.

Keywords:

Natural language processing, Semantics, Medical informatics, Risk factors, Public health informatics, Terminology.

Introduction

Risk factors jointly refer to behaviors, environmental conditions, diseases or genetic backgrounds – considered in an ample way – that actually increase people's chance of manifesting a given disease. Discovering risk factors to design prevention strategies is an important biomedical challenge. Indeed, it is an active research field, with major contributors coming from biology, epidemiology and public health programs. Within these programs, research proposes statistical studies of large populations in order to reveal risk factors for many health conditions and pathologies (*i.e.* cardiovascular diseases [1, 2], hypertension [3], atherosclerosis [4, 5], cancers [6, 7], mortality within older people population [8-10], to cite but a few). Despite this extensive activity, traditional risk factors for coronary heart disease for instance actually account for only 50% of the risk [11]. For biomedical professionals, this research assumes pushing back the frontiers of medicine and biology. Learning about risk factors not only benefits preventive healthcare; it may directly impact on patients. Indeed, accumulated and organized clinical knowledge may help counteracting disease progression, hence improving life quality in patients. The last few years have seen the proliferation of websites intended to centralize and organize widely scattered medical and healthcare information. A major concern of health information collected from the Internet, is the very quality of the data [12-14]. The Medline database [15] provides biomedical researchers/practitioners with instant access to extensive and high quality scientific literature. Yet, the huge amount of indexed peer-reviewed articles, currently over 18 million, hinders reliably sampling and selecting all relevant papers. Our central goal is to exploit the Medline repository and to extract risk factors and their associations to health conditions.

Background

Currently, genetic and medical information in bioscience papers is often exploited in a manual, expert fashion. Hence, increasing attention is being paid to the automation of natural language processing (NLP) and information extraction (IE) in biological and medical realms, as testified by the BioCreAtIvE[1] and TREC Genomics[2] challenges dedicated to extraction of gene and protein names, their interactions and functions from biomedical literature; or by I2B2 challenges[3] dedicated to extraction of various kinds of information (i.e., smoking status, signs and symptoms, medication) from clinical records. However, to our knowledge, little work has focused on risk factor extraction.

As a matter of fact, existing approaches for risk factors study are mainly issued from the data mining area. Thus, an important issue faced by these works is the large number of variables to be considered [10]: indeed, current state-of-the-art statistical algorithms are often unable to manage them. For example, data

[1] biocreative.sourceforge.net
[2] ir.ohsu.edu/genomics
[3] www.i2b2.org/NLP

mining methods have been applied to ICD-9 codes to predict groups of people with similar risk factors [16], or to data from insurance companies to get estimators of claim costs [17]. Let us mention also a KDD challenge[4] held in 2004 which addressed data mining in biomedicine, albeit confined to social subgroups of patients, the main goal being to identify atherosclerosis risk factors (and their combinations) and to monitor the evolution of these risk factors as well as their impacts [18].

A rare work related to the processing of narrative biomedical literature [19] combines manual and automatic meta-analysis-like methods for extracting facts on risk factors related to breast cancer. Findings are consistent with published studies: there is a positive association with alcohol consumption, but a negative association with former smoking.

In this paper, we attempt taking a further step from the above-mentioned approaches. Our objectives are massive extraction of risk factors from available literature and establishing their relation(s) to the corresponding pathologies. Also, this will allow providing comprehensive information on risk factors, which seems to be a missing resource currently.

Material and Methods

Material

Bibliographical database Medline

Our rough working material is Medline database, which currently hosts over 18 million citations - mainly from life sciences and biomedical research. We exploit the totality of these data, focusing on titles, abstracts and *MeSH* indexing within each citation.

Bibliographical database Medline

MeSH [20] thesaurus has been created for information storage and retrieval, and is currently used for indexing Medline database. Its descriptors are organized in a hierarchical structure, whose most general level are very broad headings such as A *Anatomy*, C *Diseases*, L *Information Science*, F *Psychiatry and Psychology*, etc., with 16 such headings in total. Within *MeSH*, we exploit headings and their notations, and thus can rely on their semantic types.

Snomed CT

Snomed CT [21] is another terminological resource of the biomedical area. The goal of the *Snomed CT* nomenclature is to provide a conceptual basis for organizing and, more particularly, for exchanging clinical data. This is a multiaxial terminology. Its terms are organized within 15 hierarchies, such as: *Clinical finding/disorder*, *Procedure/intervention*, *Environment or geographical location*, *Social context*, *Organism*, *Substance*, *Pharmaceutical/biologic product*, etc. *Snomed CT* terms are structured within a dense network of semantic relationships belonging to synonymy, hierarchy, or transversal relationchips. Among this last category, we distinguished three more precise relationships, which in our opinion may be linked with the risk factor notion: has causative agent, due to and associated with. Thus, associated with represents a clinically relevant association between concepts without either asserting or excluding a causal or sequential relationship between the two, while due to is used to relate a clinical finding directly to its cause. In this example from *Snomed CT*: *acute pancreatitis due to infection* is a *acute pancreatitis* due to *infectious disease*, infectious disease belongs to the causative agent axis and allows to identify a direct cause of a disease. Other *Snomed CT* examples state that: (1) *bacterial endocarditis* has causative agent *bacterium*; and that *fentanyl allergy* has causative agent *fentanyl*. Within *Snomed CT* we exploit these three relationships which, as far as we know, may correspond to the only resource providing an explicit and controlled information on risk factors and associated health conditions.

Methods

Bibliographical database Medline

The aim of the preprocessing step is to annotate Medline citations with linguistic information and to prepare the step of information extraction task (identification of risk factors, of pathologies and of relations between them). We use the Ogmios platform [22], suitable for the processing of large amounts of data and tunable to specialized areas. The following tasks are performed through the platform: segmentation into words and sentences, POS-tagging and lemmatization with the Genia tagger [23], term extraction and recognition[5]. These tasks, and especially the term extraction task, are performed in order to correctly tokenize and identify textual units relevant to the searched information. Thus, the next step of information extraction is performed on POS-tagged, lemmatized and term-tagged text.

Information extraction

The proposed method is designed for accessing several types of information within Medline citations. First, we aim at detecting and extracting risk factors, and as a matter of fact, this implies dealing with specific syntactic structures, such as coordination and enumeration. In the following examples, risk factors are underlined, related pathologies and health conditions are in bold, and pattern-related elements in normal font letters:

1. Risk factors for ***survival*** were *age* and *severity of aortic stenosis* ... (PMID 8705769)
2. ...a *high intake of calcium* and *phosphorus* is a risk factor for the ***development of metabolic acidosis***. (PMID 1435825)
3. ...had more than one of the common risk factors for ***cerebrovascular accidents***, including *hypertension*, *advanced age*, *hyperfibrinogenemia*, *diabetes mellitus*, and *past history of cerebrovascular accident*. (PMID 1560589)

We process such syntactic structures with specifically designed syntactic patterns, where the trigger is a mention of *risk*

[4] lisp.vse.cz/challenge

[5] search.cpan.org/~thhamon/Lingua-YaTeA

factor and the enumeration sequence (punctuation and coordination conjunctions).

Another aspect of the information extraction task consists into establishing an explicit link between risk factors and the corresponding pathologies and health conditions. We propose to use two sources for accessing such information:

- Information extracted from abstracts and titles. In this case, this information is accessed through another set of dedicated lexico-syntactic patterns, such as *risk factors for* in the previous examples.
- *MeSH* descriptors provided by the Medline indexing. In this case, we analyze all the descriptors associated to a given citation, we then match them to the *MeSH* thesaurus and select only those which belong to the heading of diseases *C*.

Evaluation

We have to evaluate various aspects of the obtained results. Our main concern is the quality of extracted information for both risk factors and associated pathologies. We propose to tackle this as follows: (1) For a given pathology, we evaluate quality and exhaustiveness of the extracted risk factors. (2) As, for certain risk factors, we have at our disposal the associated pathologies provided by two sources (information extraction and *MeSH* indexing), we propose to compare these two pathology-related data. (3) Finally, we take advantage of the causal and associative relations encoded within *Snomed CT* and compare them with the information extracted from Medline titles and abstracts. We compute the precision, i.e. ratio of correct extractions among all the results relevant to a given evaluation. All these evaluations are performed manually, as no dedicated and comprehensive gold standard is available.

Results and Discussion

Building and preparing the material

Within the Medline database, we selected those citations which contain singular or plural forms of the terms *risk factor* and *factor of risk* in abstracts or titles. This allows to reduce the whole Medline material to a reliable and homogenous subset of citations. The resulting corpus contains 187,544 citations (over 42 M word occurrences). This corpus of Medline citations have been processed through the Ogmios platform. *Snomed CT* tables were accessed through the UMLS resource [24] version 2008AB, and we could extract 154,130 pairs of registered relations between a pathology and its causative agent or another pathology. 92,807 of these relations are provided by has causative agent, 25,309 by due to and 36,134 by associated with relationships. 120 of these relations are provided by more then one relationship within *Snomed CT*.

Extraction of information on risk factors and pathologies

Patterns for information extraction from abstracts and titles were built manually on few positive examples, and then generalized and applied on the whole set of data. We distinguish three kinds of patterns (in the examples below, **<NP-RF>** indicates noun phrases corresponding to risk factors, **<NP-P>** to pathologies, ? and * for optional and recurrent elements):

1. Patterns for extracting risk factors and pathologies (n=5). This example of pattern: **<NP-RF> as a risk factor for <NP-P>** allows to discriminate this sentence: *Hypocalcemia at parturition as a risk factor for left displacement of the abomasum in dairy cows,* and to propose that *hypocalcemia* is a risk factor of *displacement of the abomasum*.
2. Patterns for extracting risk factors (n=12), among which we have a pattern for enumeration: (other)? risk factors? including **<NP-RF>(, <NP-RF>)* ((,)? and <NP-RF>)?** . From the sentence *The relationships between impaired fasting glucose, other risk factors including blood pressure, and mortality have never been clearly investigated* it extracts that *blood pressure* and *mortality* are risk factors.
3. Patterns for extracting pathologies (n=3), among which **(potential)? risk factors? for <NP-P>**, which detects in the sentence *A risk factor for poor pregnancy outcome, a population-based screening study* the health condition *poor pregnancy outcome*.

In order to get complete information on associations between risk factors and pathologies, elements extracted by patterns (2) and (3) are combined. In this way, we assume that each citation corresponds to a semantically coherent unit and that elements from its different sentences are strongly related between them. These patterns allowed us to extract information from 10,445 PMIDs. Pattern (1) extracted 313 pairs {*risk factor*; *pathology*}. Combination of patterns (2) and (3) provided 15,398 pairs more. Finally, 5,873 risk factors extracted by pattern (2) could not be associated with any pathology within abstract or title. *MeSH* indexing was analyzed and allowed us to extract 5,106 different pathologies and health conditions within the axis C related to diseases. Exploitation of the proposed approach generates triplets {*risk factor*, $pathology_{text}$, $pathology_{MeSH}$}, where the first element is always informed, the two other elements may remain empty.

We extracted 21,584 triplets, among which 17,620 pairs (14,895 of which are unique) are provided only by information extraction patterns, while 5,717 pairs (4,412 of which are unique) contain *MeSH* descriptors as pathology.

Evaluation

Analysis of the extracted risk factors for coronary heart disease

Coronary heart disease (CHD) is the most common form of disease affecting the heart and is an important cause of premature death all around the world. A medical doctor performed a qualitative evaluation of results on this disease. This evaluation appears to be encouraging: among 1,102 extractions, only 128 (11.62%) are rejected, while the remaining set is considered to provide helpful information. First of all, well known risk factors (such as *hypertension*, *smoking*, *diabetes*, *age*, *obesity*, *hypercholesterolemia*, *hyperlipidemia*, *family history*) are frequently detected in the literature and extracted. Amusingly, *work* was detected to be a risk factor for CHD in the

following sentence: *Passive smoking at work as a risk factor for coronary heart disease in Chinese women who have never smoked*. Obviously, this is an error due to an insufficient analysis of syntactic dependencies (the right risk factor is *passive smoking*). Such chunking and segmentation problems at sentence, term or word levels can appear but correspond usually to a minor problem. Another positive aspect of the method is that for several risk factors, it detects also synonyms: {*smoking; cigarette smoking; smoking history; importance of total life consumption of cigarettes*}, {*hyperhomocysteinemia; hyperhomocysteinaemia; homocysteine; plasma homocysteine*}.

Comparison between MeSH-indexed and extracted pathologies

In 291 cases, our approach generated a complete triplet {*risk factor, pathology*$_{text}$, *pathology*$_{MeSH}$}. In order to evaluate precision of the extracted pathologies, we propose to compare them with pathologies provided by *MeSH* indexing. This evaluation has been performed by a computer scientist and pointed out the following cases (in the given examples, pathologies are given in this order {*pathology*$_{text}$; *pathology*$_{MeSH}$}): 42 extracted pathologies are identical to *MeSH* indexing, 32 are their synonyms ({*breast cancer; breast neoplasms*}, {*coronary artery disease; coronary disease*}, {*cataractogenesis; cataract*}, {*postsurgical pain; pain, postoperative*}), 28 are lexically included ({*alzheimer; alzheimer disease*}, {*unsuspected anaphylaxis; anaphylaxis*}, {*hemorrhagic stroke; stroke*}, {*wound infection; surgical wound infection*}), 101 have a close semantic relation ({*poor pregnancy outcome; fetal growth retardation*}, {*development of alcohol disorders; alcoholism*}, {*stroke; cerebrovascular disorders*}, {*osteoporosis; bone diseases, metabolic*}, {*central retinal vein occlusion; vision disorders*}), 7 have a broad semantic relation ({*tardive dyskinesia; dyskinesia, drug-induced*}, {*squamous cell carcinoma of the skin; carcinoma, squamous cell*}) and 91 are not related semantically. Thus, among the set of 291 generated triplets, only 91 extracted pathologies (31%) appears to be not relevant, while nearly 70% are identical, or have a close or broad semantic relation with the *MeSH*-indexed pathologies.

Comparison of extracted risk factors with three* Snomed CT *associative relations

The evaluation question is whether relations extracted from abstracts and titles are already registered within *Snomed CT* and related through three causative relationships: has causative agent, due to and associated with. In order to analyze this aspect, we looked for those *MeSH*-indexed pathologies which are also involved in these three *Snomed CT* relationships. This evaluation is performed by a computer scientist. We obtain a set of 22,730 propositions, related to 168 various pathologies. We analyzed 20 pathologies (3,100 extractions, about 25% of the whole set), such as: *acquired immunodeficiency syndrome*, *kidney diseases*, *heart diseases*, *alcoholic intoxication*, *epilepsy*, and *cytomegalovirus infections*. Only 19 extractions (0.6%) were considered as already recorded within *Snomed CT* or very close to the recorded relations. For instance, within the sentence:

> *...how patients with abundant alcohol consumption as a risk factor develop the chronic alcohol abuse episode of care...* (PMID 10414608)

abundant alcohol consumption was extracted as risk factor for *alcoholism* C0001973, which is very close to the relation registered in *Snomed CT*: *drinking alcohol* (C0589068) has causative agent *alcoholism* (C0001973). Other comparable extractions: {*asbestos fibres* (C0003947); *asbestosis* (C0003949)} in *Snomed CT*, while in citations we obtain {*asbestos exposure*; *asbestosis* (C0003949)}; or {*cytomegalovirus group* (C0010825); *cytomegalovirus infections* (C0010823)} in *Snomed CT* and {*cytomegalovirus; cytomegalovirus infections* (C0010823)} in text. Remaining extractions share little common aspects with the analyzed *Snomed CT* associative relations. One reason is that the precision of these extractions is not perfect; but a more specific reason is that *Snomed CT* does not specifically record this type of information, although risk factors may occur among the *Snomed CT* relations. Thus, for *acquired immunodeficiency syndrome* we extracted several risk factors, i.e.:

> *bisexuality* (C0005639), *bisexual* (C0178515),
> *blood transfusion* (C0005841),
> *intravenous drug abuse* (C0086181), ...

which are *Snomed CT* concepts but have no associative relations to *acquired immunodeficiency syndrome*. The situation is similar with other illnesses: *family history*, *age*, *race*, *smoking*, *hyperlipidemia*, *diabetes*, *hypertension*, *sedentary life style, weight control*, *stress* and many others are extracted as risk factors for *heart diseases* but are not recorded as such in *Snomed CT*. This implies, not surprisingly, that the creation and maintenance of specific dedicated and comprehensive resource for risk factors, would be most welcome.

Conclusion

We presented an experience in extracting information linked to risk factors from Medline citations. The proposed approach relies on NLP and IE methods and is based on lexico-syntactic patterns. It allows extracting risk factors and the associated pathologies. We perform several types of evaluation by medical and biological experts and computer scientists. Evaluation of the precision of risk factors extracted for coronary heart disease shows that they cover a large range of risks, and that only 11.62% of them are incorrect, while the remaining 88.38% are correct. Comparison of the associated pathologies extracted from abstracts with pathologies provided by the *MeSH* indexing prove to be identical or semantically related in about 70%. These two evaluations are very positive. Finally, a comparison of pairs {*risk factor*; *pathology*} extracted from citations and those proposed by associative relationships within *Snomed CT* allowed us to observe that *Snomed CT* is not dedicated to the recording of this type of information, although some of the pathologies can be related to their risk factors in this terminological resource.

We have several perspectives for this work. Methodologically, we will design and apply other patterns for detecting and extracting information on risk factors. For instance, triggers like

predictor, *precursor* are not taken into account currently. We also plan to apply other methods, *i.e.* machine learning and text mining. From a knowledge representation viewpoint, a more precise categorization of risk factors within homogenous groups will be performed. Thus, we can distinguish groups related to environmental, social, clinical, behavioral, and other risks. Besides, this categorization can even be mentioned in abstracts:

> *Demographic risk factors (age, sex, and ethnicity), clinical risk factors (diabetes mellitus, increased cholesterol, antihypertensive medications, history of congestive heart failure, myocardial infarction, hypertension, and neurological deficits), and behavioral risk factors (smoking and heavy drinking) were controlled for statistically.* (PMID 11973166)

Another perspective is related to characterizing the extracted information itself. Thus, some of the extracted elements may occur in modal or negative contexts, which reduces their reliability. Otherwise, geographical, demographic or other variables for risk factors exist. For instance, for a given pathology, common risk factors in North America or Europe may be of less (or no) relevance to other geographical areas. Such characterization may well deserve more focus.

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A Qualitative Approach to Signal Mining in Pharmacovigilance using Formal Concept Analysis

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Abstract

"Pharmacovigilance is the process and science of monitoring the safety of medicines, consisting in (i) collecting and managing data on the safety of medicines (ii) looking at the data to detect 'signals' (any new or changing safety issue)" [1]. Pharmacovigilance is mainly based on spontaneous reports: when suspecting an adverse drug reaction, health care practitioners send a report to a spontaneous reporting system (SRS). This produces huge databases containing numerous reports and their manual exploration is both cost and time prohibitive. Existing techniques that automatically extract relevant signals rely on statistics or Bayesian models but do not provide information to the experts about possible biases lying in the data, nor about the specificity of a signal to a particular patient profile. Our extraction method combines numerical methods from the state of the art with a qualitative approach that helps interpretation. We build a synthetic representation of the database that is used to (i) identify unexpected patterns and biases (ii) extract potentially relevant signals w.r.t. patient profiles (iii) provide traceability facilities between extracted signals and raw data.

Keywords:

Adverse drug reaction reporting systems, Data interpretation, Data collection, Drug safety, Public health informatics, Information storage and retrieval, Artificial intelligence, Formal concept analysis, Data mining

Introduction

The huge and constant increasing size of spontaneous reporting systems (SRS) precludes case-by-case human analysis. Indeed, in 2008 more than 20,000 new cases were added to the French pharmacovigilance system; the WHO database contains more than 3 millions of reports. This has lead to the development of data mining algorithms (DMAs) that automatically extract signals, i.e. potentially relevant adverse drug reactions for further investigations by experts in pharmacovigilance [2].

Two main approaches to extract signals are known, both of them are based on statistical criteria: (i) the frequentist approach which establishes pertinence threshold with respect to disproportionality measures between occurrences of a drug and an adverse effect (AE), and (ii) the Bayesian approach based on probability distribution models. Most of the debate has focused on the advantages and drawbacks of these approaches and on the fine tuning of their respective measures and thresholds.

DMAs only deal with co-occurrence of drugs and AE and produce quantitative indicators. For this reason, [3] throws them back into question arguing that a drug-AE pair is, in itself, rarely sufficient to assess whether a potential signal has been generated. Indeed, using DMAs, experts have to evaluate each extracted drug-AE pair and its statistical measures with no way to estimate to what extent these measures are reliable. They also ignore if there are some demographic population restrictions or the presence of concomitant medications.

Moreover some biases in SRS databases degrade quality of the DMA results: the number of patients that take a particular drug without AE is not known (no control sample) and fields in the database are not always fully or properly filled. Experts ignore if some of the detected signals are due to biases since they have no way to evaluate the presence of specific biases or noise in the case database when they evaluate detected signals.

We argue that DMAs should provide experts disproportionality measures as well as qualitative information in order to explain or to trace the reasons why each signal has been generated. We claim that a symbolic classification method such as Formal Concept Analysis reaches this goal providing (i) a synthetic view of the database (ii) a search space for candidate signals (iii) an environment to navigate among results (iv) and a potential noise detection method.

Materials and Methods

This section presents first Formal Concept Analysis which builds a partial ordered structure called lattice. Then, we highlight some mathematical properties of the lattices used to achieve the (i) to (iv) previous goals.

Table 1 – Binary relation between objects in rows (cases) and attributes in columns (age bracket, gender, AE, drugs)

	demographic attributes					adverse effects										drugs				
	<18	18-60	>60	M	F	e1	e2	e3	e4	e5	e6	e7	e8	e9	e10	d1	d2	d3	d4	d5
#1		×			×				×		×				×		×			×
#2			×	×			×		×	×	×	×	×				×	×		
#3		×			×	×	×		×				×	×					×	×
#4	×				×	×	×						×				×	×		
#5		×		×		×		×			×	×		×	×	×				

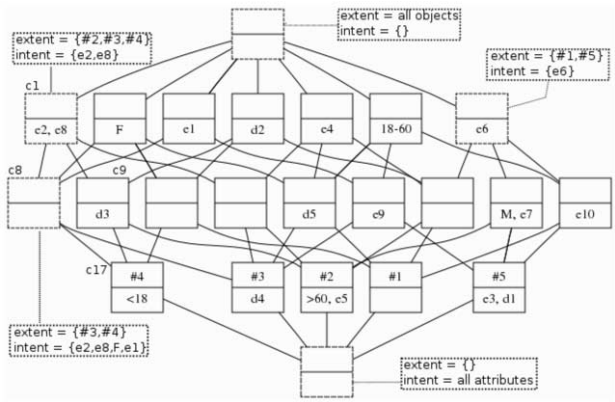

Figure 1 – Concept lattice representing the binary relation given in Table 1

Basis on concept lattices

A **formal context** [4] is a triplet (G,M,I) where G is a set of objects, M, a set of attributes and $I \subseteq G \times M$ is a binary relation and for any $g \in G$ and $m \in M$, $(g,m) \in I$ if the object g has the attribute m. Two derivation operators, both denoted $'$, link objects and attributes:

for $O \subseteq G$ and $A \subseteq M$, $O' = \{a \in A \mid \forall o \in O, (o,a) \in I\}$, $A' = \{o \in O \mid \forall a \in A, (o,a) \in I\}$. The compound operators $''$ are closure operators over 2^G and 2^M.

A **concept** c is a pair (O'',O') where $O \subseteq G$. $O'' \subseteq G$ is called the **extent** of c and $O' \subseteq M$ the **intent** of c. Both intent and extent are closed sets which intuitively means that the extent of c is the exact set of objects which share all attributes in the intent and no other attribute, and dually between the class of attributes versus objects. The set C of concepts is partially ordered: for any $c_1=(O_1,A_1)$ and $c_2=(O_2,A_2)$, $c_1 \leq c_2 \Leftrightarrow O_1 \subseteq O_2 \Leftrightarrow A_1 \supseteq A_2$. The structure $L(C,\leq)$ defines a lattice, called **concept lattice**.

Applied to pharmacovigilance, objects are cases and attributes are drugs $(d_1 \ldots d_5)$, AE $(e_1 \ldots e_{10})$, and demographic attribute such as gender (M,F) and age bracket $(<18,\ldots,>60)$ of the patient (see Table 1). In the resulting concept lattice, shown in Figure 1, concepts are represented by boxes in which the upper (resp. lower) part contains the extent (resp. intent).

A reduced labeling scheme is used so that each object/attribute appears only once in the lattice. An attribute (resp. object) label appears in the highest (resp. lowest) concept that contains it in its intent (resp. extent). A concept labeled with an attribute a is called the attribute-concept of a denoted $\mu(a)$: for instance, $c_1=\mu(e_2)=\mu(e_8)$. Therefore, the intent of a concept is made of all attributes whose attribute-concepts can be reached from the concept on an upward-heading path while extent is recovered in a dual way. For example, considering the concept c_8, its intent contains all the intent labels of its ancestors $\{e_2,e_8,F,e_1\}$, and its extent all the extent labels of its successors $\{\#3,\#4\}$.

The lattice as a synthetic view of the database

The concept lattice gives insights into the case database. We illustrate this point by few examples: $c_8 \leq c_1$ since $\{\#3,\#4\} \subseteq \{\#2,\#3,\#4\}$ and $\{e_2,e_8,F,e_1\} \supseteq \{e_2,e_8\}$. This means that among the cases containing adverse effects $\{e_2,e_8\}$, some of them (but not all) are women (F) who also suffer from e_1. By definition, the intent of a formal concept is a closed itemset[1] and the lattice contains all possible closed itemsets as intents. Thus $\{e_2,e_8,F,e_1\}$ (intent of c_8) is a closed itemset but $\{e_2,e_8,F\}$ is not closed as there is no concept with this exact intent. This means that there is no case

[1] Here, the data mining term *itemset* denotes a set of attributes.

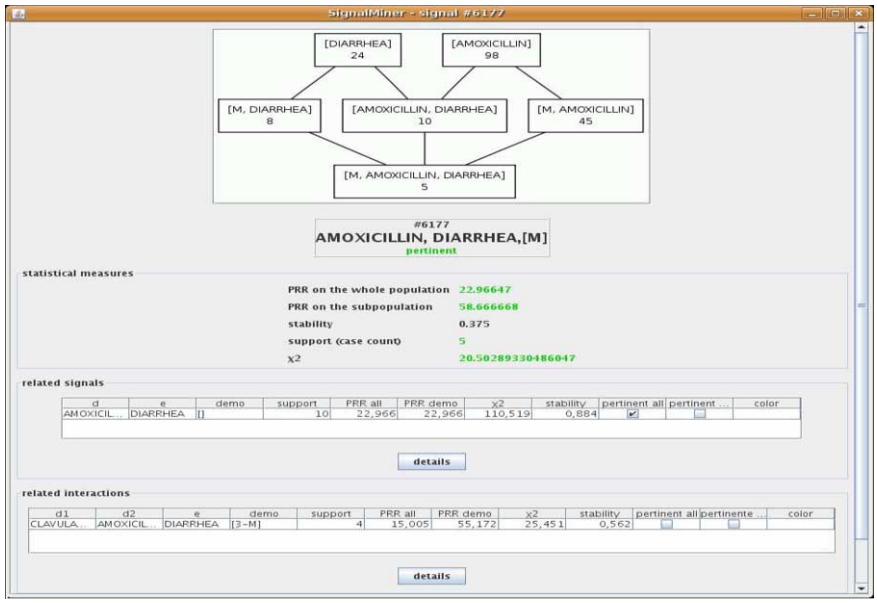

Figure 2 – graphical user interface showing the (amoxicillin, diarrhea, M) signal

in the database where a woman suffers from e_2 and e_8 without suffering from e_1. The concept c_9 with $\{e_2, e_8, d_3, d_2\}$ as intent shows that every patient who took d_3 also took d_2 and suffers from e_2 and e_8, since $c_9 = \mu(d_3)$.

Thus, through the relations existing between labeled concepts, the lattice reveals correlations between attributes: for instance "d_3 is always taken with d_2", "d_1 is only taken by men", "all and only elderly suffer from e_5"...

A search space for candidate signals and interactions

The lattice is used to identify necessary conditions for both signals (1 drug, 1 AE) and interactions (2 drugs, 1 AE). A necessary condition for a signal to occur is when the intent of a concept contains a pattern (d, e), i.e. it contains exactly one drug and one AE. Such a concept is called a "signal-concept". Note that the intent of a signal-concept may be $\{d, e\}$ or $\{d, e, X\}$ where X is a set of demographic attributes. We note signal-concepts c_{de} or c_{deX}. Similarly, the intent of an "interaction-concept" contains the pattern (d_i, d_j, e). Let us call c_{ij} (or c_{ijX}) an "interaction-concept" with the pattern (d_i, d_j, e). If its related signal concepts c_i with the pattern (d_i, e) and c_j with the pattern (d_j, e) exist in the lattice, by construction, then $c_i \leq c_{ij}$ and $c_j \leq c_{ij}$. The absence of c_i means that d_i and e never appears together without d_j. Thus the lattice defines the search space for candidate signals and interactions. It also links interactions to their related signals.

Statistical measures are then computed for each signal-concept c_{de} or c_{deX} in order to evaluate its pertinence with respect to the British Medicines and Healthcares products Regulatory Agency (MHRA) interestingness criteria [2]. We adopted three criteria for raising hypotheses regarding signals: number of cases ≥ 3, $\chi^2 \geq 4$, and PRR ≥ 2. If the three criteria are successful, the signal-concept c_{de} (resp. c_{deX}) generates a **potential signal** (d, e) (resp. (d, e, X))

For the first criterion, the number of cases is actually the extent's cardinal of the concept. The lattice contains all the information needed to compute the contingency table and therefore the two later measures [5].

Considering a signal-concept c_{de} without demographic attribute, the PRR is computed as follows:

$$PRR(d,e) = \frac{P(e|d)}{P(e|\bar{d})} = \frac{P(de)P(\bar{d})}{P(d)P(\bar{de})} = \frac{|de| \cdot |\bar{d}|}{|d| \cdot |\bar{de}|} \quad (1)$$

where $|a|$ denotes the number of cases that has attribute a.

Considering a signal-concept c_{deX} with a set of demographic attributes X, the PRR is computed as follows:

$$PRR(d,e,X) = \frac{|(de)_X| \cdot |\bar{d}_X|}{|d_X| \cdot |(\bar{de})_X|} \quad (2)$$

Formula (2) provides a PRR that takes demographic attributes into account by restricting the scope to the concerned population. Hence, $|(de)_X|$ denotes the number of patients in the X subpopulation that took d and suffer from e.

An interaction-concept with the pattern (d_i, d_j, e) becomes a **potential interaction** if it satisfies the three following criteria[2]: number of cases ≥ 3, PRR ≥ 2 and the interaction's PRR

[2] The PRR value of an interaction (d_1, d_2, e) is computed as follows: $PRR(d_1, d_2, e) = P(e|d_1 d_2) / P(e|\ not(d_1 d_2))$

has to be greater or equal to each PRR of the two related signals if the signal-concepts of these signals exist in the lattice. The later criterion means that an interaction must "override" its related signals. When it is the case, its related signals are removed from the set of potential signals.

However, related signal-concepts may not exist in the lattice. We proved that it is not worth computing the PRR for non-closed signals (d_i,e) since it is always less or equal to the PRR of the interaction (d_i,d_j,e).

Navigation through results

The user interface makes the most of all the previous observations. Experts can see what kind of relation exists between drug(s) and AE, for instance "all patients that took drug d_i suffer from e". They may access to a set of potential signals and interactions, along with their statistical measures. Each signal and interaction is linked with its concept in the lattice and a subpart of the lattice can be visualized to help experts in their interpretation task.

Figure 2 shows the user interface illustrating a signal d,e,X where d=amoxicillin, e=diarrhea, X={male}. A subpart of the lattice is shown, which contains the concepts c_{deX}, μ(d), μ(e), and all concepts on the paths from c_{deX} to μ(d) and μ(e), here c_{de}, c_{dX}, and c_{eX}.

Concepts are labeled with their intents and the number of objects in extent. Through this graph, experts can observe the distribution of cases in the database: 24 patients suffer from diarrhea (μ(e)), 98 took amoxicillin (μ(d)), 10 took amoxicillin and suffer from diarrhea (c_{de}), and among them 5 are men (c_{deX}).

Then, experts can compare PRR values for both signals c_{de} (denoted "PRR on the whole population") and c_{deX} ("PRR on the subpopulation") and understand why, in this exemple, PRR(d,e,X)>PRR(d,e). It can be seen that 5 men took amoxicillin among the 8 men that suffer from diarrhea; *i.e.* almost all of them. Unlikely, only 10 people took amoxicillin among 24 people who suffer from diarrhea, *i.e.* less that half of them. Thus, the demographic attribute M makes the signal stronger according to PRR values.

In addition, it is possible to compare the strengths on two subpopulations. The same signal on the female population shows a lower PRR (13.38). Hence, we have |(diarrhea, F)|=16 and |(amoxicillin, diarrhea, F)|=5. So the weight of amoxicillin takers within women suffering from diarrhea is lower compared to men, and compared to the whole population. Thus, examining the lattice allows experts to understand why a signal is stronger on given population.

A potential noise detection method

Trimethoprim and sulfamethoxazole come together in marketed drugs, thus a unique concept μ(trimethoprim) = μ(sulfamethoxazole) should exist in the lattice. It is not the case in Figure 3 since only one case has been badly filled in the database. The stability ratio [6] of a concept can capture such a situation. It quantifies the ability of the concept to remain existent after deletion of objects in its extent. Here a low stability can be used to identify concepts in the lattice resulting from noise in the database.

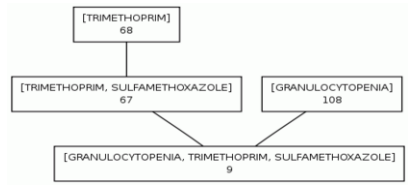

Figure 3 – an interaction example containing noise

Results

We applied our method on a subset of the French national SRS database. This subset contains 3249 cases, 976 drugs, 573 AE, and demographic attributes such as gender and age, divided in 3 brackets (<18, 18-60, >60). The resulting lattice contains 13178 concepts, among which 6788 contains at least 3 cases in the extent. The 2812 candidate signal-concepts led to 565 potential signals and the 836 candidate interaction-concepts to 102 potential interactions. Note that the exhaustive search performed by existing method would generate more than 500,000 candidate signals and more than 270,000,000 candidate interactions.

In the worst case, the lattice contains 2^n concepts where n is the minimum of the number of objects and the number of attributes. In practice and especially with SRS databases, the number of closed itemsets is much lower than 2^n and even lower than the number of candidates for exhaustive search.

Table 2 shows the distribution of the 565 signals by pattern. Interestingly, we observe that signals can be divided in four distinct categories, depending on the weight of the demographic attributes. Only 29% of the signals have the pattern (d,e), the rest of the signals have at least one (49%) or two demographic attributes (22%). The validation of such attributes *a posteriori* by manual review of all signals shows a good relevance. In the majority of cases, the demographics attributes associated to the couple drug/effect constitute a known risk factor or probable risk factor. For example, cases of Pulmonary Hypertension associated with the use of appetite suppressants amphetamine-like were observed in women, aged 18 to 60.

Secondary, all the signals were classified into 5 categories (see Table 3). Categories (1),(2) contain true positives, (3),(4) false positives and (5) unknown potential signals. Table 3 shows that our method generates few false positives that are discussed in the next section. 27 signals were classified as unknown, i.e. not reported in the literature, but interesting enough for investigation by experts.

Table 2 - distribution of the 565 potential signals by pattern

signal pattern	count (%)	example
drug, effect	160 (29%)	cefazolin, thrombocytopenia
drug, effect, gender	132 (23%)	furosemide, gynecomastia, male
drug, effect, age	148 (26%)	abciximab, thrombocytopenia, > 60
drug, effect, gender, age	125 (22%)	levofloxacin, mental confusion, female, > 60

Table 3- Classification of the 565 potential signals

category	signals
(1) known (in reference documents)	502 (89%)
(2) known (in a similar form)	24 (4%)
(3) the AE is the origin of the medication	3 (1%)
(4) due to concomitant drug	9 (2%)
(5) unknown potential signal	27 (5%)

Discussion and perspectives

In this section we discuss the efficiency of our qualitative approach, especially for handling demographic attributes. Then, we present future directions about preventing false positives.

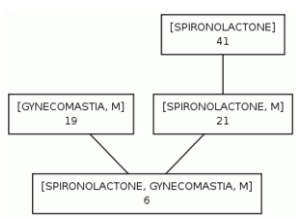

Figure 4 – a signal containing a masculine AE

The lattice helps experts in interpreting PRR variations depending on demographic attributes as shown before for (`amoxicillin, diarrhea`). Moreover, in some situations where an AE is specific to a population, *e.g.* `gynecomastia` (see Figure 4), handling demographic attributes in the PRR computation is the only way to obtain a meaningful measure.

False positives (contained in categories (3) and (4)) are common in signal detection. In the following, we give directions for preventing false positives from category (4). The signal (`hydrochlorothiazide, cough`) is detected because these drug and AE often appear together. However in these cases, `cough` is actually caused by ACE inhibitors taken concomitantly with `hydrochlorothiazide`. Since there are several `ACE inhibitors` d_i, each association $(d_i, \texttt{cough})$ appears less often than the association (`hydrochlorothiazide, cough`). Therefore, only this later signal is detected. A solution would be to introduce drug therapeutic families, such as ACE, as attributes, with $(o, \texttt{ACE}) \in I$ for each case o containing an ACE inhibitor. Then signals of the form $(\texttt{ACE}, \texttt{cough})$ would be detected, where `ACE` is a drug family, even if each signal (d, e) where d is an ACE inhibitor is too weak to be detected.

In this paper, we have presented a novel automated signal detection method that focuses on the qualitative aspects of the extracted signals. The pivot structure is a concept lattice that allows experts to identify unexpected situations in the case database, and provides information to the experts about why each signal has been detected. Besides our symbolic approach, we have implemented disproportionality measures which are commonly accepted in pharmacovigilance. Our first results based on an extract of the French database are very encouraging: our method has a very good relevance and the signal pattern includes demographic attributes. Further research will focus on (i) improvements for preventing false positives (ii) the scalability of our approach and its efficiency on a bigger database.

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Data Mining to Assess Variations in Oral Anticoagulant Treatment

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Abstract

Variations in International Normalized Ratio's (INR) are closely related to bleeding and thrombosis incidents in patients on oral anticoagulation treatment. This study investigates predictive factors that affect INR values. Data sampled with relatively high frequency allows for detection of local INR variations, and hence also allows detection and evaluation of predictive factors where time is taken into consideration. Univariate linear regression was applied and different models were reduced into a final predictive model. F-tests were utilized to test whether or not a model reduction would benefit INR predictions, in terms of decreasing observed variance. In addition to an INR submodel, the final model includes individual interaction from the last three days change in mean warfarin intake and three days change in mean vitamin K intake. Prediction residual error was mainly reduced by the INR submodel, while the warfarin model and the vitamin K submodel did not benefit predictions to same extend compared to the INR submodel. However, more studies on the temporal aspects of the effect of warfarin seem to be relevant.

Keywords:

Anticoagulation, Linear regression model, Time series model, Vitamin K, Prediction model.

Introduction

Oral vitamin K antagonists such as warfarin and other coumarin derivatives are prescribed to an increasing number of patients enrolled for lifelong therapy with underlying disorders such as heart valve replacement, atria fibrillation and venous thromboembolism. Despite well-described clinical benefits, use of warfarin is known to be associated with adverse effects, in particular haemorrhage, if too much warfarin is given. The dosage of oral anticoagulation agents should be based on minimizing both the risk of thrombotic events and the risk of bleeding [1].

Three different types of patient management exist. One is "usual-care" where patients visit the hospital-based or the GP every 4-6 weeks to have a blood sample taken to have the so-called International Normalized Ratio (INR) measured. The INR represents a patient's coagulation time compared to a normal healthy individual. An INR value of 1 is normal and, for example, a measured INR value of 2 means that blood coagulation takes twice as long compared to the normal coagulation. In the "usual-care" warfarin dosage is recommended by the doctor based on current and historic INR values. Some patients are able to take part in the management of oral anticoagulation treatment (OAT) by handling a Point-of-Care (PoC) device and measure INR values themselves. Patients assigned to "self-testing" will report this INR value to a responsible clinician who prescribes the dose of warfarin. Patients educated in "self-management" will both handle INR measurement by a PoC device, and are allowed within a preset range to change warfarin dosage. In the latter two mentioned groups, measurements of INR values are most frequent: once every week or two.

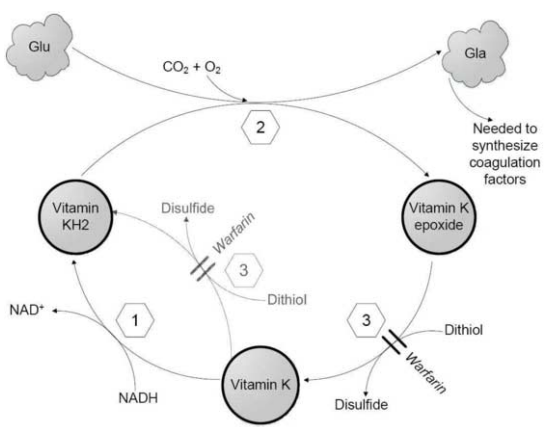

Figure 1- Vitamin K is reduced either by a NADH dependent reductase activity reaction ‹1› or a reductase reaction dependent on the conversion of dithiol into disulfide ‹3› (shaded). The carboxylation reaction ‹2›, which converts Glu (glutamate residues) into Gla (gamma-carboxyglutamate residues, aka Gla-residues), is driven by a vitamin KH2 dependent carboxylase activity, which simultaneously converts vitamin KH2 into vitamin K epoxide. The last step in the vitamin K cycle reaction ‹3› is a reductase of vitamin K epoxide dependent on conversion of dithiol into disulfide. The two reactions indicated by ‹3› are inhibited by anticoagulants as warfarin, thus dietary vitamin K sources are necessary to maintain haemostasis. Adopted from [7].

Maintaining patients within the desired therapeutic range presents a challenge due to at least three factors: (1) a target INR value restricted by a relatively narrow therapeutic range; (2) an interindividual variation of the effect of oral vitamin K antagonists, and (3) changes in dietary intake of vitamin K.[2-4] A change of 0.7 INR in two consecutive measurements has been shown to be clinically relevant for OAT.[5]

Fluctuations in vitamin K intake through dietary sources have shown clinical relevance, and must be regarded as a major independent factor that interferes with anticoagulation stability.[6] Based on known physiology the interactions between INR, warfarin, and vitamin K are well described; an overview is provided in Figure 1.

Since they are based on accessibility of Gla-residues the amount of functional vitamin K dependent coagulation factors will decrease if warfarin is administrated; this leads to an increase in INR value.

Disregarding the complexity of the vitamin K cycle, a novel approach to describe the course of action of INR values is proposed in Equation (1), where INR_t denotes the INR measurement at time t.

$$INR_t = \alpha(INR_{history}) + \beta(Warfarin_{history}) + \gamma(Vitamin\ K_{history}) \quad (1)$$

where α, β and γ are arbitrary coefficients. Due to the slow-acting physiological systems involved, one must take time into consideration, e.g. warfarin has a half-life of 36 hours. Warfarin and vitamin K interaction will have carryover effect from previous intake(s), affecting the current INR value. Being able to take into account such different predictive over-coagulating and under-coagulating factors could potentially decrease bleeding risk or decrease risk of thrombosis in patients assigned to an outpatient setting of OAT.

The purpose of this analysis is to utilize quality data to assess interactions between current and previous INR values, warfarin administration changes, and changes in dietary vitamin K intake. Such interactions might reveal important predictive factors for variation in INR values.

Methods

We have built models predicting the current INR value from available information. This is performed in three steps:

- Information on previous INR measurements
- Additional information on warfarin intake
- Additional information on vitamin K intake

The first model provides information on the serial correlation structure of individuals that are well regulated with respect to warfarin and vitamin K intake. Having established a prediction model solely based on historic INR values, the inclusion of warfarin intake in such a model provides information on the time-span of the effect from warfarin on INR. Further, it will provide information on between-subject variation of sensitivity to warfarin treatment. Finally by also including vitamin K intake in the model, it is possible to assess the time-span of the effect from vitamin K. Again, the between-subject variation of sensitivity can be assessed. The analysis also provides empirical knowledge to judge to which amount these three predictive variables reduce the unexplained variation.

Materials

All patients included in this study referred to Medicinsk Ambulatorium, Brædstrup Sygehus. Approval from the Danish Data Protection Agency was obtained prior to onset of the data acquisition program. Clinicians at the facility enrolled suitable patients to be included in a data collection protocol, and the study was conducted in the period from June 2008 to February 2009. Patients were asked to fill out a daily scheme for a one month period. Schemes included information (among others) on INR value, diet, and warfarin intake. Data were entered into Microsoft Excel ®. Nutrition data was evaluated to calculate vitamin K content. The vitamin K assessments were performed by using the USDA National Nutrient Database for Standard Reference.

Data Analysis

A retrospective statistical evaluation of variability in INR values was performed. The current INR value is predicted from previous values in a regression model, and hence the approach is auto-regressive time series modelling. However, as the data is characterized by being shorter time series from a number of independent individuals, the statistical methods applied are mainly univariate linear regression analyses rather than the classic approach developed by Box and Jenkins [8].

Prediction model based on previous INR values

Prediction of the current INR value at time *t* for the *i*th subject is given in Equation (2).

$$INR_{i,t} = \alpha_{i1}\, INR_{i,t-1} + \alpha_{i,2}\, INR_{i,t-2} + ... + \alpha_{tv}\, INR_{i,t-n} + \varepsilon_{i,t}, \quad (2)$$

where the lag time is n, $\alpha_{i,k}$ are weights in a weighted average of previous INR values, and $\varepsilon_{i,t}$ is the residual uncertainty (prediction error). We assume that $\varepsilon_{i,t} \sim N(0,\sigma^2)$. It should be noted that in this model we assume variation between individuals in weights. Reductions of this model could be:

I. Reducing the lag time of influence
II. Reducing the interindividual variation

Reductions in lag time must be performed in descending order, and likewise, reductions in interindividual variation should be done in descending order of lag time.

Prediction model based on previous INR values and changes in warfarin intake

The preceding model is now expanded by adding intake of warfarin. Assume that an individual is in steady state and dependence of previous INR values is described by $\alpha(INR_{history})$. In this case changes in warfarin dose will affect the prediction of INR. The absolute change in warfarin intake from previous days is, however, not a sophisticated way of modelling the effect from warfarin. This is mainly due to the nature of warfarin administration: the advised dosage pattern of warfarin is rarely fixed in terms of tablets per day. A normal pattern could be; 2, 2, 3, 2, 2, 3, 2 tablets per day for one week. If the absolute change in previous warfarin intake is modelled as change

from one day to another, the effect from previous changes would be negated due to this pattern of changes (i.e. positive change always followed by a negative change and vice versa). Hence, it is decided to model changes in warfarin intake based on the difference from the mean intake of the last day's change as in Equation (3).

$$INR_{i,t} = \alpha(INR_{history}) + \beta_{i,1}\,\Delta W_{i,t-1} + \ldots + \beta_{n,1}\,\Delta W_{i,t-n} + \varepsilon_{i,t}, \quad (3)$$

where $\Delta W_{i,t-1} = W_{i,t} - W_{i,t-1}$ is the change in warfarin intake compared to change in mean warfarin intake from t days. Again we model potential between-subject variations in sensitivity toward vitamin K antagonist treatment.

Vitamin K based model

Expanding the model to incorporate intake of vitamin K is done similar to the intake of warfarin, see Equation (4).

$$INR_{i,t} = \alpha(INR_{history}) + \beta_i(W_{history}) + \gamma_{i,1}\,\Delta K_{i,t-1} + \ldots + \gamma_{n,1}\,\Delta K_{i,t-n} + \varepsilon_{i,t} \quad (4)$$

where $\Delta K_{i,t-1} = K_{i,t} - K_{i,t-1}$ is the current change in vitamin K intake compared to mean intake from t days. The reduction of this model follows the same rules as the previous model. However, the reduction in interindividual variation may be performed in two steps; 1) reduction in weights modelling potential between-subject variation, and 2) reduction to weights specific to a grouping into individuals who take, and who do not take supplementary vitamins including vitamin K. The latter approach is based on Schurgers et al. who reported a threshold of 150µg/day of vitamin K supplements for having a clinically relevant effect. [9] For this reason, the vitamin K model was tested with two types of interaction: vitamin K supplements interaction and interindividual interaction.

Results

A total of 30 patients accepted to be contacted, six declined to participate. Out of the 24 patients going into the study, 18 patients completed the data collection protocol (Table 1), equivalent to a 25% dropout rate.

Results from model reductions are reported in three steps:

- Reduction of lags on previous INR measurements and individual interaction
- Reduction from INR model including reduction from information on warfarin intake and individual interaction
- Reduction from INR model and warfarin model including reduction from information on vitamin K intake and individual interaction as well as vitamin K supplement interaction

A lag of four days, meaning four historic values relative to the current INR value was selected as appropriate, taking the amount of data per individual into account.

Table 1- Outline of 18 patients receiving warfarin

Characteristics	Number (%) or Mean ± SD
Age (years)	56 ± 15
Females	8 (44%)
Days in study	27 ± 1.78
INR value	2.5 ± 0.5
Warfarin intake [mg/day]	6 ± 2.5
Vitamin K intake [µg/day]	59 ± 105
Patients on daily vitamin K supplement	7 (39%)
Indication for OAT	
Heart valve replacement	9 (50%)
Deep venous thrombosis	3 (16%)
Atria fibrillation	4 (22%)
Coronary prosthesis	1 (6%)
Thromboembolism	1 (6%)

Analysis of INR model

The initial model holds both the main effect from INR with four lags and the interaction effect from INR and the individual with four lags. The interindividual variation between patients is not significant ($p = 0.99$), and only lag 1 is significant, lag 2 to lag 4 having a p-value > 0.87. The final INR model applied in the next step, where warfarin will be included is given in Equation (5).

$$INR_{i,t} = \alpha\, INR_{i,t-1} + \varepsilon_{i,t}, \quad (5)$$

with the within-individual Standard Deviation (SD) = 0.25 and α=0.99. The regression parameter does not differ significantly from 1 ($p = 0.96$), and hence the model describes the within-individual variation in INR by independent increments with a day-to-day SD of 0.25. Likewise, α is set to 1.

Analysis of INR and warfarin model

The first noticeable result is the importance of individual interaction with a p-value <0.00005; hence further testing will be including interaction from individuals. The warfarin model is deduced from successively testing the difference in warfarin intake from the last two, three or four days mean warfarin intake. The final INR and warfarin model is provided in Equation (6).

$$INR_{i,t} = INR_{i,t-1} + \beta_i\,\Delta W_{i,t-1} + \varepsilon_{i,t}, \quad (6)$$

with a SD = 0.54 and average value $\beta = 0.52$.

Analysis of INR, warfarin and vitamin K model

The addition of vitamin K information to the model and results for reduction of INR variation are described in the following. As no interactions from vitamin K supplement will

benefit the model (p = 0.1182), further testing of model reduction related to vitamin K information will be done without vitamin K supplement.

Reduction of lags on mean intake of vitamin K is done successively by removing one lag of the time, starting from fourth lag. There is no clear indication of a beneficial model provided by this reduction method. However, utilizing lag two including interindividual interaction will be a beneficial model compared to the full interaction one, with a successive p-value from F-test between the two of p=0.8338. Hence, the final model will be as in equation (7).

$$INR_{i,t} = INR_{i,t-1} + \beta_i \Delta W_{i,t-1} + \gamma_i \Delta K_{i,t-2} + \varepsilon_{i,t}, \quad (7)$$

with a SD = 0.22, average values $\beta_i = 0.51$ and $\gamma_i = -8.16*10^{-4}$.

Model control

The serial correlation structure of the model was checked by Durbin-Watson statistic (D-W = 2.074) and autocorrelation plots of residuals indicating mutually independent residuals. Hence, it is concluded that the suggested correlation structure is adequate. However, negative lag 1 autocorrelation suggest a possible improvement by adding white noise on top of independent INR increments. The normality assumption was checked by visual inspection of QQ-plots of residuals and found adequate. Variance homogeneity was assessed by scatter-plots of residuals versus fitted values, and no indication of heterogeneity was found.

Relative benefit of each independent variable

Significance tests between different models have shown what will benefit reduction of variance in INR predictions. By assessing the relative magnitude of each independent variable, it is revealed how much variance each variable explains. Each contribution to residual error reduction relative to total variation on INR is given in the following list:

- Contribution from the INR model 95.7%
- Contribution from adding the warfarin model 15.6%
- Contribution from adding vitamin K model 7.5%

Discussion

This paper reports the outcome of utilizing univariate linear regression models on quality OAT data.

The data is characterized by a close recording in terms of interval between observations; however the dataset is small in terms of number of individuals. The advantage is that it is possible to model and study the day-to-day dynamics of INR, warfarin and vitamin K. The disadvantage is that the group is small and selected. Hence, only qualitative and not quantitative results generalize to a larger population.

The model analysis directs the potential monitor/decision support system towards a state space model [10]. One virtue of the state space approach is that it is modular and flexible. It is possible to model the dynamics of a recommended dose of warfarin, the actual warfarin intake, intake of vitamin K and the INR level, true as well as measured. By use of the Kalman filter [11] it is possible to make inference on the recommended warfarin dose (in order to keep INR within the therapeutic interval) and to predict future INR values. This approach has been used to monitor pregnancy [12] and monitor post-surgical cancer patients [13]. By using the state space approach, it will be possible to suggest an optimal dose of warfarin given past values of INR, warfarin and vitamin K. Also the suggested dose can be adjusted for expected future intake of vitamin K.

The results from warfarin modelling showed the importance of individual interactions. This is in accordance with the fact that sensitivity to warfarin therapy often is associated with an interindividual dosage. In addition it was shown how the current warfarin intake was not a significant predictor for the current INR, while information from past days intake was able to explain INR variation. This is good in accordance with the pharmacological properties of warfarin that has a half-life of 36 hours in the plasma, and for this reason have a long-lasting effect on INR values. To further elaborate the utilized approach, one might include screening for polymorphisms of the enzyme (CYP2C9) involved in warfarin metabolism. Genetic variants in CYP2C9*2 and CYP2C9*3 have been shown to require lower maintenance dose of warfarin. In addition, patients with these variations are associated with an increased risk of over-anticoagulation.[2] Further, warfarin dosage variation is closely related to CYP2C9 and vitamin K epoxide reductase complex subunit 1 (VKORC1) and account for up to 30% of the variability in warfarin dose among European-Americans, and 10% variability among African-Americans.[16] Currently, screening for CYP2C9 variants before initiating coagulation therapy is an ongoing discussion in the literature, as this may allow clinicians to develop even more individual dosing protocols to reduce the risk of adverse drug effects.

While one could be tempted to neglect both the warfarin and the vitamin K model, the frequency of INR measurement from each individual must be taken into consideration. These patients are trained to aim for a target INR value by adjusting their dose of warfarin. In a regular setting, INR measurements would be done once a week and not every day. This additional information by more frequent measurements has earlier been reported to be related to an increase in Time in Therapeutic Range (TTR). [14] This will directly raise the contribution from the INR model to explain variance on the behalf of the other models. The indeed small contribution to explain variance from vitamin K model is also associated with the amount of intake. As vitamin K is found in a limited diversity of food, the daily intake is associated with large variations. Mean intake is 59.26µg/day with a SD of 104.62 µg. These large day-to-day variations in vitamin K intake may partly be the explanation of the low contribution from this model in terms of explaining variance in INR values.

In contrast to the findings in the present study, a recent study based on a physiological model of the vitamin K cycle, and tested on 157 days of data from 5 patients, has indicated that, for days with a high dietary intake of vitamin K, adding information on dietary vitamin K seems to significantly improve the accuracy of INR predictions [15]. Other studies have also shown a much larger effect of vitamin K intake than what can

be deduced from the 7.5% contribution from the vitamin K model in the present study [3, 6].

While it from a clinical point of view is to be expected that information on the intake of the anticoagulation drug, warfarin, is important in order to predict future INR values, more studies on the temporal aspects of the effect of the drug seems to be relevant. Furthermore, the vitamin K intake has to be further studied in order to assess its importance.

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Chapter 15.

Vocabulary, Terminology and Ontology

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Addressing SNOMED CT Implementation Challenges Through Multi-disciplinary Collaboration

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Abstract

This article describes the challenges of implementing SNOMED CT into electronic clinical documentation systems for discharge summaries, synoptic operative notes and ambulatory documentation. Four significant implementation challenges were identified throughout these projects, which required collaboration between specialists across several disciplines to resolve. The challenges included: designing the graphical user interface for selecting SNOMED CT values, gathering and validating template specifications that use SNOMED CT subsets, handling SNOMED CT subsets and extensions, and, creating algorithms and the technological infrastructure to generate fast, meaningful, non-redundant search results. Our experiences suggest that, while the usage of SNOMED CT in tertiary care settings is promising, collaboration between specialists from multiple disciplines is needed to utilize their unique project management, data modeling, technical, and clinical skills in overcoming implementation challenges.

Keywords:

SNOMED CT, Electronic documentation, Synoptic notes and algorithm.

Introduction and Background

The Systematized Nomenclature of Medicine Clinical Terms (SNOMED CT) is an emergent data standard that provides the core clinical terminology for electronic health information systems and is endorsed by the International Health Terminology Standards Development Organization (IHTSDO) [1]. In the January 2009 release, SNOMED CT contained more than 350,000 concepts with unique meanings and formal logic-based definitions organized into hierarchies. [2] SNOMED CT was identified "as the most suitable choice of terminology for 24 priority clinical information groupings (or subdomains) of the core interoperable [Electronic Health Record (EHR)]." [2] With the demands to adopt EHRs across healthcare, it is increasingly important to implement SNOMED CT enabled information systems to facilitate interoperability between systems and allow consistent, reliable and comprehensive methods of capturing clinical information.[1,3]

This paper describes the implementation challenges faced when implementing SNOMED CT and the need for collaboration and expertise across several disciplines.

Methods

The University Health Network (UHN) is a tertiary care academic health centre comprised of three teaching hospitals in Toronto, Ontario. The Health Informatics Research and Medical Informatics departments at UHN have implemented SNOMED CT in several electronic documentation projects. The usage of SNOMED CT allows UHN to capture synoptic clinical data specific and adaptable enough to meet the complex needs of clinical documentation. It also provides the foundation for system interoperability with other SNOMED CT-enabled applications; it avoids the issues associated with retrospective mapping to SNOMED CT from a locally maintained vocabulary list [4]; it allows the capture of synoptic data in line with an international standard; it allows UHN to leverage future institutional benefits of the Cross-mapping mechanism to international classifications.

Electronic Discharge Summary

In 2006, SNOMED CT was used to capture diagnoses in the electronic discharge summary. The project focused on building a tool to address known discharge summary deficiencies and improve the continuity of care, clinician communication and accuracy of patient data.

Synoptic Operative Note for Ovarian Cancer

The ovarian cancer synoptic operative note uses SNOMED CT for modeling diagnosis, finding, tumour, and surgical procedure data, as part of the requirements set out by the Canadian Partnership Against Cancer Synoptic Reporting Tools Project. The goal of the project is to establish a shared national surgical outcomes database for ovarian cancer and other disease sites via pan-Canadian collaboration. [5]

Ambulatory Documentation Application

The ambulatory documentation application uses SNOMED CT to model diagnoses, physical exams, chief complaints, findings, procedures, and diagnostic tests. The application was built to provide four surgical clinics (General Surgery, Orthopedics, Plastics and Urology) with a method to document consultation and follow-up notes, reduce transcription volumes and improve access to usable electronic data for patient care, research and organizational planning.

Challenges

Creating an implementation of SNOMED CT that could leverage the comprehensiveness and hierarchy of the clinical terminology identified four significant challenges that required consultation and collaboration with specialists across a spectrum of disciplines:

1. *Designing the graphical user interface for selecting SNOMED CT values*: The graphical user interface (GUI) had to be simple, usable and intuitive. The complex relationship structures of SNOMED CT are not inherently simple to navigate.
2. *Gathering and validating template specifications that use SNOMED CT subsets*: SNOMED CT uses its subset mechanism to group meaningful concepts together. Collecting, mapping and validating the SNOMED CT terms requires additional work.
3. *Handling SNOMED CT subsets and extensions:* SNOMED CT uses its extension mechanism to allow the creation of terminology and subsets specific to local, national, or organizational needs that are missing in the core SNOMED CT content. [6]
4. *Creating algorithms and technological infrastructure for generating fast, meaningful, non-redundant search results:* GUI's involving search functionality required an effective method of navigating SNOMED CT's hierarchies to create fast and meaningful search results in real-time.

Results

Challenge 1: Designing the graphical user interface for selecting SNOMED CT values

Clinicians worked closely with the project teams to provide the functional and data requirements which directed the GUI design. Concerns were raised regarding delays to clinical workflow and the impact to medical practice. Designing a GUI that is simple, intuitive and fast-performing was difficult given the complexity of SNOMED CT. The intended clinical usage and user base of an implementation influenced the choice of interface; a multi-disciplinary application favoured a search-based interface while an application intended for a specific disease or medical specialty favoured clinically focused sets of checkboxes customized to the most common and clinically relevant options.

Electronic Discharge Summaries

To address the needs of multiple clinical services, a simple keyword-based search was implemented to select diagnoses. All disorder SNOMED CT values were copied to a local relational database for executing the search. The challenges encountered included:

1. The project and technical team initially lacked the expertise required to extract only disorder values from SNOMED CT.
2. Three iterations of the UI were required until users were satisfied with its ease of use; the interface required users to wait while the search was executed.
3. Users were frustrated with scrolling through a repetitive list of synonyms that potentially did not contain the desired search result.

34961 discharge summaries that had a value saved for most-responsible diagnosis have been created between September 2007 and October 14th 2009. In 15431 (44%) of these cases the user was able to find and select the appropriate SNOMED CT code using the basic keyword search. In 19530 (56%) of the cases the user entered free text to describe the diagnosis. Preliminary analysis showed that 50% of free text values actually had matching SNOMED CT terms, which suggested deficiencies with the GUI.

Synoptic Operative Note for Ovarian Cancer

Disease-specific subsets of SNOMED CT concepts were used to populate standard form fields such as radio buttons and checkboxes. Disadvantages of this design include:

1. Several iterations of the design were required to determine the ideal set of SNOMED CT values
2. Any clinical scenario not modeled by subset values is captured as free text.
3. Additional resources were needed to collect and map specifications specific for ovarian cancer to SNOMED CT.

260 operative note reports were created between June 2008 and October 2009. Data was entered using form fields encoded from SNOMED CT subsets a total of 8851 times. In 8572 (97%) of these occurrences, the user was able to select a synoptic SNOMED CT code; in 279 (3%) of these occurrences, the user was forced to enter free text.

Electronic Ambulatory Documentation

For this project, an interface which combines search functionality with SNOMED CT subset values was created. Developers created a web server at UHN that applications could query to search for SNOMED CT terms and subsets. This server implemented a faster, more intelligent search algorithm and real-time calculation of related concepts. For example, if a clinician indicates that bone tenderness was during a head exam, searching for a list of anatomical site options should give precedence to bones in the head. This project is currently in a

pilot phase, and data completion rates could not yet be measured.

Challenge 2: Gathering and validating template specifications that use SNOMED CT subsets

The subset mechanism enables concepts to be grouped together for "a particular language, dialect, country, specialty, organization, user or context". [6] Existing, published subsets could not address the specificity requirements of our projects. Project analysts worked with clinicians to determine the desired template specifications and the associated mapped SNOMED CT values. For example, an analyst worked with gynecological oncologists to create lists of the procedures, diagnoses, findings and tumour locations relevant to ovarian cancer. These mappings required validation for semantic correctness by a SNOMED CT specialist.

Process Challenges

Collecting, mapping and validating the SNOMED CT terms was time-consuming and project timelines had to accommodate the additional work required. (Table 1) This process involved continual communication with clinicians to identify, refine and verify mappings.

Table 1-Summary of work to gather SNOMED CT Specifications

Project	Ovarian Cancer Operative Note	Ambulatory Documentation
# of analysts	1	5
# of subsets	38	138
# of mapped concepts	276	1254
# of work hours	50	480
# of incorrect mappings	34	65
% of incorrect mappings	12%	5%

Short forms used by clinicians were a frequent cause of incorrect ontological mapping. These short forms are meaningful to clinicians, but are ambiguous or lack specificity for others without medical experience. For example:

1. In orthopedics, the term "SLAP tear" is a short form for describing a tear to the labrum.
2. In ovarian cancer, the term "lesser sac" is a short form for describing the omental bursa. The term "left adnexa" is used to describe the left uterine adnexa, but it could also refer to the left ocular adnexa.

Challenge 3: Handling SNOMED CT subsets and extensions

Out of the 1530 concepts mapped, 211 terms were not found in the January 2009 release of SNOMED CT (Table 2). These were split primarily into two categories:

1. Terms that lacked a higher degree of detail. Example: "left femur" as opposed to solely "femur".
2. Terms that were extremely specific to a specialty or service such as "Surgical repair of facial fracture" or "Debulking of tumour for symptom relief".

SNOMED CT lacked the synonym preferred by UHN clinicians for 101 concepts. (Table 2) Examples include "ovarian cancer" instead of "cancer of the ovary", and "Abdominal ultrasound" instead of "Ultrasonography of abdomen".

Table 2-Summary of SNOMED CT mapping problems

Project	Ovarian Cancer Operative Note	Ambulatory Documentation
# of mapped concepts	276	1254
# of missing synonyms	43	58
% of missing synonyms	16%	5%
# of missing concepts	43	168
% of missing concepts	16%	13%

Supplemental codes beyond SNOMED CT can be created to capture these outliers by using the mechanisms of extension and post-coordination. Canada Health Infoway (CHI) is responsible for managing a pan-Canadian extension and submitting new concepts to be evaluated and incorporated into the SNOMED CT core content. This process results in a delay for new SNOMED CT concepts to be approved and included in future releases. For project timelines it was essential to implement a form of local extension mechanism and to not be dependent on the approval process. Designing a local mechanism required the following considerations:

1. The vocabulary specialist was required to validate against adding semantically incorrect, ambiguous or poorly defined synonyms and concepts to the extension.
2. Local extension data had to be represented in a format that could be searched using the same mechanism for core content, and later mapped back to assigned ID's in the pan-Canadian extension and core dataset.
3. A liaison must be appointed to work with standards bodies and working groups, to manage submissions for new content and extension requests.

Challenge 4: Creating algorithms and technological infrastructure for generating fast, meaningful, non-redundant search results

SNOMED CT provides sets of pre-generated indexes to improve the speed of searches. Much like the index in the back of a book, indexes provide shortcuts to the desired SNOMED CT concept. The indexing mechanisms provided with SNOMED CT were implemented, but still yielded unwieldy search results. A keyword-based search for "Pain" returns 3790 results in the January 2009 release. Of the 1280 terms that are current and in a clinician-readable format, 465 are situations, procedures or therapies and are not semantically compatible to be selected as a "symptom". The remaining 815 terms require additional refinement to present an appropriate list of search results. Development of search algorithms with the following capabilities was required:

- Terms relevant to a specialty and more frequently used would appear higher in the search results.
- Unnecessary synonyms would be hidden.
- A search could be limited to terms that fall under a certain classification.
- The above search capabilities would also apply to concepts and relationships from the local extension
- Search capabilities had to be fast and efficient.

Search Algorithms

A technical specialist with experience in numerical methods and algorithm analysis was required to design a search algorithm that could perform well in a multi-user environment.

To search a specific classification the algorithms must traverse SNOMED CT's structures to locate concepts that are linked by 1 or more "is a" relationships. The "is a" relationship defines a concept's ontology relative to its parent concepts. For example, liposuction is a "cosmetic surgery (procedure)", and cosmetic surgery is a "surgical procedure". Therefore, a searching algorithm can start at the concept for "surgical procedure" recursively query all its child concepts and its child concepts' children. Benchmarks showed that this approach was too slow.

To address searching performance all possible inferred relationships were pre-generated. The collection of these relationships is called the *transitive closure*. Figure 1b illustrates the additional relationships that would be stored in addition to the relationships in Figure 1a.

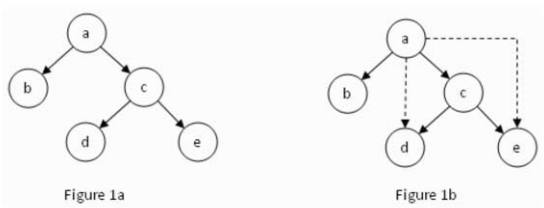

Figure 1 – Transitive Closure Illustration

Several attempts were required to successfully generate the transitive closure. The number of "is a" relationships ballooned to over 5,000,000. Further benchmarking demonstrated that the search response time using transitive closure remained constant no matter the number of child concepts.

IT Infrastructure

Search performance on the terminology server depends on factors such as network traffic and server load. IT specialists were consulted to optimize the performance of the terminology server using load balancing and database optimization.

Considerations

Further analysis and evaluation of the evolution of an ideal process for implementing SNOMED CT is necessary. Additional usability testing and analysis of data completion would assist in identifying the ideal GUI for SNOMED CT integration. Search algorithms can be improved with the help of computer experts. Institutional hardware and budgetary constraints must always be considered. The Electronic Ambulatory Documentation project requires further analysis to determine the effectiveness of the intelligent search algorithms.

Few studies have analyzed the impact that SNOMED CT changes have on clinical applications already in use or those undergoing implementation. [7] Challenges remain when integrating SNOMED CT standards into existing clinical information systems and the continued use of these standards in future EHR systems.[8]

Conclusion

SNOMED CT's comprehensiveness and tree-based data structures created a variety of implementation and resource challenges. Specialists from multiple disciplines had to be consulted for their specific project management, data modeling, technical, or clinical skills. The implementation process evolved and identified the need for several roles and skills. Table 3 identifies the roles and skill sets that were used for SNOMED CT integration across the three projects.

Table 3-Roles and skills required for SNOMED CT Integration

Role	Skills
Clinicians	• Clinical Knowledge for application design • Evaluate effectiveness and clinical value of application
Project Management	• Manage collaboration between disciplines • Facilitate communication between standards organizations • Evaluate clinical requirements, gather specifications and map terms to SNOMED CT codes
SNOMED CT data vocabulary	• Validate SNOMED CT code mapping • SNOMED CT data modeling experience for validating extension data • Train project team in SNOMED CT
Usability	• Usability testing • GUI design
Computer Science	• Improve and evaluate performance of search algorithms and data structures
Information technology	• Load balancing of servers • Database optimization

Figure 2 demonstrates the knowledge transfer required between the various roles involved.

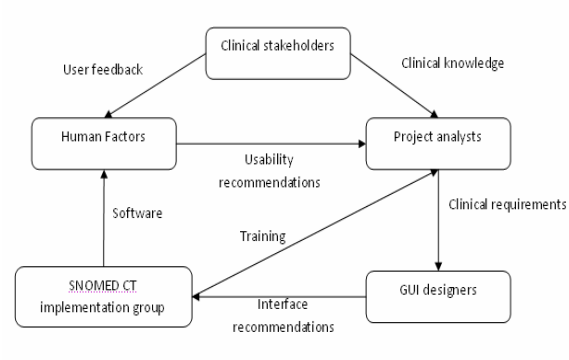

Figure 2 - Knowledge transfer between roles

Through the challenges presented in these various projects, an implementation process was established that helped our teams create working implementations of clinical documentation software that used SNOMED CT to encode data:

1. Project analysts worked with clinicians to obtain requirements for content, synoptic terms, and application workflow.
2. Project analysts and GUI designers collaborated to evaluate clinical requirements and design the appropriate interface.
3. The SNOMED CT implementation group developed the technical implementation and worked with project analysts to map values to SNOMED CT concepts.
4. When available, human factors engineers evaluated application usability at the Centre for Global eHealth Innovation in Toronto. Feedback was evaluated, and incorporated into the application design.

With additional future collaboration, experiences from other SNOMED CT implementations will only improve this process further.

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Semantic Reasoning with XML-based Biomedical Information Models

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Abstract

The Extensible Markup Language (XML) is increasingly being used for biomedical data exchange. The parallel growth in the use of ontologies in biomedicine presents opportunities for combining the two technologies to leverage the semantic reasoning services provided by ontology-based tools. There are currently no standardized approaches for taking XML-encoded biomedical information models and representing and reasoning with them using ontologies. To address this shortcoming, we have developed a workflow and a suite of tools for transforming XML-based information models into domain ontologies encoded using OWL. In this study, we applied semantics reasoning methods to these ontologies to automatically generate domain-level inferences. We successfully used these methods to develop semantic reasoning methods for information models in the HIV and radiological image domains.

Keywords:

Knowledge bases, Medical informatics applications

Introduction

The Extensible Markup Language (XML) has recently become an important technology in many medical domains, driven primarily by the desire for greater interoperability between biomedical software applications [1]. XML is used extensively to define *information models* that describe the structure and content of biomedical data that can be exchanged between applications. The general approach is to define the structure and content of an information model using XML Schema [2] and to publish this model to enable the production, consumption and validation of XML documents that conform to the model. Some organizations are working to define standard information models for particular domains [3]. For example, the Annotation and Image Markup (AIM) Project of the U.S. National Cancer Institute's cancer Biomedical Informatics Grid has defined an information model to describe annotations on radiological images [4]. Many custom models are produced for particular biomedical systems to support downloading or uploading of application data. Irrespective of their origin, these information models have become invaluable tools for dealing with the high degree of heterogeneity that is typical in biomedical data.

As useful as they have become, data in XML-based information models are not typically in a form that is directly suitable for reasoning. When dealing with these models, system developers must develop custom software to import model content and map it to internal application formats, where it can then be manipulated. This process is labor-intensive and time-consuming and is usually heavily customized to both the source information model and the final reasoning tasks. There is a pressing need for more principled methodologies to automate these processes. Ontologies provide a means of tackling this informatics challenge. The low-level information defined by information models can be significantly enhanced by transforming the data to domain-level content described using ontologies. Automated reasoning tasks can then be applied to the resulting domain-level information. These tasks can include classification, verification, temporal and spatial reasoning, and the generation of high-level domain abstractions that can be used directly by system users. This approach to reasoning with information model data provides an opportunity to leverage the reasoning mechanisms provided by ontology-based tools and to exploit the increasing use of ontologies in biomedicine.

Background

The Web Ontology Language (OWL; [6]) is increasingly being used in biomedical applications. Although OWL and XML share similar content storage goals, OWL provides much more powerful features both for representing semantic information about content and for reasoning with it. In combination with the OWL-based Semantic Web Rule Language (SWRL; [7]), OWL provides facilities for developing very powerful reasoning services. Many XML information models in biomedicine use standardized terms defined using ontologies. For example, the AIM information model supports the use of RadLex terms [5] when describing the anatomic structures in image observations. In general, however, beyond the use of these term references, there is no direct interoperation path between the data in XML-described information models and OWL ontologies. Hence, before reasoning services can be developed, this mapping challenge must be addressed

A variety of XML Schema to OWL mapping tools have been developed [14-15]. These tools typically provide custom mapping languages in combination with graphical user interfaces to allow users to produce OWL equivalents of XML Schema-described documents. The mappings supported by these tools

are generally low level and structural. Most could support the steps required to transform XML-described biomedical information models to their OWL equivalent. However, the more complex transformations needed to generate domain ontologies are beyond the capabilities of these tools. In biomedicine, the temporal components of these mappings can be particularly complex. An array of layered knowledge transformations are often required before the information is directly suitable for reasoning. These transformations usually demand custom solutions. The different approaches currently used to address these tasks can produce a disconnected, fragmented workflow. Integrating the various tools and methods that perform information model mapping, domain model generation, and the final reason tasks could help produce a streamlined end-to-end process that lowers the overall development effort.

A suite of tools to provide this workflow must support: (1) mapping information models to their ontolgical equivalents; (2) mapping these data to domain ontologies; and (3) developing standardized reasoning approaches for processing the resulting information. In this paper, we describe the development of such a set of tools. We outline a workflow that uses these tools to transform XML-based information models into domain ontologies encoded using OWL and then perform a variety of reasoning services on this domain knowledge. We show how we have applied these techniques to perform semantic reasoning with data contained in XML information models in the HIV and radiological image domains.

Methods

Our approach to transforming an XML-based information model to an OWL domain ontology comprises three tasks: (1) produce an OWL equivalent of an XML-based information model, (2) transform its content into instances in an OWL domain ontology, and (3) define and implement domain-level reasoning tasks that use the domain ontology. The goal is to produce an automated process that takes XML-encoded information model documents, transforms them to instances in an OWL domain ontology, and to then perform semantic reasoning with these domain-level instances.

Transforming an XML Information Model to OWL

This step requires development of an OWL ontology to represent the information in the original XML information model. The goal is to transform the XML Schema-described information model into an ontological representation that defines a semantically equivalent information model. This model must represent all the concepts in the original XML model. This transformation is performed by creating classes and properties in the OWL information model that correspond to respective components in the source information model.

We developed a tool called XMLMaster to define these transformations. XMLMaster was written as a plugin to the popular Protégé-OWL ontology development environment [8] and provides a graphical user interface that allows users to interactively define mappings between entities in an XML document and concepts in an OWL ontology. It can be used to define mappings between an XML model and an existing OWL ontology, or it can generate a new OWL ontology as the target of these mappings. We used this latter mode to create an OWL information model that corresponds to a source XML-encoded information model. These mappings were stored by XMLMaster in a mapping ontology. They contain a specification of how entities can be mapped from an XML document to instances in an OWL ontology. We then used an associated tool called XMLMapper to take the mappings and to automatically transform XML documents to OWL ontologies. As part of a workflow, XMLMapper can be used to process streams of XML documents and populate an OWL knowledge base with the resulting transformed content.

Most XML-based information models are designed to be somewhat human readable, so generally the transformations are not structurally complex. In many cases, the structure of the information model in OWL will be similar to the structure of the XML information model. However, specialized transformations are often required to deal with references to external terminologies. Such references to terms in controlled terminologies are common in biomedical information models. The mapping process must maintain these links if possible. XMLMaster supports links to these external terminologies if they are encoded using RDF or OWL. It currently does not support automatic references to terms defined to non OWL or RDF ontologies. In these cases, the original term identifiers are simply mapped unchanged, with additional annotations describing the source terminology.

Transforming an OWL Information Model to a Domain Ontology

An information model does not generally represent data in a form that is directly suitable for use in the complex reasoning typical in biomedicine. The second mapping step is generally required to transform instances in the OWL information model to instances in a specialized domain model. Domain-level reasoning tasks can then be defined using this representation. This second stage is typically far more complex than the primarily structural initial mapping process. It often requires in-depth domain knowledge and its requirements for data transformation are far more demanding. Depending on the complexity of the domain ontology, this process may require several mapping layers that operate at successively higher levels of abstraction. While several OWL-based mapping tools are available, they generally do not offer the flexibility to easily capture the full array of possible transformations required.

Instead of using one of these tools, we used OWL and its associated rule language SWRL [7] to define the mappings. SWRL provides particularly strong support for this type of knowledge transformation. Its tight integration with OWL allows it to be used to define knowledge-level mapping rules that are fully aware of OWL's complex semantics. Moreover, most OWL classifiers support SWRL, so they can be used to semantically validate these mapping rules. Once defined, the rules can be stored in an OWL ontology and later executed to transform information model instances to domain ontology instances as part of a mapping workflow.

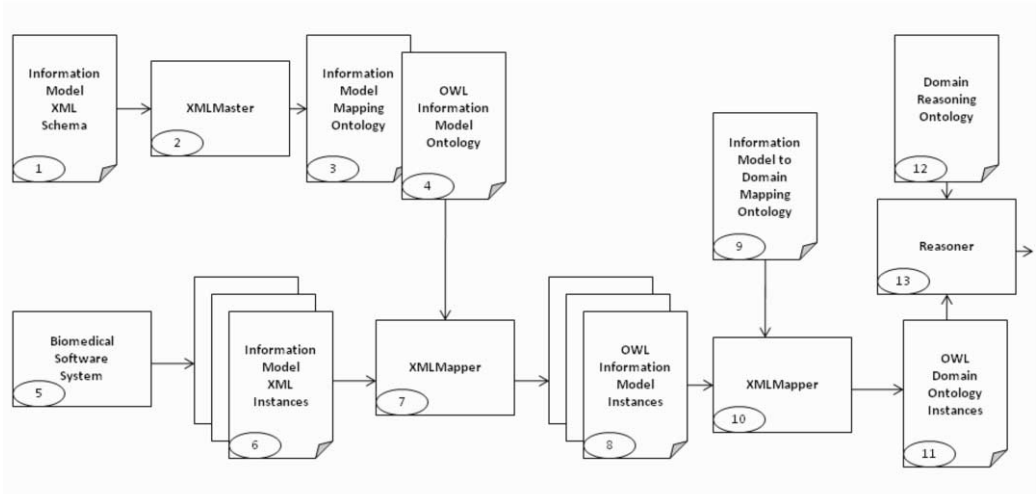

Figure 1-Outline of workflow to take XML-encoded information model instances and transform them to an OWL domain ontology and perform reasoning with them.

Reasoning Ontology and Querying

Once an XML information model is transformed to an OWL domain ontology, users can develop knowledge-level ontology-based reasoning mechanisms to work with their content. A wide array of possible reasoning tasks can then be defined. Common tasks in biomedicine include classification, and spatial and temporal reasoning. Temporal reasoning tasks are particularly central to many biomedical applications. OWL itself provides strong support for classification. It has relatively weak support for temporal and spatial reasoning, however. Fortunately, SWRL provides basic support for spatial reasoning using its core language operators. Crucially, it provides a mechanism to define custom libraries for specific types of reasoning processes. We used this extension mechanism to develop a temporal reasoning library [12].

In some cases, not all reasoning can be carried out using OWL and SWRL, and custom application methods are required. To support the necessary extraction of content from domain ontologies, we used SQWRL, a language that we developed [9]. SQWRL (Semantic Query-Enhanced Web Rule Language) is a SWRL-based query language that can be used to query OWL ontologies. SQWRL supports queries that extract information from ontologies at the knowledge level, and thus minimize the amount of custom application logic required to process this ontology-encoded information.

Defining an Automated Workflow

We defined a workflow to take an XML-based information model and perform domain-level OWL and SWRL-based reasoning with the information in the model. The numbered steps in Figure 1 outline the sequence of steps in this workflow.

We first took an XML Schema-described information model (1), and used the XMLMaster tool (2) to define mappings to an equivalent OWL information model. The XMLMaster tool also produced a mapping ontology (3) that defined how XML documents are transformed into instances of the OWL information model (4). We then produced data (5), which are encoded as document instances of the XML information model (6). These documents were fed through XMLMapper (7), which used the mapping ontology defined by XMLMaster to produce OWL information model instances (8). A separate SWRL-based mapping ontology defined how these instances were mapped to a domain ontology (9) and were used by XMLMapper to transform the instances (10) to domain ontology instances (11). Finally, a domain-level OWL reasoning ontology (12) was applied to these domain instances to reason with them (13).

Once defined, this process can establish a completely automated workflow that takes a stream of XML-encoded information model instances, transforms them to OWL, and reasons with them to generate domain-level inferences.

Results

We used our methodology to generate automated workflows for two applications: (1) reasoning with radiological image annotations for tumor assessment; and (2) discovery of associations between gene mutations, drug regimens, and outcomes in HIV anti-retroviral therapy.

Reasoning with Image Annotations

The AIM Project [4] recently developed an information model that describes the semantic contents of radiological images. AIM defines an XML-encoded information model that describes anatomic structures and visual observations in the images. Information about image annotations is recorded in its information model, with the goal of enabling the consistent representation, storage, and transfer of the semantic meaning of imaging features. A variety of tools are being developed to produce image annotations in AIM format.

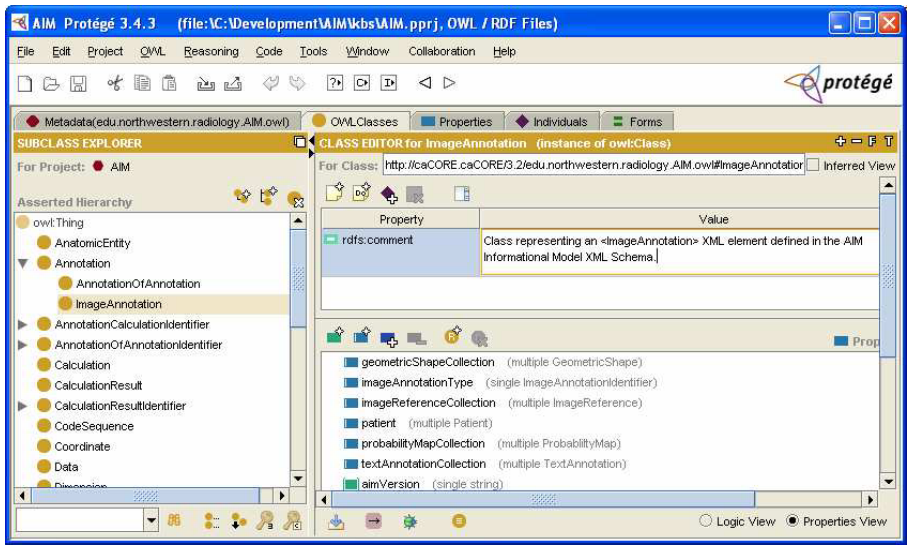

Figure 2-Screen shot of Protégé-OWL tool showing part of AIM information model encoded in OWL.

Our reasoning task employed three types of reasoning subtasks: classification, spatial reasoning, and temporal reasoning. It concentrated on classification of image findings as measurable and non-measurable using a combination of semantic information about the location and type of finding and its calculated length. These reasoning tasks were encoded using OWL and SWRL. Rules for this subtask included: classification of findings as pathologic or non-pathologic based on the imaging observation in the image annotation; temporal classification lesions as baseline or follow-up based on their temporal relationship to the start of therapy; and classification of image findings on baseline images as measurable or non-measurable based on the length of the observed mass or nodule.

We evaluated our system by defining a process to reason about cancer lesions for estimating tumor burden [11]. We used 116 AIM XML annotated images from 10 cancer patients who had serial imaging studies. Lesions in the original images were annotated in AIM format. We successfully defined a process to map image annotations encoded using AIM into OWL (Figure 2) and to reason with the resulting annotations. The image annotations were processed by our system to perform automated reasoning about the image findings.

The inferences from our system were reviewed by an oncologist, who confirmed that they were valid based on his analysis of the image annotation information encoded as instances of the AIM XML information model. In qualitative terms, the oncologist believed that our automated workflow can help streamline the process of evaluating tumor burden.

Outcome Reasoning for HIV Antiretroviral Therapy

Associations between gene mutations, drug regimens, and therapy outcomes is central in HIV therapy. In HIV research, for example, a mutation on the viral genome may be associated retrospectively to past administration of a specific drug or prospectively to the occurrence of poor clinical outcome with one or more drugs. Establishing such temporal associations may help scientists understand how certain mutations in the genome reduce drug efficacy, and can they help healthcare providers design treatment strategies.

To study drug resistance in the context of clinical care, researchers at Stanford University have developed a research system called the Stanford HIV Drug Resistance Database (HIVdb) [10]. This database contains time-stamped data on drug regimens, HIV reverse transcriptase (RT) and protease sequences, and HIV viral load collected at local clinics. Some of this information is downloadable as XML-encoded information model instances from the HIVdb website. An XML Schema for this information model has been published by the developers of HIVdb [13]. This information model describes individual patient therapies—which are termed *treatment change episodes* (TCEs)—and lists the drugs in the therapy, together with each patient's viral load response and mutation information treatment. By using information encoded in TCEs, the website can suggest ranges of suitable drug therapies.

Reasoning with TCEs requires strong temporal reasoning support. As mentioned, we have developed a temporal reasoning library for use with SWRL [12]. We used it to develop domain reasoning tasks defined in terms of these TCEs. These tasks encode several drug resistance interpretation algorithms for predicting the value of genotypic resistance test interpretation algorithms that have been described in the literature [10]. Subtasks of the reasoning task include examining patient treatment histories for particular treatment combinations, viral load patterns, and genotypic test results.

Using the HIVdb XML Schema, we defined an OWL equivalent of the information model it describes. We mapped the

information model to a domain ontology modeling TCEs and then developed a temporal reasoning module to reasoning with the resulting OWL instances. The reasoning mechanisms use OWL and SWRL, and produce high-level abstractions of patient outcomes based on a temporal analysis of their viral loads. This information can then be used for further analysis. The ultimate goal is to replicate a large subset of the therapeutic suggestion functionality of the HIVdb site. We successfully defined an automated workflow that took XML instances of the TCE information model and generated an intermediate analysis of patient outcomes.

Discussion

The increasing use of XML information models in biomedicine provides an opportunity to develop methods to automatically reasoning with the content of these models. However, XML-based information models do not typically represent information in a form that is directly suitable for reasoning—they provide a standardized interchange and storage format only. Elevating the information content from this primarily structural level to the domain level is a prerequisite to performing semantic reasoning. Using a suite of open source Semantic Web tools, we show how we have developed an approach to perform this transformation and to carry out OWL-based reasoning on information encoded in XML-based information models. We show how semantics reasoning methods were applied to these ontologies to generate domain-level inferences. Our approach establishes an automated workflow, taking XML-based information models, transforming them to an OWL domain ontology, and reasoning with the resulting information to generate inferences necessary for the domain task. We applied this workflow to perform semantic reasoning with data contained in information models in the HIV and radiological image domains.

Our approach can be used to take any XML-based information model, generate its OWL equivalent, and then reason over it to produce high-level abstractions. This approach maintains all knowledge of these transformations in OWL mapping ontologies. As a result, these mappings can be maintained at the knowledge level using standard OWL tools. Modifications to the mappings to cater for changes or extensions to the information model or domain ontologies can also be carried out using these tools. We believe that this approach provides a flexible, expandable, and robust mechanism for defining the information transformations necessary to support semantic reasoning on a large variety of biomedical data.

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Characterizing Consumer Health Terminology in the Breast Cancer Field

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Abstract

Despite the large availability of medical information on the Internet, health consumers still encounter problems to find, interpret and understand this information. These problems are mainly due to their lack in medical knowledge and the difference between their language and the language of health professionals. In order to propose information retrieval services more adapted to health consumers language and knowledge, we have developed techniques to collect, identify and analyze the terms and the expressions used by lay persons to talk about breast cancer. The study of health consumers' language is a relatively recent research field. Many studies have been conducted to analyze and characterize the vocabulary used by health consumers to talk about medical subjects in English. We have conducted the same study for the French language in the breast cancer field. We have gathered a corpus of texts to identify terms and expressions used by health consumers who talk about breast cancer in French. The terms have been organized in a concept-based terminology. This terminology has been analyzed on several levels: concept level, term level, term-concept level and finally relation level.

Keywords:

Consumer health terminology, Natural language processing, Breast cancer.

Introduction

A person when she/he is faced with a health problem needs to understand her/his illness, its diagnosis and the different treatment options that she/he is liable to follow. The doctor still remains the more natural way to find such information. However, more and more people are turning to different resources on health information.

A Eurobarometer survey published in 2003 [1] showed that the main source of health information used by European citizens is health professionals (pharmacists, doctors, etc.) 45.3%, followed by television 19.8%, books and medical encyclopaedia 7.7%. Internet is less widely used with 3.5%.

The survey also showed that only a small proportion (23.1%) of people in the EU use the Internet to find health information. Nevertheless, 41.5% of the people within the EU think that the Internet is a good way to get health information.

The Internet has become a popular way to access up-to-date information, and more and more people are turning to it to find information about health. However, technical, cultural and linguistic barriers are numerous when using Internet sites since most health-related information is available in English and uses specialized medical terminology [2-4].

A patient-oriented terminology aims at gathering the different ways lay people express themselves and talk about health topics, and linking them to the medical jargon used by health professionals. Using such a terminology will help bridging the communication gap between the two communities [5].

A terminology reflecting the patients' common language is the first phase of an ambitious project aiming at helping patients to better understand and master their health situation. We have worked on a common terminology in the field of breast cancer. This particular domain has been chosen because of its interest for the citizens and also as a testing ground for a methodology which could be extended both to other health domains and to other languages.

Although it has been long recognized that health consumers talk about and interpret differently medical concepts than health professionals, little efforts have been done to effectively build terminologies to bridge the gap between the two communities. These terminologies gather the terms used by health consumers to talk about their condition, and link them to the underlying medical terms and concepts.

An open source and collaborative development of a consumer health vocabulary has been initiated by the Harvard Medical School (HMS) and the National Library of Medicine in the USA [6]. Their aim is to develop an open source Consumer Health Vocabulary (CHV) by identifying consumer friendly names of medical concepts, correctly map them to UMLS (Unified Medical Language System) the reference terminology in the health domain, and create consumer health-specific concepts and relations. They have gathered 12 millions query log data and then performed automated term mapping and statistical analysis to select candidate terms for manual review. A web-based tool for collaborative review has also been devel-

oped. They have exhibited 90 000 concepts over the whole health domain in their consumer text corpus. The development of the CHV is still in progress.

In France, a team in the Rouen University Hospital has initiated the CISMeF project (acronym for Catalog and Index of French Language Health Resources on the Internet)[1] in February 1995. Its main objective is to catalog and index the most important and quality-controlled sources of institutional health information in French. For this purpose, CISMeF uses: the MeSH thesaurus (the National Library of Medicine's controlled vocabulary thesaurus) and several metadata element sets, including the Dublin Core (a metadata standard). In December 2007, the number of indexed resources totalled over 41 300 with a mean of 80 new resources each week.

CISMeF-patient is the French counterpart to MEDLINEplus [7]. It is a dedicated Website for patients, their families, and the general public. CISMeF-patient has been under development since 1997. CISMeF-patient has been created as a response to a growing need for consumer health information and to extend the awareness of quality health information resources available on the Internet. It uses the MeSH thesaurus end metadata to index web sites. The team has included many health consumer terms into the MeSH in order to facilitate health information seeking for non-professionals.

Materials and Methods

In this section, we describe the materials and the methodology used to develop the breast cancer terminology. This work is based on the experience of Tony Tse with the difference that T. Tse has worked on the whole health domain and for the English language [8].

Building a breast cancer terminology from a corpora of texts

A terminology is the set of words and expressions used to designate the concepts of a domain. A breast cancer terminology for lay people is made of the terms (i.e., words and expressions) that patients use to speak about breast cancer and also the terms they are liable to meet in their medical files or in the breast cancer literature. Therefore, a breast cancer terminology for lay people should contain terms specific to the patients' language, such as *breast pain* for *mastodynia*, but also medical terms such as *pyrexia*, which they are faced with.

Terms which are considered as synonyms are grouped into concepts. The concepts themselves are structured through different relationships. For example: *"Chemotherapy"* Is-A *"Breast cancer treatment"*. We have collected the terms from two types of corpus of texts: a mediator corpus and a health consumer corpus. Tony Tse calls "mediator corpus" a set of texts written by health information mediators (i.e., persons whose intent is to inform or influence the lay public about various medical topics, products, and services) and "health consumer corpus" texts written by participants in Web-based health discussion forums [8].

[1] http://www.cismef.org

The mediator corpus has been built manually by selecting 575 documents issued from the answers of the search engine "Google" to the query "breast cancer". The selection has been done according to several criteria: domain representativeness, targeted public, page author, complexity of the used language. The consumer corpus has been built automatically by the extraction of 9 843 users' messages on two Web-based breast cancer discussion forums: The French League against Cancer and Essentielles.net.

We have used statistical methods to extract n-grams (a n-gram is a sequence of n consecutive words) from our corpora. We have obtained 6 896 candidate terms from the mediator corpus and 11 723 candidate terms form the consumer corpus.

The analysis of the list of candidate terms has been done manually with the help of a concondancer, a tool which helps visualizing each expression in its context [9]. It allows the user to look for terms in the corpus by using regular expressions and it produces concordances, (i.e., lists of occurrences of a term in a source text, surrounded by an appropriate portion of its original context). We have also studied the structure of web pages to identify the important concepts of the domain and to get a first hierarchy of concepts. The building of the terminology has been done progressively by studying every term and creating the appropriate concepts and relations every time it is needed.

The Protégé ontology editing tool has been used to represent the terminology in several standard languages including the W3C languages RDF(s) and OWL. By doing so, the terminology becomes usable by computer applications.

- We have tried to map the concepts of this terminology to those of UMLS and CHV. The connection between these terminologies has been done manually by using the UMLS identifiers, which are attached to the concepts in both terminologies (UMLS and CHV). Only the case of exact matches has been retained. We have obtained 83% of exact matching, 3% of partial correspondence and 14% of no correspondence.

Terminology analysis

The terminology has been analyzed on several levels:

- Term level;
- Concept level;
- Term-concept level;
- Relation level.

The objective of this analysis is to better understand the way lay persons talk about concepts and notions in the breast cancer field and structure them. Recent studies have shown significant differences between the professional and lay languages. However, these studies were conducted on the entire health domain and for the English language [8,10]. The produced terminology will be the core of an Information Retrieval system.

Term analysis

Many studies have used the length of the terms as an indicator of their complexity in order to evaluate the readability of documents [10-12]. We have compared the length of the terms coming from the two types of corpus. The results are shown in Table 1.

Table 1- Length of terms

	Health consumers	Mediators
Mean characters/term	21,5	22,8
Mean words/term	3.1	3

This comparison does not show significant differences between lay terms and mediators terms. The length of terms in this context is not an indicator of their complexity.

Concept analysis

The mapping of the breast cancer terminology to UMLS terms has revealed many interesting situations:

- Five concepts have multiple correspondences in UMLS. For example: *Cancer de l'ovaire* can be mapped to *Ovarian carcinoma* or *Malignant neoplasm of ovary.*
- Two pairs of concepts have a unique correspondence in UMLS. The concepts *Mammography* and *Mammogram* are mapped to the concept *Mammography* in UMLS. The same thing is observed for the concepts *Primipare (primipare)* and *Primiparité (primiparity)* and the concept *Primiparity.*

These cases show problems in the UMLS conceptualization. For example, *mammography* and *mammogram* designate two different concepts: a type of x-ray imaging used to create detailed images of the breast for the first, and an x-ray picture of the breast for the second.

Terms-Concepts analysis

Expressive variability of concepts: For each concept, we have calculated the expressive variability (number of terms which designate the concept) [13]. The objective of this step is to learn about the types of concepts with a high expressive variability. The mean of the expressive variability in the terminology is 2.16 terms. Most concepts are designated by one term (Figure 1).

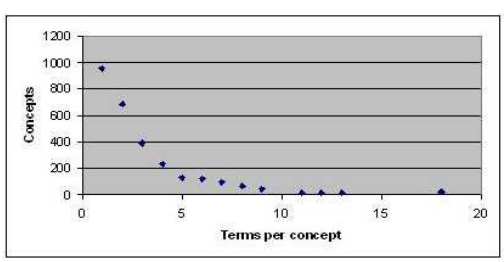

Figure 1- Terms distribution per concept

The study of the concepts with an expressive variability higher than 5 has shown that these concepts concerns medical concepts that we encounter in everyday life and which correspond to complex medical terms. Lay persons tend to describe concepts, which lead to a big production of terms. However, concepts with an expressive variability lower than 5 are of two types: either very well-known concepts like names of common organs (liver, lung, etc.) or highly technical terms like: tamoxifene.

Overlapping between health consumers and mediators terminology: We have compared the sets of terms coming from the two types of corpus (health consumers and mediators) in two steps:

1. Conceptual overlapping: identify the concepts common to both terminologies and the concepts specifics to each of them.
2. Terminological overlapping: for the common concepts, identify the terms common to both terminologies.

The Table 2 shows the results of this comparison.

Table 2- Overlapping between the two terminologies

	Common	Health consumers	mediators
Concepts	1 254	8	25
Terms	2 238	289	182

Relation analysis

Health consumers, in addition to their terminological problem, have often difficulties to understand how medical concepts are related. Among the defined relations in the terminology we have used the relation *Relation_X* to link two concepts without specifying the relation. This type of relation is used to define links between concepts that health consumers link without a medical argument. For example, the concept *contraceptive pill* is linked to the concept *breast cancer* because some health consumers believe that it is the case, although it is not scientifically established. *Relation_X* is also used to link the concepts which are not well understood by health consumers. For example, the concept *Vagina disorders* and the concept *Vaginitis* are linked by both relations *Is-A* and *Relation_X.* Most of health consumers believe that *vagnitis* embraces all the *vagina disorders*; however *vaginitis* represents only the inflammation of the woman's vagina. The use of this type of relation for representing this kind of phenomena preserves the "good" structure of the terminology.

Results

In the resulting breast cancer terminology, we have 1 287 concepts, designated by 2 783 terms in French. We have defined a set of 61 relations in addition to the classical Is-A and Part-Of relations to structure the concepts of the terminology.

Discussion and Conclusion

This work has shown some differences that exist between professional and health consumer terminologies. We have observed that the main differences are not at the concept level but at the term level. However, the current ontology representation languages do not offer the possibility to annotate a term by its "technical" level (lay or professional). An interesting alternative is offered by SKOS[2] which provides metadata to indicate the language of a term (i.e., lay or professional).

The bilingual terminology which has been built for breast cancer is the basis of future extensions to other health fields and other languages. The first considered application will be concept-based information retrieval, which will enable people to ask questions by using their everyday words and retrieve results in any language.

Such work is important for both patients and doctors because through a better understanding of her/his medical situation a patient will be able to better collaborate with the doctor, provide him more pertinent information on her/his situation and become a fully responsible partner in the decisions about her/his treatment. Informed Patients require less time for doctor explanations, and may be more likely to comply with doctors' instructions and to adopt a healthy lifestyle [14].

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Exploring Relations among Semantic Groups: A Comparison of Concept Co-occurrence in Biomedical Sources

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Abstract

It has been observed and reported that the patient's mental model of the medical domain is different from that of a health professional and this difference is one of the primary obstacle in the effective communication of health information to patients. In this study, to better understand these mental models, we explored the relations among different semantic groups of concepts in consumer- and professional-generated health content by analyzing concept co-occurrence information in three biomedical sources. We found significant differences in the prevalence of the semantic groups and the strength of co-occurrences between semantic groups in the three sources. The co-occurrence defined by consumers differs from that defined by professionals. The two professional sources have noticeable differences with each other as well. We believe that addressing these differences can help us generate more informative and consumer-friendly health content as well as develop better consumer health informatics applications.

Keywords:

Mental models, Concept co-occurrence, UMLS semantic groups

Introduction

The past decade has seen an exponential increase in the development of health content and informatics applications for consumers. From web sites to search engines to decision support tools to personal health records, a common theme of the applications is to provide consumers with useful information and help them utilize the information to improve their health outcome. However, many obstacles remain: for example, it is recognized that most health information that is accessible to patients in the US is too hard to understand [1, 2]. While millions of consumer search for health information online, their queries are not always efficient or effective [3-5].

To improve consumer health content and applications, prior research has suggested that we need to understand the gap between lay consumers' and healthcare professionals' mental models [5-8]. A better understanding of the lay consumer mental models could help us anticipate consumers' information needs, organize the content being presented to consumers, explain concepts to consumers in a question-answer system or through the process of text simplification, and to provide decision support at the point of need. A related study we have been involved with is the development of a consumer health vocabulary that suggests consumer-friendly synonyms for difficult medical terms [9, 10].

In this study, we examine the differences between a layperson's and a professional's mental models through the use of co-occurrence information. We believe that the co-occurrence of two terms or concepts in a textual artifact indicates the belief of the creator of the artifact that these are related though the exact relation may not be known and by analyzing co-occurrence information we can understand the mental models of the content creators. Here we use the term *artifact* quite broadly to include a wide range of health content types such as consumer health education articles, medical records or a series of terms queried on a search engine.

In the following sections, we analyze and compare the co-occurrence information in three (two professional-generated and one consumer-generated) biomedical sources – a repository of clinical reports, a collection of biomedical journal citations and a log of search queries to a health information website.

Since the number of terms/concepts in these sources is quite large, studying co-occurrence data at the concept-level is too complex and may not be useful. Hence, we use a mechanism to group the concepts into broader categories and analyze co-occurrence information at the group level. This is done in two phases. First, we map the concepts to semantic types defined by Unified Medical Language System's (UMLS®) Semantic Network. UMLS' semantic network defines a set of subject categories, or semantic types that can be used to consistently categorize the more than million concepts defined by UMLS Metathesaurus® [11]. This aggregates all concepts in the three sources to a more manageable 135 categories.

Second, we partition the semantic types into 15 semantic groups using a partitioning scheme proposed by Bodenreider and McCray [12]. This scheme adequately adheres to partitioning principles such as semantic validity (the groups must be semantically coherent), completeness (the groups must cover the whole concept domain) and exclusivity (a concept must belong to a single group). Table 1 has a partial list of semantic groups and examples of semantic types in each group[1]. We refer to the semantic group of the semantic type to which a concept maps as the concept's semantic group

[1] A complete listing is available elsewhere [12]

and the exclusivity principle of partitioning ensures that a concept's semantic group is unique.

By analyzing this co-occurrence information at the semantic group level, we try to understand: a) the differences in prevalence of semantic groups in the three sources; b) the difference in mental model of a health consumer from that of a professional; c) the difference in professional-generated co-occurrence with change in the context of communication.

Table 1 - Common semantic groups and associated semantic types

Semantic Group	Semantic Type (TUI[2])
Concepts & Ideas	Quantitative Concept (T081); Functional Concept (T169); Qualitative Concept (T080); Temporal Concept (T079)
Disorder	Disease or Syndrome (T047); Finding (T033); Sign or Symptom (T184); Injury or Poisoning (T037)
Anatomy	Body part, Organ or Organ Component (T023); Body Location or region (T029); Body Space or Junction (T030)
Chemicals/ Drugs	Organic Chemical (T109); Clinical Drug (T200); Pharmacologic Substance (T121); Amino acid, peptide or protein (T116)
Procedures	Therapeutic or Preventive Procedure (T061); Laboratory Procedure (T059)

Materials and Methods

Data Collection

As mentioned in the previous section, we use concept-level co-occurrence information from two sources of professional-generated health content and one source of consumer-generated health content. The sources and definitions of co-occurrence in these sources are described below. Using these concept-level co-occurrence frequencies, we compute co-occurrence frequencies between semantic groups.

Research Patient Data Repository (RPDR)

This is a centralized repository of physician generated electronic medical reports such as discharge summaries and outpatient notes from several clinics and hospitals in the Partners HealthCare system [13]. Though the number of reports available through RPDR is quite large we used a subset of 5500 discharge summaries and mapped the reports' text to UMLS concepts[3]. The co-occurrence frequency of a pair of concepts is defined as the number of reports in which the two concepts occur in the same section of the report.

UMLS Co-occurrence (MRCOC)

The *mrcoc* table is distributed as part of the UMLS Metathesaurus and contains the co-occurrence frequencies of keywords in MEDLINE citations [15]. As MEDLINE is considered to be a comprehensive source of publications in biomedical journals, *mrcoc* is a good resource for studying concept co-occurrence in professional-generated health content.

MedlinePlus Query Log (QLOG):

MedlinePlus is an open-access website with an extensive collection of health information from the National Library of Medicine, National Institute of Health and other US government agencies targeting lay health information seekers [16]. Users can search the site for health topics of interest. We used an anonymized log of user queries to MedlinePlus as an example of consumer-generated co-occurrence. A pair of concepts is considered to have co-occurred if they (or the terms that map to these concepts) are queried in the same user session (from the same IP address within five minutes of each other)

Calculating co-occurrence of Semantic Groups

In the above sources, co-occurrence frequency is defined only at the concept-level and the frequency at the semantic-type and semantic-group level needs to be computed.

In a given source s, if the co-occurrence frequency of concepts c_i and c_j is $f_s(c_i, c_j)$, the co-occurrence frequency at the semantic-*type* level is defined as $f_s(t_p, t_q) = \sum_{i,j} f_s(c_i, c_j)$ where c_i is of semantic type t_p and c_j is of semantic type t_q. Similarly, the co-occurrence frequency at the semantic-*group* level can be defined as $f_s(g_m, g_n) = \sum_{p,q} f_s(t_p, t_q)$ where t_p belongs to semantic group g_m and t_q belongs to semantic group g_n.

Note that,

- $f_s(X, Y) = f_s(Y, X)$ at the concept-level and hence also at the semantic-type and semantic-group level;
- $f_s(c_i, c_j)$ is undefined if $i = j$, but $f_s(t_p, t_q)$ when $p = q$ and $f_s(g_m, g_n)$ when $m = n$ are both valid and well-defined;
- a concept can be mapped to more than one semantic type and in such cases needs to be considered in calculation of $f_s(t_p, t_q)$ for all t_x to which it maps. A semantic type, however, will belong to exactly one semantic group.

Results

Using the methods described above, we found 1.1 million co-occurrences in QLOG and a comparable number of co-occurrences - 0.8 million - in RPDR. MRCOC has larger number of unique concepts and hence a larger number of co-occurrences (11 million).

Figure 1 shows the co-occurrence distribution of the semantic groups in each source. For example, a value of 13% for the DISO semantic group in RPDR indicates that 13% of all co-occurrences defined in RPDR involved at least one concept of the semantic group DISO. As can be seen in the figure, in all the three sources, the semantic groups Anatomy, Chemical & Drugs, Concepts & Ideas, Disorders and Procedures together

[2] UMLS defined unique identifier for semantic type

[3] The text-to-concept mapping is done using the Health Information Text Extraction (HITEx) [14] system - an open source natural language processing tool.

account for about 85% of all co-occurrences. However in RPDR, *Concepts* is the dominating semantic group (33%) while in MRCOC *Chemicals and Drugs* contributes 43% of all co-occurrences. In contrast to these two professional-generated sources, the consumer-created QLOG data shows higher number of co-occurrences in concepts of semantic group *Disorders (32%)*.

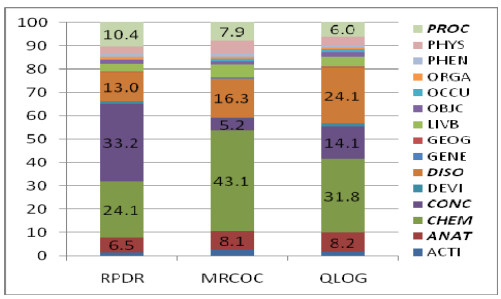

Figure 1- Co-occurrence distribution in each source

It is more interesting to look at co-occurrence between pairs of semantic groups in each of these sources. Figure 2 shows a graph[4] depicting the co-occurrences defined in QLOG. The nodes of the graph represent the semantic groups while the edges show the strength of co-occurrence between the semantic groups. The color and thickness of the edges is proportional to the strength of the co-occurrence between the semantic groups. Additionally, to reduce clutter only the top 20% of the edges have been shown in the graph and loop-edges (source = target) were ignored. Figure 3 and Figure 4 show the graphs for RPDR and MRCOC respectively.

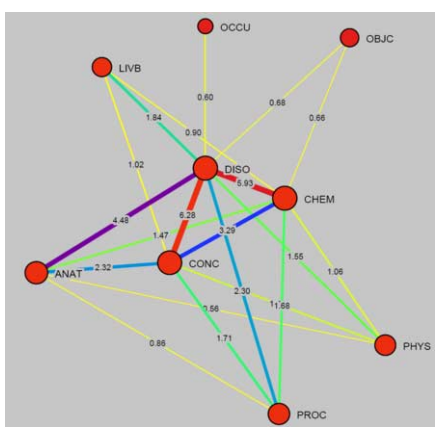

Figure 2 - Co-occurrence in QLOG

In Figure 2 it can be observed that the top three edges are DISO-CONC (6.28%), DISO-CHEM (5.93%) and DISO-ANAT (4.48%) and all three involve concepts of DISO. In RPDR (Figure 3) similar dominance is noted for concepts of CONC with the top three edges being CONC-CHEM (14.4%), CONC-DISO (7.94%) and CONC-PROC (6.12%), while the other professional-generated source MRCOC (Figure 4) has a greater representation from concepts of type Chemicals & Drugs - CHEM-DISO (9.89%), CHEM-ANAT (6.50%) and CHEM-PHYS (4.05%).

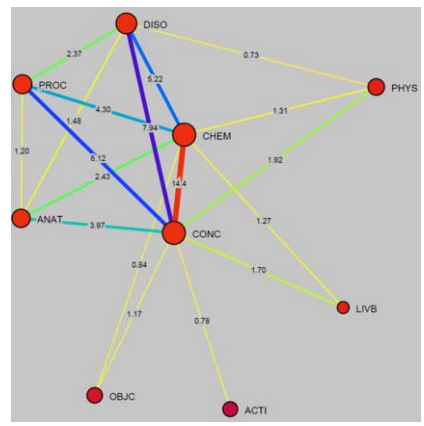

Figure 3 - Co-occurrence in RPDR

We believe that these graphs represent a difference in a consumers' interest in the medical domain and the professionals' interest. The consumers appear to be more inclined to learn about a disease condition and concepts of other semantic groups are explored in their relation to the DISO concept. The other two sources have different focus and the information retrieved from these sources may not be of equal interest to the consumers.

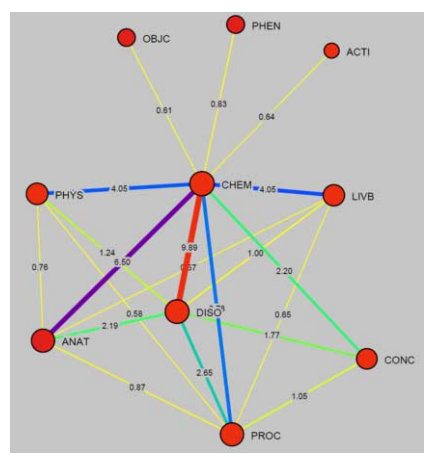

Figure 4 - Co-occurrence in MRCOC

[4] The graphs are generated using visualization software, Himmeli (v3.0.1), provided by the Folkhälsan Research Center at University of Helsinki, Finland.

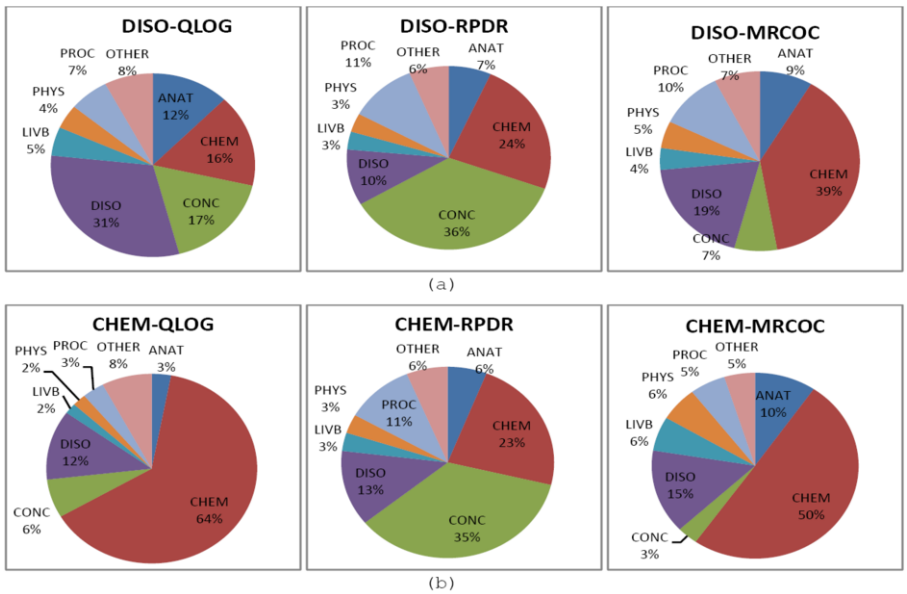

Figure 5 – Charts representing co-occurrence distribution for (a) DISO and (b) CHEM semantic groups in the three sources.

We analyzed the co-occurrence of DISO and CHEM semantic groups from the three sources in greater detail (Figure 5) as we believe they are of higher interest to consumers. The pie charts show the distribution of concepts among the semantic groups when one of the concepts of the co-occurring concept pair belongs to DISO (Figure 5(a)) and CHEM (Figure 5(b)).

Semantic group DISO

Figure 5(a) shows the co-occurrence of concepts of DISO semantic group with each other and concepts of other semantic groups in all three sources. For instance, the 12% ANAT in DISO-QLOG implies that in 12% of all co-occurrences defined in QLOG involving a concept of group DISO, the other concept is of type ANAT. Low frequency groups have been aggregated under OTHER.

DISO in QLOG shows a high intra-group co-occurrence (31%) which probably hints at scenarios where consumers query multiple symptoms they are experiencing or a disease name and follow it up with symptoms that are related to the condition. In neither RPDR nor MRCOC, DISO exhibits similar self co-occurrence. A related observation is the higher co-occurrence of ANAT with DISO concepts in QLOG (patients querying for body parts which are affected or in which the symptoms are manifested).

MRCOC shows a high co-occurrence between DISO and CHEM which may be indicative that in this source the disease terms co-occur with medications that are commonly prescribed to treat the disease or the results of experimental studies (since these are biomedical citations) on the efficacy of a chemical substance in the treatment of a condition. In RPDR, the high co-occurrence between DISO-CONC is consistent with the overall high prevalence of CONC in this source (as seen in Figure 1).

Semantic group CHEM

Figure 5(b) shows the corresponding pie charts for semantic group CHEM. Compared to DISO, CHEM shows a higher degree of intra-group co-occurrence in all three sources.

In QLOG, 64% of the CHEM concepts co-occur with other concepts of the same semantic group. This can mean that when consumers query for a medication or chemical substance they do so in the context of another term of similar type (substitutes or generic alternatives, for instance) or to understand its' chemical composition. The most significant inter-group co-occurrence is with concepts of group DISO (either as prescribed for or as a potential complication of). Similar distribution is observed in MRCOC except for a higher co-occurrence with concepts of ANAT.

CHEM in RPDR, on the other hand exhibits a much higher co-occurrence with concepts of CONC (35%) compared to QLOG (6%) and MRCOC (3%). The self-co-occurrence is also significantly lower.

Discussion

We found significant differences in the prevalence of the semantic groups and the strength of co-occurrences between semantic groups in the three sources. The co-occurrence defined by consumers differs from that defined by professionals. The two professional sources have noticeable differences with each other as well.

We believe these differences are a reflection of the mental models of the content creators in specific communication contexts: QLOG is authored by consumers in the context of information seeking, RPDR is authored by clinicians in the context of documenting patient care, and MRCOC is authored

by researchers (clinical as well as basic science) in the context of describing research studies findings.

In a way, the differences we have found are to be expected. Nevertheless, they have direct implications in consumer health informatics. Professional medical records, for instance, are the content source of many personal health record applications. The differences observed between QLOG and RPDR suggest that the content of medical records in its current form may not sufficiently satisfy patient information needs and has to be re-organized to facilitate information retrieval and understanding by patients.

For example, we have identified that consumers querying signs, symptoms or disorders tend to be very interested in associated signs, symptoms or disorders. While it is fairly easy to find diagnoses in professional or personal medical records, the relations between diagnoses and signs and symptoms are often not explained – this is partially reflected in the relatively low self co-occurrence in the DISO group. For the lay consumers to comprehend the content in their medical records, personal health record applications need to consider ways to help consumers connect the diagnoses with related signs and symptoms.

Similarly, consumers who queried for medications appeared to be very interested in other medications. In this regard, medical records are quite different – the self co-occurrence in the CHEM group in RPDR is 23% while it is 64% in QLOG. On the other hand, CHEM in MRCOC showed fairly high self co-occurrence (50%) compared to RPDR, suggesting that medications are discussed far more frequently in the context of other medications in biomedical literature than in medical records. While we would not expect an average consumer to use medical journals as the primary information source, the information in medical records may not be sufficient either.

We recognize that our analysis just scratched the surface in terms of understanding the layperson's and professional mental models. However, we hope the differences revealed by this study will help draw the consumer health informatics researchers' and developers' attention to the issue.

We also realize that our study can benefit from additional types of consumer generated content and we are looking into using data from online patient fora and from health-oriented social networking sites like PatientsLikeMe [17].

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Bridging the semantics gap between terminologies, ontologies, and information models

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Abstract

SNOMED CT and other biomedical vocabularies provide semantic identifiers for all kinds of linguistic expressions, many of which cannot be considered terms in a strict sense. We analyzed such "non-terms" in SNOMED CT and concluded that many of them cannot be interpreted as directly referring to objects or processes, but rather to information entities. Discussing two approaches to represent information entities, viz. the OBO Information artifact ontology (IAO) and the HL7 v3 Reference Information Model (RIM), we propose an integrative solution for representing information entities in SNOMED CT, in a way that is still compatible with RIM and the IAO and uses moderately enhanced description logics.

Keywords:

SNOMED, Information models, Ontologies

Introduction

SNOMED CT, the emerging global health terminology standard is published by the International Health Terminology Standards Development Organisation (IHTSDO) as a "core general terminology for the electronic health record" [1]. It provides unified meanings for clinical terms from different languages by assigning them to concepts as language-independent identifiers of meaning. Terms are, according to ISO 1087, "*designations of defined concepts in a special language by linguistic expressions*" [2]. Although there are very different, partly contradicting approaches of which criteria should be used to classify a linguistic expression as a term, there is an increasing consensus of terms having both structural (noun phrases) and statistic properties (occurring with a certain frequency and specificity in written and oral communications) [3]. However, any cursory inspection of SNOMED reveals tens of thousands of entries for which it is at least debatable whether they should be regarded as terms along the above criteria, see Table 1:

Here, rather than to terms proper, SNOMED CT concepts correspond to more or less complex linguistic assertions, which include statements of facts, beliefs, and orders. This raises the hypothesis that these "concepts" fulfill tasks that differ from the provision of controlled terms.

Table 1-"Non-Terms" in SNOMED CT

#	SNOMED ID	"Term"
1	59000001	Surgical pathology consultation and report on referred slides prepared elsewhere
2	418577003	Take at regular intervals. Complete the prescribed course unless otherwise directed
3	39399006	Natural death with probable cause suspected
4	168383004	Helicobacter blood test negative
5	281581004	Poor condition at birth without known asphyxia
6	413241009	Suspicion of gastritis

Since SNOMED RT, CT's predecessor, description logics (DLs) [4], formal languages with a well-understood semantics, have been used to formally describe the meaning of SNOMED CT concepts in terms of the common properties of the particular things that instantiate them. We consider these formal descriptions as SNOMED CT's ontology component, considering ontologies as theories that attempt to give precise mathematical formulations of the properties and relations of real-world particulars [5].

Formal representations of electronic health record content have also motivated another line of effort, *viz.* the development of information models for messages and documents in the framework of HL7 Version 3 [6].

In this paper we want to explore the qualitative boundary between "terms" and "non-terms" in SNOMED CT. We postulate that only for the representation of concepts that are instantiated by objects in reality the current logic framework is appropriate, whereas for SNOMED CT concepts that are instantiated by information entities, this framework needs to be extended. We will investigate what kind of things SNOMED CT "non-terms" denote, in which parts of SNOMED CT they occur, and how they relate to clinical information models.

Materials and Methods

Description Logics

SNOMED CT uses a description logics dialect known as **EL**, we will shortly introduce. As a running example, we use the English term "Liver", which belongs to a concept uniquely identified by the number 181268008 and the human-readable

name "Entire liver (body structure)". SNOMED CT concepts are arranged in taxonomic (subsumption) hierarchies. This means that all instances of this concept (i.e. all individual livers) are also instances of its taxonomic parent identified by "272627002|Entire digestive organ (body structure)". We express this as *Liver* ⊑ *Digestive Organ*. Beside the taxonomic arrangement the meaning of SNOMED CT concepts can be further described by the properties all their instances have in common. In the following example, we employ the ⊓ ("and") operator and add a quantified role, using the existential quantifier ∃ ("exists"). For example, the expression *Inflammatory disease* ⊓ ∃ *has-location.Liver* extends to all instances that both instantiate *Inflammatory disease* and are further related through the relation *has-location* to some instance of *Liver*. This example actually gives us both the necessary and the sufficient conditions needed in order to fully define a class, e.g.:

Hepatitis ≡ *Inflammatory disease* ⊓ ∃ *has-location.Liver*, with the equivalence operator ≡ telling that (i) each and every particular *Hepatitis* instance is also an instance of *Inflammatory disease* that is located in some instance of *Liver*, and *vice versa* (ii) that every instance of *Inflammatory disease* that is located at some *Liver* is an instance of *Hepatitis*.

SNOMED CT, in its current version is limited to the constructors summarized in Table 2.

Table 2-SNOMED CT's logical constructors, corresponding to the description logics ***EL***

DL Constructor		Meaning	Example
⊓	$E \sqcap F$	Intersection between E and F	*Acid* ⊓ *Organic Molecule*
∃	$\exists r.G$	Existential restriction of the relation r by the filler G	∃*part-of.Liver*
⊑	$A \sqsubseteq B$	B subsumes A	*Liver* ⊑ *Organ*
≡	$C \equiv D$	C and D are equivalent	*Organic Acid* ≡ *Acid* ⊓ *Organic Molecule*

It is not possible to express value constraints, e.g. that the relation *has-laterality* can only have the values *Right* and *Left*. It is equally impossible to express cardinalities, such as precisely defining a *Coronary bypass with three grafts*. And it is not possible to formulate negations, such as *Injury without infection.*

These restrictions can be tolerated as well as SNOMED restricts itself to the definition of the meaning of simple terms like "Hepatitis" or "Nephrotomy". It is, however, problematic, whenever more complex terms or whole statements as in Table 1 have to be compositionally represented.

Information models

Statements as illustrated in Table 1 typically belong to information models, such as underlying data acquisition templates, questionnaires and the like. Typical standards for clinical information models are open EHR archetypes [7] and HL7 version 3 information models [6]. The Reference Information Model (RIM) is the general structure that guarantees the coherence of the complex set of HL7 version 3 models, which may be used in many contexts to describe particular administrative or clinical health care information. Table 3 contrasts what is typically represented by ontologies with what is typically represented by information models. For example the definition of the class *Act* in the HL7-supported code system is "*a record of something that is being done, has been done, can be done, or is intended or requested to be done*".

Table 3-Ontologies vs. Information Models. In practice the distinction is less crisp. Especially the HL7 RIM contains many classes that can be assumed to represent non-informational entities.

Domain Ontologies	Information Models
Contain classes that have really existing domain entities (particulars) as members	Classes have information entities as members
Represent real-world particulars in terms of their inherent properties	Represent artifacts that are build to collect or annotate information
Can exist independently of information models as long as only the existence of particular things is recorded	Are required to record beliefs or states of knowledge about real things or types of things (as represented by ontologies)
Context independent	Context dependent

Examples are clinical observations, the assessment of health conditions, healthcare goals, treatment services, assisting, monitoring or attending, patient training and education services, editing and maintaining documents, and many others. *Acts* (besides *Entities* and *Roles*) are the pivots of the RIM; all domain information and processes are represented primarily in acts. Any profession or business, including healthcare, is primarily constituted of intentional actions, performed and recorded by responsible actors. An act-instance is a record of such an intentional action. The fundamental difference between such a RIM act instance and an instance of an ontology class (or also most SNOMED CT concepts) is to bring the aspect of recording and thus the person who edits EHR content into the picture. At least in theory, an instance of RIM:*Operation* refers to an information object which is "*about*" some type or concept, which not necessarily is instantiated. Representing discourse about operations that are being planned, postponed, or suspended is quite different from creating and instance of an ontology class *Operation*, as the latter one makes an existence claim which is often too strong.

The Ontology – Epistemology Divide

We may be able, in theory, to draw a crisp line between what is the representation of real objects or processes on the one hand, and what represents information entities on the other hand. In current information models and ontologies this distinction is blurred, and users of both systems tend to be unaware of the very nature of things they represent. The resulting overlaps give rise to conflicting representations, which require sophisticated mitigation strategies (TermInfo). Such a mixed representation of the invariant (and possible definitional) properties of entities as they *are* (ontology) and how they are *seen / known / recorded* (epistemology) is prevalent in most biomedical terminology systems [8, 9].

Ontologies of Information Entities

Whether these epistemic aspects are considered relevant for ontology is a matter of definition. In the Information Artifact Ontology, under the OBO Foundry initiative [10], they are included in an ontology framework as information content entities, and their classes have representations of information as members. Information content entities are immaterial objects (more precisely: generically dependent continuants according to the Basic Formal Ontology, BFO [11]) that can be borne in material objects. So can the latter be a photographic print, and the former an (immaterial) photograph:

PhotographicPrint ≡ *MaterialEntity* ⊓
∃ *bearerOf*. (∃ *isConcretizationOf*. *Photograph*)

Information content entities encompass documents, document parts such as sentences, texts, data, measurement results, serial numbers, datatypes, databases, and ontologies, and the processes in which they are created and consumed, totaling 131 classes. Information content entities are related by the relation *isConcretizationOf* to their material bearers, and by the relation *isAbout* to the things they denote.

There is a rough correspondence between IAO information content entities and the HL7 classes that derive from the class *Act*. In this context, *Act*, in contrast to its implicit meaning is to be understood as an information entity, i.e. *information about* a real act. This becomes obvious by the fact that HL7 acts can be modified by so-called mood or uncertainty codes.

The so-called *moodCode* in the information model distinguishes between acts that occurred and acts that are only planned (ordered, scheduled, rescheduled, etc.). Mood codes encompass intent, appointment, appointment request, promise, proposal, recommendation, resource slot, predicate, criterion, event criterion, expectation, goal, option, permission, permission request, risk.

The *uncertaintyCode* indicates whether the *Act* statement as a whole, with its subordinate components has been asserted to be uncertain in any way e.g., a patient might have had a cholecystectomy procedure in the past (but is not sure). When the uncertainty is associated with an *Observation.value* alone or other individual attributes of the class, such pointed indications of uncertainty should be specified by applying the *Uncertain Value – Probabilistic* (UVP)[1] or the *Parametric Probability Distribution* (PPD)[2] data type extensions to the specific attribute. Particularly if the uncertainty is uncertainty of a quantitative measurement value, this must still be represented by a PPD<PQ> in the value and NOT using the *uncertaintyCode*. Also, when differential diagnoses are enumerated or weighed for probability, the UVP<CD> must be used, not the *uncertaintyCode*. The use of the *uncertaintyCode* is appropriate only if the entirety of the *Act* and its dependent *Acts* is questioned. Finally, the attribute *negationInd* indicates that the *Act* statement is a negation of the *Act* as described by the descriptive attributes.

For example, to test for "systolic blood pressure of 90-100 mm Hg," one would use only the descriptive attributes *Act.code* (for systolic blood pressure) and *Observation.value* (for 90-100 mm Hg). If one would also specify an *effectiveTime*, i.e., for "yesterday," the criterion would be more constrained. If the *negationInd* is true for the above criterion, then the meaning of the test is that a systolic blood pressure of 90-100 mm Hg yesterday does **not exist** (independent of whether any blood pressure was measured).

The IAO does not have so far a fine grained model of moods and probabilities such as the HL7 RIM, but its architecture does not preclude such an extension.

These examples show the crucial difference between a model of information and a model of reality. In the former, "*information related to an act*" can be subsumed by "*information related to a planned act*", whereas in a model of reality, i.e. an ontology in a narrower sense "*act*" and "*planned act*" are not related by taxonomic subsumption.

In the following we are studying several SNOMED CT concepts that clearly belong to the category of information entities. We critique their current representation and propose an alternative representation as information content entities.

Case Study

We center our forthcoming discussion on four SNOMED term cases (C1-C4) which, in our view, represent epistemic states rather than ontological concepts:

C1: ***Absent nose*** (111317000) is stated to imply: *Congenital malformation* ⊓ ∃ *FindingSite. Nasal Structure*

C2: ***Heart operation planned*** (183983001)[3]. This concept is in SNOMED CT's *Situation with explicit context* branch and is fully defined as

∃ *rg.*(
∃ *Associated procedure.Operation on heart* ⊓
∃ *Procedure context.Planned* ⊓
∃ *Temporal context. Current or Specified* ⊓
∃ *Subject relationship context. Subject of record*)

C3: ***Operation on heart, rescheduled***. (64915003|: 272125009|=58334001), This is a postcoordinated concept, refining operation on heart by using the qualifier *Priority* with the value *Rescheduled*, in DL notation: *Operation on heart* ⊓ ∃ *Priority. Rescheduled.*

C4: ***Suspected gallstones*** (390926006). This concept is also in SNOMED CT's *Situation with explicit context* branch and is fully defined as

∃ *rg.*(∃ *Associated finding.Gallstone* ⊓
∃ *Finding context.Suspected* ⊓
∃ *Temporal context. Current or Specified* ⊓
∃ *Subject relationship context. Subject of record*)

Case critique

All four concepts have in common that in their definition they are related to other concepts that are definitely not, or not nec-

1 A generic data type extension used to specify a probability expressing the information producer's belief that the given value holds.
2 A generic data type extension specifying uncertainty of quantitative data using a distribution function and its parameters (mean, standard deviation)

3 *rg* means „role group", cf [12].

essarily, instantiated. SNOMED CT's description logics notation, however, by using existentially quantified roles (∃), asserts the existence of at least one instance of the concepts in question. So does the expression

∃ *FindingSite. Nasal structure* formally assert that some instance of *Nasal structure* exists, whereas the intended meaning is exactly the contrary. Similarly, the expression *Operation on heart* ⊓ ∃ *Priority. Rescheduled* states that there is a heart operation, whilst the intended meaning refers to some heart operation in the future, which still includes the case that there will not be any operation at all (e.g. due to worsening conditions of the patient). The same argument holds for the planned heart operation. Regardless the syntactic difference (the rescheduled operation is a operation, whilst the planned operation isn't), the expression

∃*rg.* (∃ *Associated procedure.Operation on heart*)

is a necessary condition for *Heart operation planned*, i.e. the plan implies its execution, which is certainly not always the case. In exactly the same way, the definition of *Suspected gallstones* leads to the conclusion that there exist real gallstones even in case a doctor registers a suspicion only.

What is wrong with these concept definitions? There is no doubt that there must be a way to refer to "something" which does not exist now, which existed in the past, or which may exist in the future. But statements about non-existence are not terms, although they syntactically include terms. Ideally, they should be represented in an information model, which is distinct from the ontology, or is expressed in an "information Entity" branch in the same ontology. However, there are strong reasons why application builders want to have "real" concepts as well as whole assertion in one and the same representational artifact such as SNOMED CT. So has it been a precondition for the use of this standard with in the UK National Health Service, that the former CTV3 terminology was fused with SNOMED RT. One characteristics of CTV3 (the successor of the former Read Codes) was its abundance of epistemic laden concepts such as in our examples.

Case remodeling

We here propose alternative representations based on the information artifact ontology, using information content entities such as Plan and Suspicion. All the four concepts *Absent nose*, *Heart operation planned*, *Operation on heart, rescheduled*, and *Suspected gallstones* represent information content entities. In order to make this clear (and because the language is often misleading), we slightly rename the concepts to *Patient without nose, Plan of heart operation, Rescheduled plan of heart operation, Suspicion of gallstones.*

To express this adequately, we need to enhance our description language by the constructors given in Table 4.

A further extension of the logics including concrete domains (in this case numeric values) will be necessary if probabilistic values are to be represented such as UVP and PPD in HL7 RIM. This is already possible, e.g. using data properties in Protégé, but it is not yet covered by off-the-shelves terminological reasoners such as Fact++ and Pellet.

Table 4-Additional description logics constructors

DL Constructor		Meaning	Example
¬	¬ *A*	Negation of *A*	*Base* ⊑ ¬ *Acid*
∀	∀*r.G*	Value restriction of the relation *r* by the filler *G*	*Hand* ⊑ ∀*has-Laterality.* (*Left* ⊔ *Right*)
⊔	*A* ⊔ *B*	Union of A with B	

Case remodeling

Coming back to the running examples, we propose the following representations:

C1: ***Person without nose***:

Human ⊓ ¬ *hasPart. Nasal Structure*

C2: ***Plan of heart operation*** (183983001):

Plan ⊓ ∀ *isAbout. Operation on heart*

with *Plan* being an information content entity. The universal quantifier ∀ means that this plan can only be realized by a heart operation. In contradistinction to the existential quantifier ∃ the formula does not assert that there must be an operation for each and every plan.

C3: ***Rescheduled plan of heart operation***:

Plan ⊓ ∀ *isAbout. Operation on heart* ⊓
∃ *hasQuality.Rescheduled*

Alternatively:

Plan ⊓ (∀ *isAbout. Operation on heart*) ⊓
∃ *participantOf.Rescheduling*

with *Rescheduling* being an event.

C4: ***Suspicion of gallstones***.

Suspicion ⊓ ∀ *isAbout. Gallstones*

with *Suspicion* being an information content entity.

Variations

There may be a need to distinguish simple instantiations (e.g. asserting that there is an instance of *Gallstones*) from a record of a finding (i.e. that some physician has diagnosed gallstones).

Note that all version of SNOMED CT until now, have placed *Gallstones* (a material entity), together with processes like *Myocardial infarction*, *Headache* and *Hypercholesterolemia* into an epistemology-infested *Findings* hierarchy.

The subtle difference between instantiations and findings is that there are undiagnosed diseases just as there are false diagnoses (which continue being diagnoses even being false). These special cases should be accounted for in a medical record, and the terminology should provide the means for this. We propose a solution using again the example C4.

We may want to distinguish between:

- C4a: A diagnosis "Gallstones" whatsoever
- C4b: A confirmed diagnosis "Gallstones"
- C4c: A suspected diagnosis "Gallstones"
- C4d: A false diagnosis "Gallstones"
- C4e: Gallstones that have not been diagnosed

In all these cases diagnoses are information content entities. According to the diagnosing person they can be subdivided in terms of medical diagnosis, nursing diagnoses, etc.

C4a: *Diagnosis* ⊓ ∀ *isAbout.Gallstones*

C4b: *Diagnosis* ⊓ ∀ *isAbout.Gallstones* ⊓ ∃ *isAbout. Gallstones*

C4c: *Diagnosis* ⊓ ∀ *isAbout. Gallstones* ⊓ ∃ *hasQuality.Suspected*

C4d: *Diagnosis* ⊓ ∀ *IsAbout.* ⊥

C4e: *Gallstones* ⊓ ¬∃ *inv(IsAbout).Diagnosis*

The examples show the possibilities but also the limitations of using the proposed description logics. If we wanted to represent quantitative statements, e.g. in C4c that there is a probability of 0.1 that the diagnosis is true, then we would need to include numeric values as data properties. As C4d shows, there is no possibility to distinguish between different kinds of false diagnoses. From a HL7 point of view, the establishment of a diagnosis is an observation, a sub-class of the class *Act* defined as "An act that is intended to result in new information about a subject." Being a sub-class of the class *Act*, the class Observation inherits of the attributes of the class Act including *moodCode*, *uncertaintyCode* and *negationInd*. In addition UVP or PPD data type extension may be used to express respectively a probability expressing the information producer's belief that the given qualitative observation value holds or the uncertainty of quantitative data using a distribution function and its parameters.

Conclusion

Numerous SNOMED CT concepts are representations that are more adequately described by complex linguistic statements than by domain terms in a stricter sense. These complex statements address epistemic notions, i.e. information about the user and the context, which clearly extends the realm of ontology. Those SNOMED CT concepts that correspond to "real" terms can generally be defined using the very inexpressive logic **EL**, currently used for SNOMED CT.

In our finding that there are numerous SNOMED "non-term" concepts that cannot be adequately represented giving the current restrictions of SNOMED CT's logic, we are close to the analysis done by Rector & Brandt [13]. Just as we do, they defend the (controlled) use of a more expressive description logic, analyzing a similar scope of concepts as we do. However, the model they propose is different. By understanding findings, procedures, and observables as *situations* they manage to solve the negation problem. Yet their approach reaches short when it comes to uncertainty, such as speculative diagnoses, or plans that have not yet been executed at the time of recording.

Our approach comes closer to what is possible to encode using the HL7 RIM, where medical record entries can be modified in terms of "mood codes" like *Event, Goal, Risk, Expectation, Intent*, or uncertainty codes such as *Possibly done* or *Probably done*. It is also consistent with the Information Artifact Ontology, which, however, lacks detail for representing diagnostic statements. Thus, using one single representation formalism, our proposal brings different worlds together: real-world, heterogeneous terminologies, HL7 information models, as well as philosophically founded ontologies.

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Modeling, building and evaluating an ontology for the automatic characterization of adverse drug effects during pharmacovigilance

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Abstract

Background: The characterization of spontaneous reported cases is fundamental for pharmacovigilance. This task is time consuming and its reproducibility is low. Objective: To develop a system founded on an ontology that automatically instantiates spontaneous reported cases as "known" adverse drug effects (ADE) only if the reported ADEs are described in drug compendia. Methods: A simple ontology of drugs and their related adverse effects represented in description logics was developed from a drug database. Manual evaluation was carried out on 378 spontaneous reported cases instantiated as "known ADE of a chemical class". The initial manual characterization was reviewed by a pharmacovigilance expert to validate the generated automatic characterization. Results: The ontology is composed by 57,704 concepts and 5 relations. It was successfully validated thanks to Pellet reasoner and it contains neither inconsistencies nor cycles. In this validation, 86% of the instantiated spontaneous reported cases effectively concerned notorious ADEs, whereas only 75% were initially identified manually as related to notorious ADEs. Conclusion: This system can assist characterization by applying a reasoning process similar to that used by experts in the search for ADEs.

Keywords:

Adverse drug reaction, Reporting systems, Iatrogenic disease/classification, Knowledge bases, Ontology, Description logics, Reasoning.

Introduction

Pharmacovigilance process has been developed at the local, national and international level to facilitate the collection and analysis of spontaneous reported adverse drug effects (ADE) in treated patients. This process aims to identify rare and dangerous adverse events likely to result in an unfavorable benefit risk ratio.

The nature of the relationship between an adverse event and a drug in a spontaneous reported case is defined by a pharmacovigilance expert on the basis of intrinsic and extrinsic imputability criteria. The intrinsic imputability is founded on chronological (the time interval between the drug intake and the occurrence of the adverse event) and semiological (the symptoms observed are compatible with this type of drug) criteria. Extrinsic imputability (characterization) is based on bibliographic references concerning existing knowledge about the adverse effects associated with the drug (well known effect described in drug compendia, predictable or previously reported side effects and side effects not described or not published).

When considering what is known about the possible adverse effects of the drug, the expert must consult several sources: (a) the drug monograph which reports all the side effects observed during development and post-marketing of drug, (b) a drug compendium reporting the side effects of active substances [1-2], (c) a specific side-effect compendium reporting side effects of active substances and classes of active substances [3], (d) published articles dealing with the reported side effects of the substance.

The automation of these tasks would help the expert considerably in his or her interactions with the available resources. It should also save time and result in more reproducible bibliographic documentation. One possibility for automation would be to develop a dedicated tool which automatically classifies a spontaneous reported case as a "case with known ADE" or as a "case with unknown ADE". To automate this task it is necessary to check the existence of known side effect at different levels : for the substance, for the pharmacological class of the substance and for the chemical class of the substance. For example, a patient takes ibuprofen and a gastric ulceration is reported. This spontaneous report can be characterized as a known ADE because non steroidal anti-inflammatory drugs (NSAID) are known to give gastric ulceration and ibuprofen is a NSAID. As illustrated, this characterization process should use subsumption reasoning.

Ontological reasoning based on formal representation languages such as description logics can be used for this type of classification. The use of description logics has several advantages including the possibility of using advanced inference services (satisfiability, subsumption, classification, consistency checking, instantiation and realization) [4].

An ontology is therefore required. This ontology must describe the drugs prescribed and their known related ADEs, but also the classes to which the drugs belong (chemical and, pharmacological properties, etc...) and the related ADEs of these classes.

The existing ontologies (Galen Drug ontology [5], VA NDF-RT [6], SNOMED CT [7]) do not completely satisfy these requirements: (a) ADEs of drug classes, or of drug are not always given, (b) these ontologies deal essentially with American or English pharmacopoeias but not French ones, (c) they are not necessary kept up to date, may contain information for obsolete drugs and lack information for new drugs.

Information about drugs can also be obtained from commercial drug databases which are regularly updated but have a formalism unsuitable for complex reasoning such as subsomption, classification or consistency checking [4].

In this work, we aimed to develop and use an ontology to describe drugs and their known ADEs, through the following steps: (a) modeling known ADEs, (b) representing the ontology with a formal language, (c) populating it with data from a French drug database, (d) instantiating it with reported cases from a pharmacovigilance center (CRPV), (e) evaluating the results obtained through a classification process.

Materials and Methods

Known ADEs model

The general ways a side effect can occur are explained using pharmaceutical and toxicological knowledge. The main needed concepts and relations are identified.

Modeling the known ADEs is guided by the objectives of the reasoning tasks:

- Classification task should provide (1) a hierarchy of drugs on the basis of their pharmacological and chemical properties (2) a hierarchy of "cases with known ADEs" on the basis of the side effect concerned and the drug involved.
- Instantiation task should provide the list of "cases with known ADEs" for which a "spontaneous reported case" is an instance.

Ontology building

We represent the ontology of drugs and their related ADEs using OWL-DL, a web Description Logics (DL) language [4]. DL structures the domain knowledge on two levels: a terminological level (TBox or ontology) containing the classes of domain objects (concepts) with their properties (roles), and an assertional level (ABox), containing individuals (instances).

The ontology was constructed in a sequential manner. The TOP ontology was first created and stabilized. We then added in the TBox subconcepts of TOP ontology using knowledge from a drug database. Finally, the instances were added in the ABox using a pharmacovigilance database.

TOP ontology

The TOP ontology was stabilized by (a) implementing the general concepts and relations previously identified in Protégé 4.0 ontology development environment[1] and (b) verifying the principles on which our model was based using fictive cases with known ADEs, reported cases and the Pellet reasoning engine [8].

Populating the ontology

We used the French drug database Thesorimed[2] to populate the drug iatrogeny ontology because :

- This drug database is highly structured,
- It includes side effect descriptions at various levels (chemical, pharmacological, active substance),
- It indexes side effects with normalized terms and will soon include a MedDRA (Medical Dictionnary of Regulatory Affairs) indexation of side effects. MedDRA is a terminology commonly used to describe side effects in spontaneous reported cases [9].

The pertinent tables and fields of this drug database were identified. They constitute a subset of the database dealing particularly with the side effects of drugs. Thesorimed side-effect terms were converted into MedDRA terms by computerized string matching and manual matching. A specific script was written to convert the drug database subset into subconcepts of the TOP ontology. The OWL-DL file obtained was concatenated to the TOP ontology OWL-DL file.

Instantiating the ontology

Instances of the ontology are the spontaneous reported cases included in the CRPV pharmacovigilance database. Side effects are expressed using MedDRA terminology, and drugs are expressed as active substances. A script generating the OWL file of these instances was concatenated to existing OWL files. The methodology is presented in Figure 1.

Classification, Instantiation

The ontology OWL file was imported in Protégé 4.0 ontology development environment, and the reasoning engine Pellet was then used for both classification and instantiation.

Classification computes the sub-concept relations between every named concept to create the complete hierarchy. It can be used to answer queries such as getting all or only the direct sub-concepts of a concept.

Instantiation finds the most specific concepts that an instance belongs to (direct types for each instance). It can only be performed after classification since direct types are defined with respect to a concept hierarchy. Using the classification hierarchy, it is then possible to get all the types for that instance.

[1] http://protege.standford.edu
[2] http://www.giesips.org

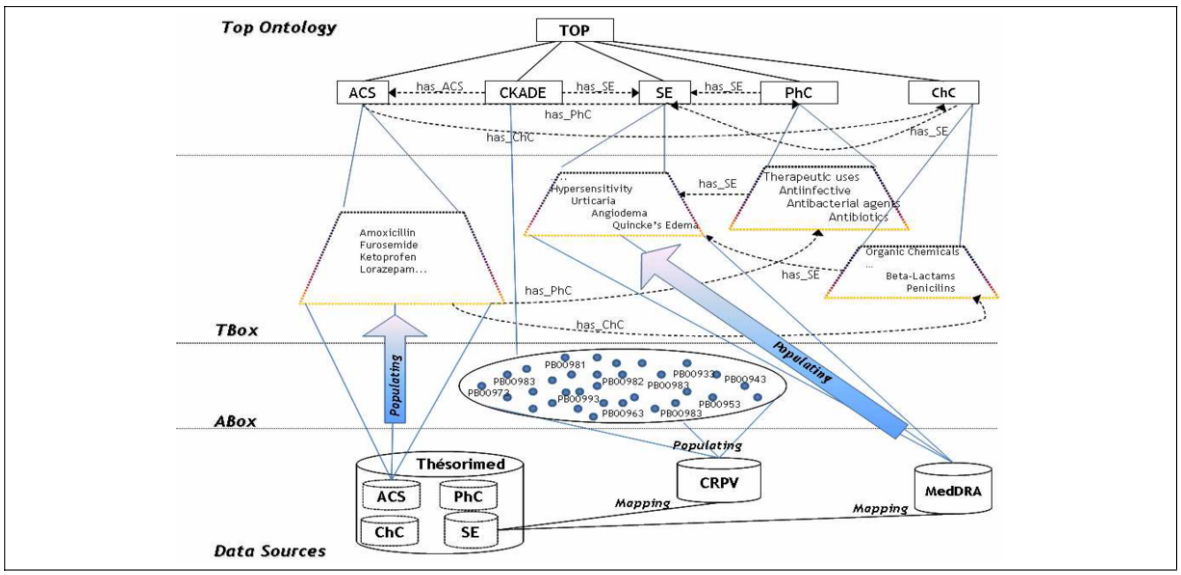

Figure 1 - Methodology of construction of ontology of drugs and their related ADEs. TOP ontology is composed by the concepts: ACS (Active Substance), CKADE (Case with known ADE), SE (Side Effect), PhC(Pharmacological Class) and ChC(Chemical Class).

Ontology evaluation

The logical consistency of the whole ontology (TOP, subconcepts, hierarchies, relations and instances) was analyzed by the reasoning engine. The conceptual validity of the ontology was evaluated by comparing the extrinsic imputability criteria of instantiated reported cases. If cases are instantiated, there is already bibliographic knowledge relating to them. Their extrinsic imputability criteria should therefore be 3 (well known effect described in drug compendium) or 2 (published side effect).

The list of instantiated cases was analysed by a pharmacovigilance expert that was asked to review the characterization of reported cases according to the information given by the "case with known ADE" concepts. The expert was asked whether the case should be considered "notorious" and had to select one of the following options for each reported case: she agrees and the initial criterion should be 3, she does not agree and the initial criterion is true, she partly agrees because she has other information explaining the initial criterion.

This evaluation was first performed on a preliminary set of "case with known ADEs" concepts dealing with chemical classes of drugs associated with side effects (*e.g. oxicam causing diarrhea*).

Results

Known ADEs model

Domain description

An adverse drug effect may be linked to:

- An active substance in the drug (*e.g. amoxicillin may cause tooth discoloration*),
- An auxiliary substance present in the drug with no therapeutic properties (*e.g. the aspartame present in oral formulation of amoxicillin may be dangerous for patients with phenylketonurias*),
- A chemical class of a drugs (*e.g. amidine penicillin may cause nausea*),
- A pharmacological class of a drugs (*e.g. antitussives may cause insomnia*).

An adverse effect may be due to:

- A generic interaction with an organ (non specific action),
- A molecular interaction (enzymatic induction, molecular competition, etc),
- An intrinsic toxicity of the drug (*e.g. ototoxicity of aminosides*).

An adverse effect may occur in various contexts:

- Patient context : physiological, pathological, genetics, allergy,
- Dose context : daily dose, frequency, duration of treatment,
- Administration context: form, route, flow,
- Exposure context: cumulative toxicity,
- Co-administration context (drug interactions).

Model of known ADEs

Modeling focused on the concept of "*case with known ADE*" relating to one or two drugs, one side effect and various con-

texts (patient, exposure, dose or administration contexts). The *case with known ADE* is a kind of *case*.

The drug involved may be a clinical drug (CD) or one of its components (active substance (ACS), auxiliary substance (AS)) or a substance belonging to a particular pharmacological class (PC), chemical class (CC) or interaction class (CI).

Figure 2 shows the model to describe known ADEs.

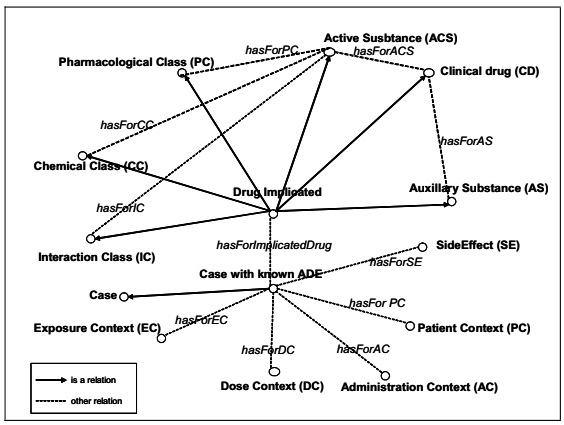

Figure 2- Model of known ADEs

Ontology Description

For the first version of the ontology, we limited the concept "*drug implicated*" to the: "*active substance*", "*pharmacological class*" or "*chemical class*" of the drug concerned. Context concepts had not been included in the ontology at this point.

TBox

Concepts relating to the drug implicated

Active substances are primitive concepts (n=4,481) described by two relations:

- *hasForPC* relating the active substance to its pharmacological class
- *hasForCC* relating the active substance to its chemical class

We created two defined concepts (*owl:Equivalent Class) - ActiveSubstanceHavingPC* (n=844) and *ActiveSubstanceHavingCC* (n=386) - making it possible to link *pharmacological* or *chemical class* to the "*drug implicated*".

Described case concepts

A "*case with known ADE*" is a defined concept based on 2 relations (*owl: ObjectProperty*):

- *hasForImplicatedDrug* relating the case to the drug implicated,
- *hasForSE* relating the case to a side effect

The *cases with known ADE* can be divided in 11,697 concepts of *PC causing side effect*, 5,198 concepts of *CC causing side effect*, and 32,685 concepts of *ACS causing side effect*.

Hierarchically organized concepts

Pharmacological class, chemical class and *side effects* are primitive concepts and are organized hierarchically (*owl:SubClassOf*). There are 844 concepts in the pharmacological hierarchy, 386 in the chemical one and 1,183 in the side effect one.

ABox

We consider all the "*spontaneous reported cases*" to be instances of the concept "*Case*".

Each "*spontaneous reported case*" is described with one or many instances of *drug implicated* and one or many instances of *side effects*. There are 2,555 instances in ABox.

Ontology evaluation

Neither inconsistent classes nor inconsistent instances have been inferred using our modeling principles.

For the preliminary evaluation, we considered only a subset of reported case instances of *"cases with known ADE"* defined as having a side effect related to a particular chemical class (378 of the 1,694 spontaneous reported cases in the CRPV database, corresponding to 565 side effect/substance pairs).

The initial extrinsic criterion was greater than 2 for 75% of the instantiated reported cases. For the others, the initial criterion was less than 2, indicating that the side effect concerned had not previously been described for this drug.

After review by the pharmacovigilance expert,

- 86% of the instantiated reported cases had a criterion greater then two (maintenance of the high initial criterion or increase in the criterion from an initial low value).
- 3% of the instantiated reported cases still had an extrinsic criterion below 2 after review (*e.g.* the reported case "clonazepam causing dyspepsia" is an instantiation of the described case "benzodiazepine causing dyspepsia", but the pharmacovigilance expert did not consider it to be notorious that benzodiazepine gives dyspepsia).
- 11% of the instantiated reported cases could have been given a criterion greater than 2, but the expert maintained the initial criterion because (a) other drugs were involved in the reported case for which the observed side effect had never been described (n= 44), (b) there were other side effects in the reported case that had never previously been described for the drug implicated (n=15), (c) the side effect was merely a sign that the drug was not effective (n=3) (*e.g. pain and ketoprofen*).

One of the benefits of this experiment was that the pharmacovigilance expert obtained new knowledge about drug properties. Indeed, some drugs were found to be classified exclusively on the basis of pharmacological principles and never on the basis of chemical principles (for example amprenavir is a sulfamide but is systematically described as an antiretroviral drug).

Discussion

The ontology we have developed is based on the pharmacovigilance observation and reasoning for the characterization of spontaneous reported cases. Based on these observations, we have repurposed the knowledge contained in a drug database to make it possible automation of the ADEs searching.

This method of ontology building also facilitates the maintenance of the ontology as the drug database is regularly updated and scripts automatically convert some parts of it into OWL-DL.

The automatic instantiation process efficiently identified spontaneous reported case of notorious bibliographically documented effects. Nevertheless, further evaluations with the whole ontology are required to quantify the specificity and accuracy of the instantiation process (true described reported cases, true not described cases, false described reported cases, false not described cases).

The evaluation of the ontology by the pharmacovigilance expert indicated several ways in which the ontology could be improved. New sub-concepts of cases with known ADEs could be created totally or partially matching to the reported cases in term of the number of drug/side effect pairs for the reported case automatically instantiated as cases with known ADEs.

The hierarchies included in the ontology are those provided by the drug database. They suffer from a lack of structure (no polyhierarchy and a very flat hierarchy). We are investigating ways to dissect concepts in these hierarchies to facilitate their reclassification.

In the near future, we will integrate the side effect ontology developed by another team of the VigiTermes project [10] into our system. This should greatly extend reasoning concerning the classification of side effects.

Other drug classification systems are currently integrated into the ontology (*e.g*: MeSH), which can thus be used to generate clusters of reported cases on the basis of common drug clusters. It will be used for the signal detection complementary to the approach developed by Henegar *et al* [11].

As our resource gives the knowledge about a drug and its known side effects, it could also be used to filter results of ADEs detection issued from Electronic Heath Records using NLP tools and data mining methods [12]. Among detected ADEs, known ADEs (True Positives) should be then automatically identified.

Finally, all the documentation services should be implemented in a web service.

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Internal Structure of a Disease Name and its Application for ICD Coding

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Abstract

ICD-coding is a complex and difficult task. Coding results vary a great deal depending on each coder's ability. Although the Japanese Standard Disease-Code Master facilitates the coding tasks, it also engenders post-coordination problems derived from combinations of basic diseases (with ICD code) and modifiers. Post-coordination sometimes alters the original ICD code dramatically. To solve this problem, this paper presents a proposal for using internal structures of disease names to correct the ICD code. First, we built an internal structure analyzer, which achieved high (83.7%) accuracy. Results demonstrated that the analyzed output is helpful for precise ICD-coding tasks.

Keyword:

ICD-10, Disease name, Multi-word expression, Internal structure, Dependency analysis, Post-coordination

Introduction

The international standard diagnostic classification for all general epidemiological purposes and many health management purposes is ICD-10. It is used for analyses of general health circumstances of population groups and monitoring of the incidence and prevalence of diseases [1]. However selecting a suitable disease code for each patient requires a high level of understanding of both patient data and medical knowledge.

We classified the complex language phenomena in ICD coding into three types:

1. Spelling variation
   Myo**c**ardial infarction / Myo**k**ardial infarction [I21.9]
   (value in brackets: ICD code)

The first type, spelling variation, mostly originates from transliteration problems, which occurs in vocabulary importing. Because this phenomenon is a general research topic, and because various methods have been proposed [2,3], this paper does not address this problem.

2. Synonym / Hypernym
   Coats' disease / exudative retinitis [H35.0]

The second type, synonym/hypernym, requires extra knowledge such as ontology. It is also beyond this paper's scope.

3. Order / Existence of Modifier (Post coordination)
   femoral fracture / femoral incomplete fracture [S72.9]
   femoral shaft fracture [S72.3]

The third type—the target of this paper—is *post coordination*, which is the combination of a disease whose correct ICD code is known and modifiers. Post coordination must cope with the expansive variety of disease names. Moreover, it sometimes changes the original ICD code.

The terms "femoral incomplete fracture" and "femoral shaft fracture" are illustrative examples of the post coordination problem. In fact, "femoral incomplete fracture" shares an ICD code [S72.9] with "femoral fracture", however "femoral shaft fracture" [S72.3] does not, even though they appear to have the same structure. The difference between them is the dependency inside of the term: "incomplete" modifies "fracture", whereas "shaft" modifies "femoral". To address the problem, this paper uses an internal structure of disease names (Figure 1).

This paper presents (1) automatic ICD-coding based on internal structure of disease name and (2) a method to build an internal structure analyzer, including internal structure representation for disease names. The experimental results for internal structure analysis achieved high accuracy (83.7%), demonstrating the fundamental feasibility of the proposed ICD coding.

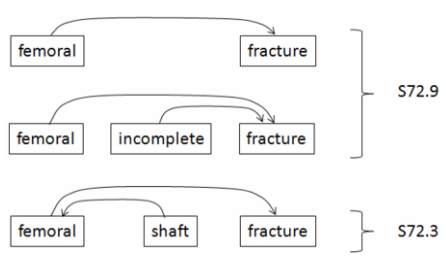


Figure 1 - Internal structures

It must be noted that the automatic ICD-coding task in Japanese is more difficult than that in English because Japanese does not use spacing for word/morpheme separation. That difference complicates Japanese processes.

Although experiments described in this paper are related to Japanese medical terms, the proposed method does not depend on a specific language. The proposed method could be applied with the other languages; especially efficient for Chinese, German and so on, which are also without word/morpheme separation.

Internal Structure Analysis

The core problems examined in this study are: (1) how to represent internal structure, (2) how to train the analyzer.

(1) Representation of Internal Structure

An "internal structure of a disease name" is represented as a collection of dependency relations between the morphemes in a disease name. Figure 2 presents an example of "大腿骨頚部骨折" which means a femur neck fracture. An arrow indicates a dependency relation. Because of the difficulty in defining the adequate unit (morpheme), we regarded a character as a unit. Japanese character "Kanji" are ideographs.

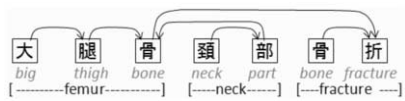


Figure 2 - An example of an internal structure

A basic representation of an internal structure is shown above. However, two exceptions exist: omission and contraction.

Representation for omission

The first exception is OMISSION as shown below:

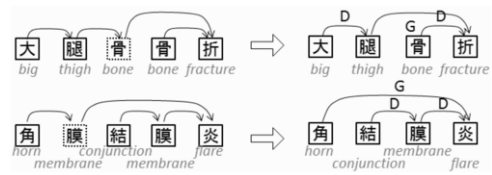
Therein, "臓" is omitted when "心臓" and "疾患" are compounded into "心疾患" (In fact, "心" itself does not mean "heart organ"). To represent the omission, we introduced a new dependency label "G" and assigned label "D" to the normal dependency relation.

In this example, "心" generates a character (actually "臓") and depends on the generated character, the generated character depends on "患".

Representation for contraction

The framework shown above can deal with another phenomenon: CONTRACTION. Contraction resembles omission, but it differs in that morphemes share the omitted character ("骨" for "大腿骨折", "膜" for "角結膜炎").

The internal structures of these two disease names are represented as follows.



A dotted square represents a contracted character.

As in the previous example, the dependency label G represents that "腿"/"角" generates a character ("骨"/"膜") and depends on the character. The character depends on "折"/"炎".

To process the internal structure adequately, it is necessary to reconstruct omitted and contracted characters. Two points must be specified during reconstruction: 1) the position in which the omission/contraction occurred, and 2) the omitted character. As described in this paper, our internal structure analysis has a framework for the first point.

This study does not examine the inference of omitted characters. That point can be solved using other techniques such as predictive transforms.

Dependency relation – which is the head?

Two morphemes in a dependency relation are not symmetrical: one (head) depends on the other (dependent). Here, the question is: Which is which? Regarding the structure of sentences, a head is a constituent that defines the part of speech of a phrase. However, this definition is inapplicable here because a disease name and its constituents are all nouns in Japanese.

We adopted a definition of a head based on an is-a / part-of hierarchy: for a compound noun *C*=<*unit 1, unit 2*>, *unit 1* is the head if unit 1 *is-a C*, else *unit 2* is the head. The next step is to apply a *part-of* relation instead of an *is-a* relation if both do not exist. For example, in the case of "distal femur":

× distal femur *is-a* distal

× distal femur *is-a* femur

No *is-a* relation exists. (We adopted a policy that "distal" is a role concept depending on the context. Here, We use a region of "femur", instead of *is-a* relation between basic concepts.) Next we present a *part-of* relation:

× distal femur *part-of* distal

○ distal femur *part-of* femur

Therein, "femur" is a hypernym of "distal femur" in the *part-of* relation, so "femur" is the head and "distal" is dependent.

Table 1 - Features used by the internal structure analyzer
("Stack[]" and "Input[]" are the data structure used in MaltParser)

Character feature	1	Character	STRING
	2	The type of character (Chinese character, number, etc.)	STRING
	3	Position of the character	INTEGER
Dictionary feature	4	If a substring of the input disease that end with this character is in the dictionary	BOOLEAN
	5	Length of the word in (4)	INTEGER
	6	MeSH category of the word in (4)	STRING
	7	If a substring of the input disease that end with this character is a suffix	BOOLEAN
	8	If a substring of the input disease that contains this character is in the dictionary	BOOLEAN
	9	If a word that is consist of this character and another is in the dictionary	BOOLEAN
	10	Distance between two characters in (9)	INTEGER
Previous label	11	Dependency labels of Stack[0], Stack[1], Input[0], Input[1]	
	12	Dependency labels of the right/leftmost dependent of Stack[0]	
	13	Dependency labels of the leftmost dependent of Input[0]	
	14	Dependency labels of the character left to Stack[0] in the input disease	

The internal structure presented above can be analyzed automatically in the framework of dependency analysis studied in the area of natural language processing.

(2) Training of Internal Structure Analyzer

As a training corpus, we annotated the Japanese Standard Disease-Code Master [14]. We randomly chose 114 disease names from C (Neoplasms), 96 from E (Endocrine, nutritional and metabolic diseases), 101 from G (Diseases of the nervous system), 125 from H (Diseases of the eye and adnexa), 123 from K (Diseases of the digestive system), 137 from L (Diseases of the skin and subcutaneous tissue). As an extraction condition, we apply the condition that the length of a disease name is longer than six characters. Then we defined internal structures manually. Shorter words appearing within the target words are also annotated. For example, "**肝炎**"(two characters) were annotated because it appears within "慢性非活動性**肝炎**"(eight characters).

As an analyzer, we used MaltParser [12], which is an implementation of shift-reduce parsing. Table 1 presents features used by the analyzer.

Experiment

To investigate the performance of the proposed method, we conducted experiments on the performance of internal structure analysis, and discuss its promise for ICD coding. The experimental setting is the following.

Comparable methods

PROPOSED: the proposed method described in the previous section.

BASELINE: method by which each character depends on the subsequent character (majority baseline).

Evaluation Metrics

According to the sentence parse evaluation manner, we adopted two types of evaluation metrics:

Table 2 – Accuracy of Internal Structure Analysis

		C	E	G	H	K	L	C-L	Overall
Average Word Length		7.6	9.0	8.8	7.3	7.3	5.3	7.4	6.1
PROPOSED	C-ACC	91.7±3.3	96.4±2.3	94.4±1.9	95.3±2.4	94.0±2.8	96.3±3.7	94.0±0.9	95.4±0.8
	E_W-ACC	52.8	71.9	60.2	70.4	63.7	81.9	63.3	75.0
	W-ACC	57.5±11.7	77.4±14.0	64.5±14.6	77.0±8.4	71.5±12.3	86.4±11.3	70.1±2.9	83.7±3.8
BASELINE	C-ACC	81.5±2.5	85.5±1.9	84.8±1.5	81.9±1.6	79.7±4.7	83.3±2.6	82.6±0.9	83.3±1.0
	E_W-ACC	21.1	24.4	23.4	23.3	19.1	38.0	24.3	32.8
	W-ACC	8.5±7.0	7.5±11.0	6.8±6.0	12.0±5.6	9.6±6.3	27.6±4.5	12.2±2.8	27.6±1.8

Accuracies with 95 percent confidence intervals. The first line indicates subset of our training corpus:* **C *Neoplasms,* **E** *Endocrine, nutritional and metabolic diseases,* **G** *Diseases of the nervous system,* **H** *Diseases of the eye and adnexa,* **K** *Diseases of the digestive system,* **L** *Diseases of the skin and subcutaneous tissue. "***C-L***" is aggregation of 6 categories, i.e.* **C**, **E**, **G**, **H**, **K**, **L**. *"***Overall***" is the full set of the*

(1) C-ACC: Character level accuracy

(2) W-ACC: Word level accuracy

For the following example (Figure 3), C-ACC is 2/3 and W-ACC is 0/1.

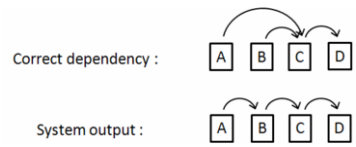


Figure 3 - Example of two accuracies

Materials

Using the annotated corpus, the internal structure analyzer was trained and evaluated using five-fold cross validation.

Results

Table 2 shows the obtained result. An example of the system output is portrayed in Figure 4 (dependency labels were all "D" in the example).

The overall accuracies were 95.4% (C-ACC) and 83.7% (W-ACC). The proposed method is superior to the baseline, especially for W-ACC. The E_W-ACC in this table was calculated as C-ACC to the <average length>-th power. It is the expected word level accuracy with an assumption each character's dependency relations are independent. Actually, W-ACC was superior to E_W-ACC in PROPOSED, although it was not in BASELINE, which shows that the character level-dependency relations are not mutually independent and that the analyzer (proposed method) learned the internal structures well.

The overall accuracy was lower than the reported for an earlier study [11]. As a likely cause, it must be considered that the dependency relation used in our study differs from that in the previous study: the root of the dependency tree was always the end of a word. This difference can influence the result.

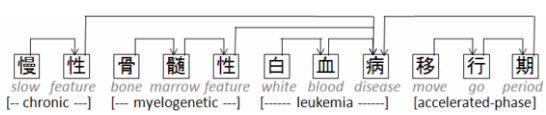


Figure 4 – Example of a correctly analyzed disease

Discussion for ICD coding

The proposed internal structure and its analyzer are helpful for precise ICD coding.

Generally speaking, rule-based ICD coding necessitates two points: coding rules and analyzing input diseases. Coding based on the internal structures proceeds as follows: (step 1) obtain the internal structure of the input disease, (step 2) use coding rules by the internal structure acquired at step 1. At step 1, the analyzer described the work explained above. Next, we discuss the coding rules in step 2.

We defined the representation of the coding rule as "an internal structure => an ICD code". The problem is how to make the rules. The left-hand-side of the rule should be the essence of the concept that the corresponding ICD code (the right-hand-side) denotes.

We propose an example based method: extracting the essential structure from examples sharing the same ICD code.

Figure 5 presents an example of the essential structures of S72.3 and S72.9 based on Figure 1. The structure of S72.3 is the same structure as that of "femoral shaft fracture" in Fig. 1, whereas "incomplete" disappeared in the case of S72.9. That is to say, the essential internal structure for ICD coding is the maximum common subtree of the examples for the ICD code.

The approach described above deals with the order/existence of modifiers (post coordination) that this paper targets. First, the difference of modifiers order is solved by the representation itself because the internal structures of two disease names, which differ from each other merely by the modifier order, are the same. Second, non-essential modifiers disappear when the coding rule is generated.

Once the coding rules have been prepared, the most appropriate rule is sought. An internal structure could fire more than one rule (presuming an input "femoral fracture" and rules presented in Figure 5). Therefore, the question arises: "Which is the correct one?" For this approach, we defined that the rule among candidate rules for which the internal structure (left-hand-side of the rule) size is greatest is the most appropriate.

Coding rules can be adapted even better by changing the comparison strategy: "string match" to "class match". For example, if "femur fracture" is input, neither of the two rules above fire because of the difference of two strings: "femur" and "femoral". The solution is "knowledge", like an ontology, which tells the system that the two strings are of the same class.

As an example, we can presume generation of a rule from two disease names sharing an ICD code, "supracondylar femur fracture" and "distal femoral fracture". The coding rule generated by the strategy "string match" is the same as S72.9. The information that the left-hand-side contains is insufficient. The strategy "class match" is the solution: "supracondylar" and "distal" belong to the same class, at least in the "femur fracture" context.

The rules can be generated automatically by humans or the internal structure analyzer. Which is the better solution—the analyzer or human—presumably depends on the situation.

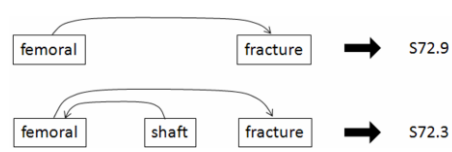


Figure 5 - Examples of coding rules

Previous works

Numerous researchers have examined automatic coding. Such efforts are separable into two groups: (1) term-based [8–10], for which the input is a disease name; and (2) text-based [4–7], for which the input is text such as discharge summaries. The latter have an advantage over the former because they use richer information. Such rich information, however, is not always utilizable. Therefore, it does not motivate our approach.

Another important aspect of coding studies is the coding algorithm such as frequency statistics [10], a Naïve-Bayes classifier [8], and an open registry algorithms [7]. Although various approaches have been proposed, they make use of the input disease name as string, ignoring its internal structure.

Our study differs from these works in the sense that: (1) we use internal structures of disease names, (2) we deal with omission and contraction of characters.

From the perspective of natural language processing, many researchers have examined parsing, i.e., analyzing sentence structures or discourse structures, although they paid less attention to the term structure. Neither is associated with medical informatics. Morphosaurus[13] segments a term into semantically annotated morphemes, however they does not deal with dependency relations.

Conclusion

This paper proposed a new representation for internal structures of disease names. Our character-based representation can deal with peculiar linguistic phenomena—omission and contraction—that previous works have not addressed. For ICD coding, it would be useful to generate coding rules and to analyze the input disease names to be coded.

Acknowledgements

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Exploitation of linguistic indicators for automatic weighting of synonyms induced within three biomedical terminologies

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Abstract

Acquisition and enrichment of lexical resources is an important research area for the computational linguistics. We propose a method for inducing a lexicon of synonyms and for its weighting in order to establish its reliability. The method is based on the analysis of syntactic structure of complex terms. We apply and evaluate the approach on three biomedical terminologies (MeSH, Snomed Int, Snomed CT). Between 7.7 and 33.6% of the induced synonyms are ambiguous and cooccur with other semantic relations. A virtual reference allows to validate 9 to 14% of the induced synonyms.

Keywords:

Natural language processing, Semantics, Vocabulary, Terminology, Medical informatics, UMLS.

Introduction

Within the biomedical area, practitioners and institutions may use different terms, which can convey the same or a close meaning. For example, the terms heart attack, myocardial infarction, and MI present the same meaning to a medical expert, while these expressions remain different to a computer, unless suitable resources and tools are available and used. The purpose of these resources and tools is to compute the semantic similarity between terms and to guarantee semantic interoperability between automatic systems. Such need appears whenever applications like information exchange and retrieval, knowledge extraction, terminology matching are addressed. Lexica of synonyms and of morphological or orthographic variants are typically used for the computing of semantic similarity. Depending on languages and domains, these lexica are not equally well described. The morphological description of languages is the most complete thanks to databases like Celex [1] for English and German, MorTal [2] for French, UMLS Specialized Lexicon [3] for medical English, and similar resources for German[4] and French [5]. At the level of synonyms, little available resources can be found: WordNet [6] proposes synonym relations for English, but the corresponding resources for other languages are not freely available. Otherwise, various existing biomedical terminologies provide complex terms, but their use is less suitable for the biomedical applications [7].

In a previous work, we proposed a method for filling the gap and for acquisition of synonymy resources within biological area: we used an existing structured terminology Gene Ontology [8] in order to induce a lexicon of elementary synonyms. The induced synonyms were then profiled through endogenous information acquired within the same terminology [9]. In the current work, we propose to generalize this method and to apply it to three other biomedical terminological resources: MeSH [10], Snomed Int [11] and Snomed CT [12]. Since synonyms are a contextual phenomena and they may convey more or less close or ambiguous meaning, we propose also a method for transformation of linguistic profiling indicators into numeric values, which are to be used to automatically weight the acquired synonyms. The objective of this part of work addresses the degree of semantic similarity and reliability of synonyms.

Material: semantic relations between terms

Our material is provided by three biomedical terminological resources: MeSH [10], Snomed Int [11] and Snomed CT [12]. These three terminologies are generic to the biomedical area: they propose its general descriptions, although they aim at satisfying different needs. The goal of the MeSH thesaurus is to provide a terminological resource for information retrieval. The goal of the Snomed Int nomenclature is to help the computerization of clinical data. Finally, the goal of the Snomed CT nomenclature is to provide terminological resource for organizing and, more particularly, for exchanging clinical data.

These three terminologies are structured: their terms are related among them with various semantic relationships. We access this information through the UMLS [3], version 2008AB. We extract the semantic relations according to their broad categories as they are defined by the UMLS. These categories are the following: AQ (allowed qualifier), CHD (has child), DEL (deleted concept), PAR (has parent), QB (can be qualifier by), RB (has a broader relationship), RL (has similar

or like relationship), RN (has narrower relationship), RO (has relationship other than synonymous, narrower or broader), RQ (related and possibly synonymous), SIB (has sibling), SY (source-asserted synonymy). These UMLS categories of relationships are assigned on the basis of the source documentation or on the basis of the NLM understanding of the sources. For extraction of our material, we focus on four categories of relationships:

- synonymy relations provide identical or similar meanings. They are extracted within UMLS concepts and correspond to the category SY which links preferred term labels to their synonyms;
- is a relations provide the hierarchical structure for terms. We consider that they are indicated by four broad categories: PAR, RB, CHD or RN;
- sibling relations link terms that have the same hierarchical father. They are indicated by SIB category;
- associative relations may convey various kinds of semantic relations. We consider they are indicated by RO category.

The extracted terms related by these relationships are always restricted to the corresponding terminology. is a, sibling and associative relations take into account preferred and synonymous labels of terms.

Methods

Inducing and profiling synonymy relations

In order to induce and to profile resources of synonymy relations, we applied the method described in previous work [9]. Here, for the sake of clarity, we will mention the general principles of the proposed approach.

Biomedical terms are often coined on the same syntactic scheme and show the compositionality through the substitution of one of their components (underlined):

infection of navel cord; infection of umbilical stump

benign tumour of scrotal skin; benign neoplasm of scrotal skin

We proposed to exploit the compositionality and to induce paradigms of elementary semantic relations (i.e., {*navel cord, umbilical stump*}, {*tumour, neoplasm*} in the examples above). Compositionality of biomedical terms has been exploited previously, especially through Gene Ontology, for consistency checking [13], for adding missing synonym terms [14] or for deriving simple graphs from relations between complex terms [15]. While the cited works are based on the string matching within terms, our approach aims at exploiting the syntactic analysis of terms, according to the compositionality definition [16]: the meaning of a complex expression is fully determined by its syntactic structure, the meaning of its parts and the composition function. We assume that relationship between elementary terms is inherited from the relationship between complex terms having the same syntactic schema and components at the word or semantic level. In this work, we apply the method to several relationships: synonymy, is a, sibling and associative.

Terms are processed through the Ogmios NLP platform[1], and are syntactically analyzed by a dedicated term parser: syntactic dependencies between term components are computed according to assigned POS tags [17] and shallow parsing rules[2]. Thus, each term is considered as a syntactic binary tree (see fig. 1) composed of two elements: head component and expansion component. For instance, *infection* is the head component of *infection of navel cord* and *navel cord* is its expansion component. According to the compositionality principle, the synonymy terms from figure 1 enrich synonym lexicon with {*navel cord, umbilical stump*}. In these two terms, the variation occurs within the expansion components. Besides, the variation can also occur within head components, or even within both components (head and expansion). Each of these cases will be exploited for inducing semantic relations.

Figure 1 - Parsing tree of the synonym complex terms infection of navel cord and infection of umbilical stump

However, semantic relationships as synonymy, are contextual [18]: for a given relation, its profile can vary according to contexts of its instances. In order to help the NLP to exploit such resources, we profile the induced synonymy relations through several types of linguistic indicators generated within the same terminologies:

- Cooccurrence of several elementary semantic relations induced by our approach;
- Lexical inclusion controlled within each induced synonymy pair, because lexical inclusions may convey a hierarchical relation: in the pair {*arterial embolism, embolism*}, *arterial embolism* is a kind of *embolism*;
- Productivity (or number of original pairs from which an elementary relation is inferred) for each induced semantic relation, including lexical inclusion.

Weighting and evaluating induced synonyms

The linguistic indicators (productivity, lexical inclusion, cooccurrence of semantic relation) will be used for automatic computing of weights for each induced synonymy relation. Currently, these indicators are descriptive and symbolic: they are meaningful to human users, but they have no exploitable meaning to a computer. In that respect, we have to: (1) transform the symbolic indicators into numeric values, and (2) propose an approach for combination of these values into a weight associated to each synonymy relation.

According to our general observation, reliability of the induced synonymy relations is closely related to its profile: pro-

[1] http://search.cpan.org/~thhamon/Alvis-NLPPlatform/
[2] http://search.cpan.org/~thhamon/Lingua-YaTeA/

ductivity and cooccurrence with other semantic relations. For computing the numeric weight and reliability of each synonymy relation rel_i, we propose to sum weights of all the cooccurring indicators. The weight of each indicator corresponds to the product of its productivity $prod_j$ and coefficient α_j. The general formula is the following:

$$weight(rel_i) = \sum_{j \in \{syno, is\_a, asso, sib, incl\}} \alpha_j \times prod_j(rel_i)$$

Values of coefficients α_j were determined empirically, they are amplified by their productivity values.

- α_{syno} was set to 1: it is the highest value established, which gives more reliability to a given relation.
- Since is a relation weakens the synonymy reliability, its value α_{is_a} was set to 1.
- Lexical inclusion may convey both hierarchical relation, like is a, and synonymy through the elision phenomena. Its value α_{incl} was thus set to 0.5.
- associative and sibling relations also weaken reliability of synonymy but to a lesser extend than is a: there values α_{asso} and α_{sib} were set to 0.75.

With such set of α values, positive weights signify more reliable synonymy relations. The reliability increases as the positive values increase.

There is no gold standard for the evaluation of a lexicon of synonyms within the biomedical area: the only available WordNet resource appears to be unsatisfying [19, 20]. Here again, we propose to take advantage of the exploited terminologies in order to evaluate our results. We will generate a *virtual truth*: set of synonyms induced by our method, which are already present in the exploited terminologies.

Results and Discussion

Building the material

In Table 1, we give indications on volume of material available in UMLS for the three processed terminological resources: numbers of terms (labels) and of the corresponding CUIs, and numbers of the extracted semantic relations (synonymy, is a, sibling and associative). We can observe that Snomed Int provides low number of semantic relations, but it has also the lesser number of terms. While MeSH and Snomed CT propose a richer network of relations and of the involved terms. Otherwise, sibling relationship is proposed only by MeSH.

Table 1 - Number of terms (labels and CUIs) and number of semantic relations (synonymy, is a, sibling, associative) provided by three exploited terminologies

	MeSH	Snomed Int	Snomed CT
number of terms	684,211	164,180	1,143,186
number of CUIs	291,746	112,709	313,612
Synonymy	469,847	57,111	399,712
is a	1,627,703	237,702	2,496,097
Sibling	7,870,078	—	—
Associative	265,178	213,108	6,166,776

Inducing and profiling the synonymy relations

All the semantic relations among complex terms from the three processed terminologies have been fully analyzed through the Ogmios platform. Compositional rules have been applied and allowed to induce elementary synonymy, is a, sibling and associative relations. Numbers for each type of the induced relations within each terminology are indicated in Table 2. Lexical inclusions have been controlled for each synonymy relation: they are indicated in Table 2, line *l.inclusion*. The last two lines of the table indicate the number of synonymy relations which cooccur with other semantic relations, and their percentage. Productivity of the induced relations within original complex terms have been also computed.

Table 2 - Number of induced semantic relations (synonymy, is a, sibling, associative and lexical inclusion) in three exploited terminologies, and number of ambiguous synonymy relations

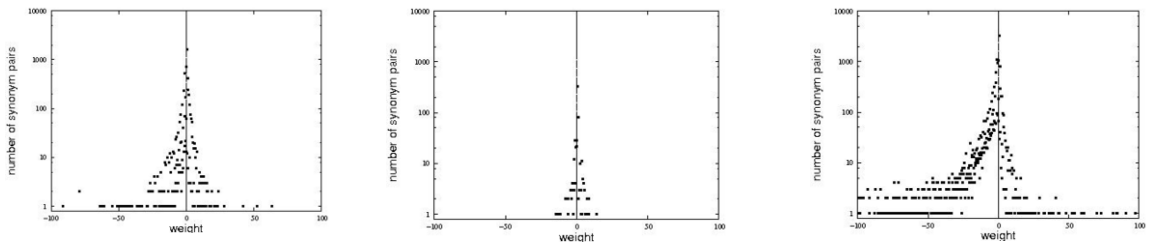
	MeSH	Snomed Int	Snomed CT
Synonymy	29,741	7,950	39,921
is a	53,015	3,906	127,197
Sibling	(142,360)	—	—
Associative	4,623	2,248	96,862
l.inclusion	7,777	999	28,633
common (number)	3,847	611	13,409
common (%)	12.9%	7.7%	33.6%

7.7% of synonymy relations induced within the Snomed Int are cooccurring and ambiguous with other induced semantic relations, while within the MeSH ambiguous synonymy relations are more frequent (12.9%). As MeSH is the only terminology that proposes sibling relationship, these are not taken into account. If they are, number of ambiguous synonymy relations is 6,809 (22.9%). The highest ambiguity is observed within Snomed CT: up to 33.6%.

Weighting and evaluating induced synonyms

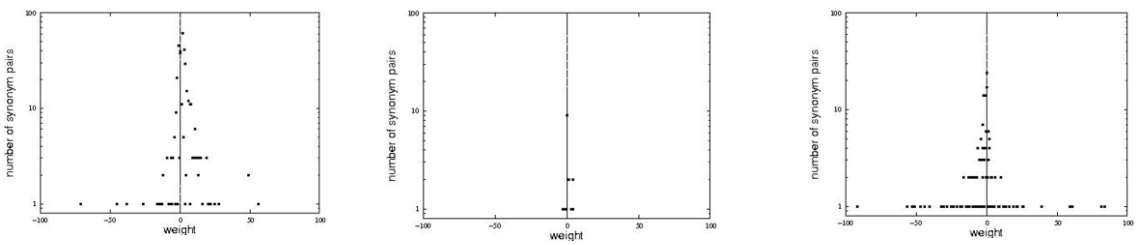
Weights of the synonyms induced within the three processed terminological resources have been computed according to the proposed formula. Figure 2 indicates distribution of these weights (x-axis) for synonyms that cooccur with other semantic relations.

The central vertical line materializes the frontier between positive and negative weights. The y-axis of the figure is



MeSH Snomed Int Snomed CT

Figure 2 - Weights of induced synonymy relations cooccurring with other semantic relations



MeSH Snomed Int Snomed CT

Figure 3 -Weights of induced synonymy relations within the set of the virtual truth (subset of relations from Figure 2)

algorithmically scaled and indicates number of synonym pairs that show a given weight. For instance, within Snomed Int, 2 pairs of synonyms -{*bleeding, haemorrhage*} and {*bleeding, hemorrhage*}- have been assigned the weight of 8.75: they occur 11 times as synonyms and cooccur 3 times with associative relations. The extremities of the weight values can exceed the figure. Thus, the interval of values for MeSH is [-393, 388], [-14.25, 14] for Snomed Int, and [-510.5, 404] for Snomed CT. We can observe that the negative and positive frontiers of these intervals are parallel, except for Snomed CT; and that the amplitude is the highest within Snomed CT and lowest within Snomed Int. But the latter provides also the lowest number of terms and relations. There is a tendency of the point's cloud to be attracted to negative values, except for Snomed Int-induced synonyms.

Table 3 - of induced synonyms which are present in the three terminologies: validation through a virtual truth

	Existing synonyms				
	MeSH	***SNInt***	***SNCT***	***VT***	**%**
MeSH	2,438	198	560	2,692	9%
SN Int	290	438	979	1,102	13.9%
SNCT	1,043	1,322	5,211	5,575	14%

Table 3 indicates number of induced synonyms that are already known in the three processed terminologies. For instance, 2,438 MeSH-induced synonym pairs are already registered in this terminology, and 198 MeSH-induced synonyms are already registered in Snomed Int. We can observe a large number (5,211) of Snomed CT-induced synonyms that are already known in there: this resource provides many elementary, or non defined, terms of the biomedical area, although it doesn't allow to build an extensive set of the synonyms. The total number of the induced synonyms that exist within at least one of the exploited terminologies is 8,023. This set of synonyms is used to build up the virtual truth, on which basis we perform a further evaluation of the results. The last two columns of Table 3 indicate number and percentage of the induced synonyms that are also in the virtual truth (VT) set: 9% of MeSH synonyms, 13,9% of Snomed Int and up to 14% of Snomed CT-induced synonyms are thus validated. Other induced synonyms are new. Figure 3 indicates the distribution of weights for the induced synonyms that are also part of the virtual truth set. We can observe that number of ambiguous synonymy relations is very small among Snomed Int-induced synonyms, and that the point's cloud of MeSH is now attracted to positive values. Within Snomed CT, the ambiguity of synonyms is still the most important.

Quality of results provided by this method depends (1) on precision of POS-tagging and we tried to apply the best currently known tagger [17]; (2) on quality of the source material; and (3) on the verification of a compositional structure of terms: up to now we have found only one pair of French terms where the compositional structure was not respected {*coup de soleil, sensibilité au soleil}* meaning (*Solar sensitiveness*), where *coup de soleil* is not compositional.

Conclusion and Perspectives

We proposed a novel method for inducing a lexicon of synonyms from structured terminologies and for its weighting in order to help the natural language processing-based applica-

tions. This method exploits the compositionality principle and three rules based on syntactic dependency analysis of terms for inducing the synonyms. We exploit also a set of endogenously generated linguistic indicators (is a, sibling, associative, l.inclusion and their productivity) for profiling the induced synonymy relations and for computing their weight. If a synonymy relation is free of other semantic relations, its reliability is not hindered. Otherwise it suffers from these cooccurring relations. Thus, up to 33.6% of synonymy relations induced within Snomed CT are ambiguous with other semantic relations. The ambiguity is lower within MeSH (12.9%) and Snomed Int (7.7%). Weights of these ambiguous synonyms are attracted to negative values, which indicate less reliable synonyms. A virtual truth set of synonyms is built up with those induced synonyms that are also provided by the exploited terminologies. It allows to validate 9 to 14% of the induced synonyms. It also allows to observe that within this set, the ambiguity of the induced synonyms is lesser, particularly within MeSH and Snomed Int. Weights provided by the current work are helpful for the filtering step of synonyms and for preparing their validation. We noticed that the used material can be improved. For instance, it seems that there is an inconsistency in creating the broad categories of relations within UMLS: mapped to relations from source terminologies are currently assigned to RL, RQ, RN and RO relationships, which means that they may appear in both is a and associative categories. If a specific filter is applied, the material may provide less ambiguous set of induced synonyms. Besides, other NLP methods suitable for analysis of corpora may be used in order to enrich or cross-validate lexicon of synonyms acquired in this experience. Once thoroughly validated, this lexicon will be made available to the community. This lexicon can be exploited within various NLP tasks and applications.

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Auto-selection of DRG Codes from Discharge Summaries by Text Mining in Several Hospitals: Analysis of Difference of Discharge Summaries

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Abstract

Recently, electronic medical record (EMR) systems have become popular in Japan, and number of discharge summaries is stored electronically, though they have not been reutilized yet. We performed text mining with Tf-idf method and morphological analysis in the discharge summaries from three Hospitals (Chiba University Hospital, St. Luke's International Hospital and Saga University Hospital). We showed differences in the styles of summaries, between hospitals, while the rate of properly classified DPC (Diagnosis Procedure Combination) codes were almost the same. Beyond different styles of the discharge summaries, text mining method could obtain proper extracts of proper DPC codes. Improvement was observed by using integrated model data between the hospitals. It seemed that huge database which contains the data of many hospitals can improve the precision of text mining.

Keywords:

Text mining, Discharge summary, Electronic medical record.

Introduction

With the spread of recent hospital information systems, the discharge summary begins to be saved electronically at many hospitals in Japan. However, every hospital has its own style of discharge summaries. In addition, an inconsistent form is used in every hospital, so there is no suitable study samples comparisons of discharge summaries among different hospitals.

In Chiba University Hospital, full text computerization of electronic discharge summaries began in 1999. We reported to past MEDINFO congress that useful information was obtained from summaries by text mining [1-3]. However, we were not able to conclude that the results were generally valid, since the styles of summaries are different. Therefore, it is necessary to review whether our conventional method can be applied to other hospitals. We tried a cross-sectional comparison experiment for the discharge summary of the St. Luke's International Hospital and the Saga University hospital. All these hospitals are major hospitals in Japan.

Using text mining we performed an experiment to select DPC (Diagnosis Procedure Combination) from the discharge summary. DPC or so called Japanese version of DRG (Diagnosis Related Group) is a classification that has become the basis of an inclusive evaluation system of hospitalization health care cost.

Figure 1 shows the structure of the DPC code. The first two digits are the Major Diagnostic Category (MDC) and the next four digits stand for the disease name. The remaining eight digits indicate the admission purpose, age, operation, treatment, complication, and severity.

DPC code is given to the discharge summaries of all hospitals. Therefore, we consider that we can compare between different hospitals using a DPC code. We examined the differences in the structure of the discharge summaries of each hospital by examining the type and the frequency of the extracted terms.

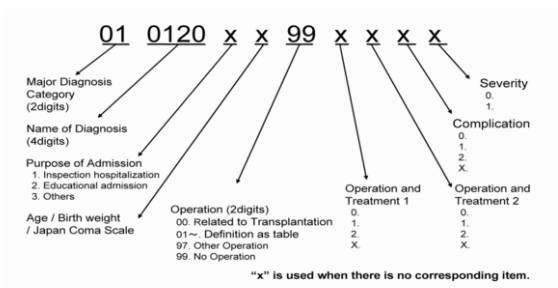

Figure 1 –Sample of DPC code "Idiopathic mono neuropathy; no operation"

Materials

Discharge Summary

We have analyzed discharge summaries of patients, who had been discharged from Chiba University Hospital, St. Luke's International Hospital and Saga University Hospital between April, 2006 and March, 2008. All analyzed discharge summaries had been written and stored electronically and had been

assigned a DPC code. The numbers of discharge summaries extracted from each hospital are as follows.

1. Chiba University Hospital: 24,594
2. St. Luke's International Hospital: 24,002
3. Saga University Hospital: 1,188

Problems with discharge summaries in each hospital

Each of the three hospitals has original discharge summary formats. We describe the general conditions and problems with the discharge summaries of the hospitals in the following.

Chiba University Hospital

A chief physician inputs the discharge summary as free text within two weeks after patient's discharge. The entry item is standardized, but there is no clear standard about the length of a summary, and a significant difference occurs between departments.

St. Luke's International Hospital

Both entry item and length are standardized. Because the length tended to get too long before, they set up one page limit. Their aim was a concise summary which could be read within twenty seconds.

Saga University Hospital

A chief physician can extract necessary information from the electronic patient record semi-automatically to make a discharge summary and convenient for physicians.

Methods

Morphological Analysis and Reconstruction of the Dictionary

Morphological analysis that decomposes a character string into elements such as a noun, adjective, and particle, is necessary for the analysis of Japanese sentences. Chiba University Hospital and St. Luke's Hospital have improved the precision of the Japanese medical dictionary conventionally for the process of morphological analysis. We use the user's medical dictionary of both hospitals together in this study.

The PHYXAM dictionary was used as a Japanese medical technical dictionary for the physical examination field [4]. Terms from the master table of both hospitals were added to the dictionary. The unknown terms from the discharge summaries were also added to the dictionary. Then our dictionaries included about 320,000 terms.

We used Mecab ver0.96 developed at Kyoto University information science graduate course as a morphological analysis system for Japanese sentences [5].

Investigate the characteristics of the summaries

We compared the following points among hospitals. We extracted only the nouns to characterize a sentence, and counted the number of terms and their type that appear in each summary.

Number of terms included in summary

We compare a difference of the summaries by the number of terms which were extracted by morphological analysis. We examined dispersion of the number of terms by values of mean, median, standard deviation, maximum and minimum. Normality was certificated by the Kolmogorov-Smirnov official.

Comparison by MDC

Discharge summary may be different between different medical departments, because the day of hospitalization, surgery and treatment varies according to a disease.

MDC is called major Diagnostic Category, and is expressed with the first two digits of the DPC code. MDC divides all diseases into 16 categories of a macrotaxonomy.

The hospitals we intended for this study were general hospitals with a vast array of medical departments. Therefore we could extract MDC from all discharge summaries (Table 1).

Table 1 - Disease of MDC

MDC	Disease
01	Nervous system disease
02	Ophthalmologic disease
03	Otorhinolaryngological disease
04	Respiratory disease
05	Circulatory disease
06	Digestive system disease
07	Musculoskeletal system disease
08	Skin and Subcutanea disease
09	Breast disease
10	Endocrine and Metabolism disease
11	Urogenital system disease
12	Gynopathy and Obstetrical disease
13	Blood and Immunological disease
14	Anomary and Newborn infant disease
15	Pediatric disease
16	Injury, Toxicosis and Other diseases

Comparing the precision of DPC selection

Grouping of data

We arranged the summaries of each hospital according to a discharge date and divided them into two groups in a ratio of 7:3, each of which had at least 10 cases in St. Luke's International Hospital and Chiba University Hospital. The first group was collected to generate document vector space model according to the DPC, the second group was collected as a test group to verify automatic DPC selection. In Saga University Hospital, all the summaries were assigned to a second group. In this way, we selected 20,013 cases for this study. The cases contained 97 different DPC codes. We show the number of the cases in Table 2.

Table 2 - Number of summaries

	Data for model	Data for verify
Saga university hospital	0	218
St. Luke's International Hospital	7,421	3,197
Chiba University Hospital	6,416	2,761
Total	13,837	6,176

Vector Space Model

The vector space model, which converts the characteristics of a document into a multidimensional vector, is a technique widely used in the field of information retrieval [6, 7]. In this study, we calculated the weights of each term to convert the characteristics by term frequency–inverse document frequency (tf-idf) method. The targeted discharge summary set is assumed to be $\boldsymbol{D}$, and the discharge summary sets of each disease are assumed to be $\boldsymbol{d_1, d_2, \cdots, d_j, \cdots, d_n}$. Next, $\boldsymbol{m}$ pieces of index terms extracted from $\boldsymbol{D}$ are assumed to be $\boldsymbol{\omega_1, \omega_2, \cdots \omega_i \cdots \omega_m}$. Thus, the weight in the discharge summary $\boldsymbol{d_j}$ added to index term $\boldsymbol{\omega_i}$ is assumed to be $\boldsymbol{\alpha_{ij}}$. Then, discharge summary $\boldsymbol{d_j}$ can be expressed by a matrix composed of $\boldsymbol{m}$ pieces of element $\boldsymbol{\alpha}$. Consequently, the sets of discharge summary $\boldsymbol{D}$ can be defined as a collection of matrices of $\boldsymbol{d_n}$, as shown in Figure 2.

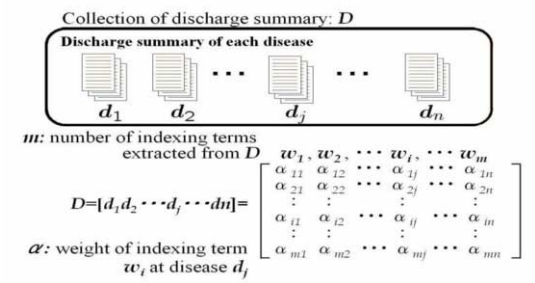

Figure 2 - Vector space model

tf-idf Method

In tf-idf method, weight $\boldsymbol{\alpha_{ij}}$ is shown by $\boldsymbol{\alpha_{ij}=(l_{ij}\times g_i)/n_j}$.

$$\boldsymbol{\alpha_{ij}=(l_{ij}\times g_i)/n_j} \quad (1)$$

$$\boldsymbol{l_{ij}=log(1+f_{ij})} \quad (2)$$

$\boldsymbol{l_{ij}}$ is local weight, and it is calculated based on the frequency data in document D_j of index term $\boldsymbol{\omega_i}$ and a big value is given to the index term that appears frequently in the document. Frequency data $\boldsymbol{f_{ij}}$ in discharge summary $\boldsymbol{d_j}$ of DPC classification $\boldsymbol{j}$ of index term $\boldsymbol{\omega_i}$ was used this time.

$$\boldsymbol{g_i=log(n/n_i)} \quad (3)$$

$\boldsymbol{g_i}$ is global weight, and it is calculated based on the index term $\boldsymbol{\omega_i}$ distribution over the entire document set, and a big value is given to the index term that appears only in a specific document. $\boldsymbol{n}$ is total number of the discharge summary, and $\boldsymbol{n_i}$ is a number of discharge summaries including index term $\boldsymbol{\omega_i}$.

$\boldsymbol{n_j}$ is a document normalization coefficient to which removes the influence by the length of the discharge summary.

DPC Selection

We determined the DPC code from discharge summaries based on the calculated vectors. We calculated the inner products of the vectors to compare the similarity between each summary and the DPC code of a model group. When we select a DPC code of the summary for inspection, we use a DPC code from models that have high similarity. However, as for just using a DPC code of the summary that shows a highest similarity, is influenced by accident. Therefore we judged a DPC code of a test summary by a weighting point calculation of multiple summaries (Figure 3)

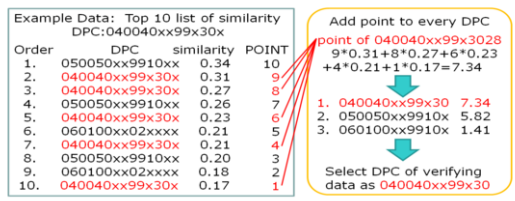

Figure 3 - DPC selection by weighting point

At first we select the top 10 summaries from a model group by similarity, and calculate a weighting point based on order and ratio. We expressed the weighting point (P) by the product of order (Rank) and similarity ratio (S (A, B)).

$$\mathbf{P\ (Rank) = S\ (A, B) \times (11 - Rank)} \quad (4)$$

Then we selected a DPC code of which sum of points was the greatest among DPC code test data. By this technique, precision was improved from 2% to 5% (Data not shown). Next, we counted the cases in two groups. Selected code was exactly the same as the original code of test case in the first groups, and it matched the first 6 digits of the code in the second group.

Cross match selection

We replaced or integrated the data of multiple hospitals and carried out the selection experiment as follows.

- We verified test data with their own model data. (experiment No.1,2)
- We verified test data with other hospital's model data. (experiment No. 3 - 6)
- We verified test data with integrated model data (experiment No. 7-9)

Results

Comparison by morphological analysis

Comparison by number of terms

We have shown the number of terms in the discharge summaries from each hospital in Table 3. The average number of terms is almost the same between St Luke's International hospital and Saga university hospital, however about twice that of Chiba university hospital. St. Luke's International Hospital has a small difference of the median and the mean, and the standard deviation is small, too, Chiba University Hospital has a large standard deviation and the median is smaller than the mean. In Saga University Hospital, the gap is smaller than that of Chiba University Hospital, but standard deviation is the largest among the three hospitals.

The normality of all hospitals was dismissed by the Kolmogorov-Smirnov certification, however St. Luke's International Hospital is the nearest in normal distribution.

Table 3 - number of terms in discharge summary

	Chiba University Hospital	St. Luke's International Hospital	Saga university hospital
mean	136.4	285.0	281.7
median	79	295	247
SD	164.4	123.5	181.5
minimum	1	24	5
maximum	1921	830	1261

As shown in Figure 4, the numbers of cases according to the number of terms in one summary are in inverse proportion at Chiba University Hospital. By contrast, they are distributed in the neighborhood of a mean at St. Luke's International Hospital. Saga University Hospital was in the middle.

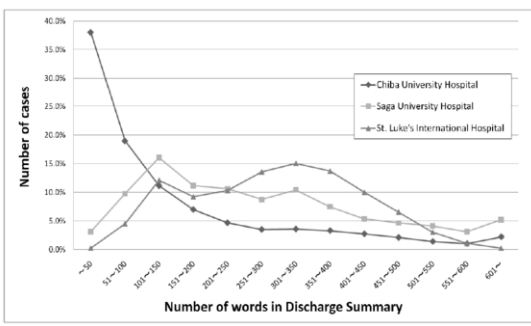

Figure 4 - Number of cases according to the number of terms

Comparison among number of terms by MDC

Figure 5 shows the comparison of the average number of terms according to MDC. Pattern of St. Luke's International

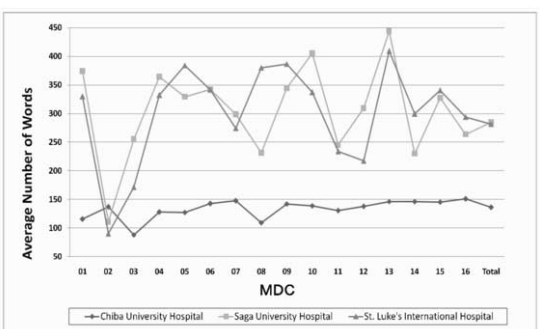

Figure 5 - Comparison among number of terms by MDC

Hospital resembles Saga University Hospital except 06 (Digestive system disease). Chiba University Hospital has a smaller number of terms and smaller difference between diseases than the other hospitals.

Comparison by precision of DPC selection

Selection by the data of same hospital

At first, we show a DPC selection rate where we used the model data of the same hospital for verification (see Table 4). Selection rate at Chiba University Hospital and St. Luke's International Hospital is approximately of equal value. These results show that the application of the method is independent of each institute.

Table 4 - DPC selection by same hospital data

No.	Data for selection		Precision of DPC selection	
	verify	model	Match 14 digit	Match 6 digit
1	Chiba (2761)	Chiba	75.9% (2097)	85.8% (2370)
2	St. Luke's (3197)	St. Luke's	78.9% (2524)	84.7% (2708)

Selection by the data of different hospital

Next, we show a cross match selection where we used the model data of different hospitals (see Table 5). For Chiba University and St. Luke's International Hospital, it seems that the selection rate falls about 10-20% in comparison to experiment 1, 2.

Table 5 - Selection by the data of different hospital

No.	Data for selection		Precision of DPC selection	
	verify	Model	Match 14 digit	Match 6 digit
3	Chiba (2761)	St. Luke's	62.5% (1725)	73.4% (2029)
4	Saga (3197)	Chiba	61.9% (1979)	68.2% (2182)
5	Saga (218)	St. Luke's	56.4% (123)	72.0% (157)
6	Saga (218)	Chiba	50.9% (111)	63.7% (139)

Selection by the integrated data

Finally, we show the DPC selection rate when using the integrated model data of Chiba University and St. Luke's International Hospital and verify data of each hospital (see Table 6).

Precision of St. Luke's International Hospital was the same as the result of experiment 2 where only its own data was used. The results of Chiba University hospital slightly improved in comparison with experiment 1.

The data of Saga University hospital also improved by using integrated data. The ratio extracted from the two hospitals was almost the same (Chiba 54%, St. Luke's 46%).

Table 6 - Selection by the data of integration

No.	Data for selection		Precision of DPC selection	
	verify	model	Match 14 digit	Match 6 digit
7	Chiba (2761)	Chiba + St. Luke's	76.5% (2114)	85.9% (2374)
8	Saga (218)	Chiba + St. Luke's	56.8% (124)	70.6% (154)
9	St. Luke's (3197)	Chiba + St. Luke's	77.1% (2465)	82.7% (2644)

Discussion

In the medical field, text mining applied to clinical contents are still rare [8]. One of the reasons is the lack of accumulated electronic medical documents to be analyzed, although there is a suitable target, Medline, which integrates numerous medical abstracts [9,10].

We described the different and common characteristics among the three hospitals. The length of the summary at Chiba University Hospital is half of that at other hospitals. At St. Luke's international and Saga University Hospital, about 30% of the summary surpasses 400 words. In Saga University hospital about 30% of the summaries have less than 150 words, indicating a big difference of the summaries. The length of the discharge summaries was also different by MDC. For example, 03 (otolaryngology diseases) have fewer words, adversely 13(blood/immune organ diseases) has many words. It was considered that these were common characteristics of the diseases and independent from hospitals.

The DPC selection rate at Saga University hospital is not high, implying that the terms of their summaries were not included in a dictionary. Difference of term structure of the summaries of each hospital decreased the precision of the DPC selection when we use the model data of another hospital. However the difference is not so large that we can consider the vector space model by tf-idf method selects a DPC independent from an institution. Improvement of the precision was observed when we use integrated data of hospitals. It suggests the possibility to improve precision by correct summaries from many hospitals.

When an integrated database of discharge summaries beyond hospitals is available, text mining will provide us with various application, such as acquisition of knowledge [11], similar case search [12], automatic coding of findings [13], extracts cancer staging from pathology reports automatically [14], and making classification automatically [15, 16] as well as comparison of many quality indicators between facilities.

Conclusion

Using a vector space model by the text mining method, we carried out a DPC selection based on the discharge summary from multiple hospitals. We have shown by morphological analysis that there was a difference in term structure among the discharge summaries of each hospital.

We were able to carry out a DPC selection independently of hospitals. Furthermore, improvement was observed by using integrated model data between the hospitals. A giant database which contains the data of many hospitals could improve the precision of text mining.

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Can F-MTI semantic-mined drug codes be used for Adverse Drug Events detection when no CPOE is available?

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Abstract

Background: Adverse Drug Events (ADEs) endanger the patients. Their detection and prevention is essential to improve the patients' safety. In the absence of computerized physician order entry (CPOE), discharge summaries are the only source of information about the drugs prescribed during a hospitalization. The French Multi-Terminology Indexer (F-MTI) can help to extract drug-related information from those records. Methods: In first and second validation steps, the performance of the F-MTI tool is evaluated to extract ICD10 and ATC codes from free-text documents. In third step, potential ADE detection rules are used and the confidences of those rules are compared in several hospitals: using a CPOE vs. using semantic mining of free-text documents, diagnoses and lab results being available in both cases. Results: The F-MTI tool is able to extract ATC codes from documents. Moreover, the evaluation shows coherent and comparable results between the hospitals with CPOEs and the hospital with drugs information extracted from the reports for potential ADE detection. Conclusion: semantic mining using F-MTI can help to identify previous cases of potential ADEs in absence of CPOE.

Keywords:

Adverse drug events, Electronic health records, Semantic mining, F-MTI, Medical reports, Discharge summaries, Terminology as topic.

Introduction

Adverse drug events (ADEs) are situations where some drugs, eventually combined with other drugs, lab abnormalities or clinical context lead to adverse events. Those events endanger the patients and induce extra costs. Many of those events can be prevented thanks to appropriate prescriptions or monitoring. ADE study often relies on electronic health records (EHRs). In those EHRs, computerized physician order entries (CPOEs) are the most important components because they provide reliable and available information about drug prescriptions. Unfortunately, many hospitals do not have any CPOE at disposal. But in that case, the free-text documents usually contain the main drug prescriptions: discharge summaries, discharge letters, exam reports, etc. A semantic-mining tool can extract that information from the text. The objective of this work is to check if a semantic mining tool can be used to extract drug codes in order to identify previous ADEs and to compute the confidences of potential ADE detection rules.

A tool has been developed since 2005 by the CISMEF team (Rouen University Hospital) and the Vidal company [1] and is called "F-MTI" French Multi-Terminology Indexer (a generic automatic indexing tool able to index documentation in several health terminologies). F-MTI is the property of the VIDAL Company. The aim of this study is to evaluate the F-MTI's performances for potential ADE detection.

Rationale

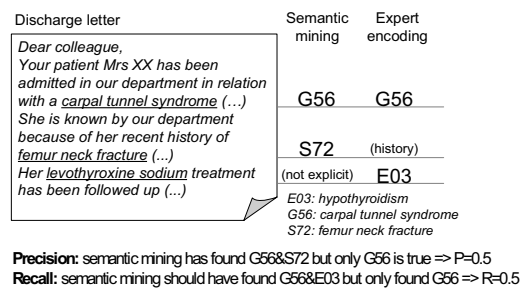

Figure 1 - Example of semantic mining applied on a discharge letter; precision and recall computation

FMTI (the French Multi-Terminology & Multi-Lingual Indexer) indexes any electronic text document with several terminologies. Work on the 2008 European Union funded PSIP project devoted to optimizing patient safety during drug prescription led to the addition of four new terminologies devoted to drugs into F-MTI's knowledge sources: the Anatomical Therapeutic Chemical (ATC) Classification (N=5,514), drug names with international non-proprietary names (INN) and brand names (N=11,353), the Orphanet thesaurus for rare dis-

eases (N=7,424) and the chemical substances and pharmacological action terms of the MeSH Supplementary Concepts translated into French by the CISMeF team (N=6,505 out of over 180,672) [2].

Actually, FMTI includes 16 terminologies and 5 languages (French, English, Spanish, Portuguese and Danish).

- Terminologies : ICD10 (fr/eng/dk), SNOMED3.5 (fr), CCAM (fr), MeSH (fr/eng), TUV (fr/sp/pt/eng), DCI (fr), NC (fr), MeSHSC (fr), ATC (fr/eng/dk), VCM (fr), ICD9 (eng/fr), ICPC (fr), DRC (fr), IUPAC (dk), ACTS (dk)
- Mappings : ICD10-MeSH, ICD10-SNOMED3.5, SNOMED3.5->ICD10, MeSH-SNOMED, ATC->MeSH, MeSHSP->MeSH, ATC->VCM, ICD10->VCM. Some mappings are taken from the UMLS, other mappings were manually created by several experts team from Orphanet, Vidal and CISMeF.

FMTI is called via a Web API, where the terminologies and the languages used for indexing can be selected. The results are returned in HTML, TXT and XML.

For each discharge letters, the document is first broken into sentences. Then each sentence is normalized (accents are removed, all words are switched to lower case and stemmed…) and stop words are removed to form a bag of words containing all the content words. The "bag" thus obtained is matched independently of the order of the words against all the 15 terminologies terms that have been processed in the same way. All terms formed with at least one word of the sentence are retrieved. Longer matches are preferred to shorter ones. All these candidate indexing terms are restricted to the semantically closest ATC and ICD10 terms using inter-concept relationships. FMTI can index a discharge letter in less than 1 second.

Semantic Mining is mainly oriented towards automatic indexing. For the evaluation of automatic indexing, different criteria can be measured, according to the literature [3-4]. The quality of the automatic indexing is evaluated by comparing the results of this automatic indexation (the candidate set) and the results of a gold standard (the gold standard set) on an evaluation dataset. The gold standard is the manual indexing performed by a human expert (Figure 1). For that purpose, different measures are commonly recognized as pertinent:

- **Precision (P)** is the number of indexing terms present in both candidate and gold standard sets divided by the total number of indexing terms in the candidate set. It measures the ratio of signal.
- **Recall (R)** is the number of indexing terms present in both candidate and gold standard sets divided by the total number of indexing terms in the gold standard set. It measures how well gold standard indexing terms are retrieved.
- **F-measure (F)** is the weighted harmonic mean of precision and recall. The traditional F-measure or balanced F-score is: $F = 2 * P * R / (P + R)$ where F is the F-measure, P is the precision and R is the recall.

In this study, three main metrics are calculated to show the performance of F-MTI indexing compared to the gold standard manual indexing: Precision, Recall and F-measure. These metrics are often used to evaluate the performances of automatic indexing tools [5].

Materials and Methods

In order to evaluate the equivalence of Semantic Mining and complete EHRs including CPOEs for ADE detection, three complementary validation methods are applied. The 10th revision of the International Classification of Diseases (ICD10) classification is used for diagnoses. The Anatomical Therapeutic Chemical classification is used for drugs.

Step 1- extraction of ATC codes from free-text documents: agreement between F-MTI and experts

The aim of this first phase is to measure the accuracy of the extraction of the drug names included in the various free-text documents by means of the F-MTI Semantic Mining Analyzer.

Several de-identified discharge letters are obtained:

- 4,000 from the Rouen University Hospital (F), from which 50 are used for the validation task
- 10,000 from the Denain General hospital (F) , from which 32 are used for the validation task

The drug names extracted by automatic semantic mining (F-MTI) are compared with the ones obtained from human medical expertise.

In the discharge letters, the drug names appear as brand or commercial names in 90% of cases, or as international names (INN). The list of brand names and INN names available in France are provided by the Vidal Company [1].

F-MTI indexing tool is used to extract the drug names and index them into ATC Codes: the results are gathered in the candidate set. The gold standard set is the result of the manual indexing performed by a human expert: the gold standard set. Human experts are a pharmacist and a medical archivist in Rouen; and two physicians in Denain.

In each free-text document, the Experts list

- the drug names recorded in the document (this is the "gold standard"),
- the drug names extracted by the F-MTI semantic tool.

Those lists are used to compute the precision and the recall.

Step 2- extraction of ATC & ICD10 codes from free text: agreements between F-MTI and EHR

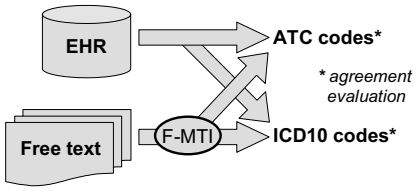

Figure 2 - Second validation step

In the Denain General Hospital, both the CPOE and the free-text documents are available. In this phase, the results of the semantic mining of the free-text documents (for the identification of the drugs prescribed or administered to the patient) are compared with the ones registered in the CPOE (Figure 2). This phase allows for computing the concordance between semantic mining analysis results and CPOE extraction for the identification of the drugs potentially linked with potential ADEs. This phase is only feasible in a hospital equipped both with a Hospital Information System containing the free-text documents and a CPOE System.

37 anonymized patients' complete EHRs from the Denain General Hospital are used. Those records include:

- data from the EHR and the CPOE: ICD10 codes for diagnoses, ATC codes for drugs,
- the free-text documents and the results of the automatic indexing of these letters by Semantic Mining (F-MTI): ICD10 codes and ATC codes too.

The Method consists in the careful comparison of the codes obtained from semantic mining of the free-text documents with the codes contained in the EHR and CPOE. The comparison of drug codes (through ATC Classification) and the comparison of diagnosis codes (through ICD10 classification) are performed separately. The so-obtained codes are compared. The recall R and the precision P are computed in each case.

This third validation phase consists in exploring the results of data-mining-based potential ADE detection rules when drugs are obtained from Semantic Mining of the various free-text documents, in case of absence of CPOE. This is done by studying the frequency of potential ADEs in the Rouen university hospital and comparing this frequency with the ones observed in hospitals where a CPOE is implemented (Copenhagen and Denain) (Figure 3).

The Material is represented by 245 data-mining-based detection rules obtained from various departments [6]. Those rules are a set of conditions that can lead to a traceable potential ADE. For each rule, the confidence is computed in Denain, Copenhagen and in the Rouen University Hospital where Drugs are obtained from Semantic Mining Analysis.

Step 3- validation of the use of the semantic mining results for data-mining-based ADE detection

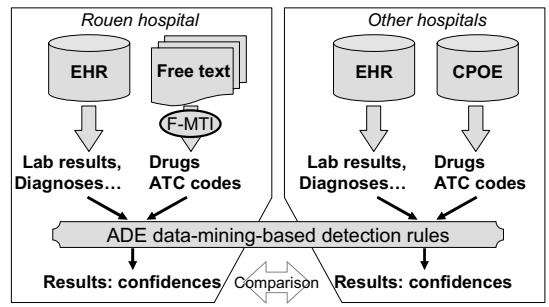

Figure 3 - Third validation step

Each rule is characterized by its confidence (1: proportion of outcome knowing that all the conditions are met) and its support (2: proportion of records matching both conditions and outcome).

$$\text{Confidence} = P(E \mid C_1 \cap \ldots \cap C_k) \quad (1)$$

$$\text{Support} = P(E \cap C_1 \cap \ldots \cap C_k) \quad (2)$$

The Method consists in the comparison of the confidences (positive predictive values) of the rules in the different places:

- the Rouen hospital where ATC codes are extracted from summaries,
- the other hospitals where ATC codes are extracted from CPOEs. The datasets from Denain and Copenhagen are pooled together to have only 2 datasets to compare. Moreover, pooling all the other datasets allows to get a better estimate of the confidence of the rules.

For each rule, all the stays that match the conditions of the rule are considered. The aim is then to test the independency between two binary variables using a Fisher's exact test:

- the occurrence of the effect (0 = "No" / 1 = "Yes"),
- the drug extraction method (CPOE/semantic mining)

For a given rule two results can be obtained:

- if p value < 0.05 then there is a significant difference between the confidence of the rule in Rouen and in other hospitals (the variables are not independent)
- if p value > 0.05 then no significant difference is observed between the confidence of the rule in Rouen and in other hospitals.

None of those results is interesting rule by rule. If significant p value is obtained for one rule, it is not surprising because the PSIP project showed that the confidences of the rules depend on the context in which they are used in (the patients, the practices and the knowledge are different) [7]. But if most of the rules look like having similar confidences in Rouen than in

other places, it is an argument to say that the results of rules evaluation are consistent in Rouen compared with other hospitals.

Results

Step 1- extraction of ATC codes from free-text documents: agreement between F-MTI and experts

The main results in the Rouen university hospital are:

- the overall Precision is **P = 0.84**
- the overall Recall is **R = 0.93**
- the F-measure is **F = 0.88**.

The main results in the Denain General Hospital are:

- the overall Recall is **R = 0.88**
- the overall Precision is **P = 0.88**
- the F-measure is **F = 0.88**

These results are coherent although the hospitals use different Hospital Information Systems, employ different physicians and take in care different populations of patients.

They appear as so successful as compare to the literature [8-10] particularly in the context of the French language where some particular difficulties have to be overcome (particularly negations or some verbal passive forms).

Step 2- extraction of ATC & ICD10 codes from free text: agreements between F-MTI and EHR

ATC codes extraction:

The ATC codes from the semantic mining are considered as "candidates" while the ATC codes from the CPOE are given as "the "gold standard". The results are (Table 2):

- the overall Recall is **R = 0.37**,
- the overall Precision is **P = 0.73**,
- the F-measure is **F = 0.49**

Table 2 - Ability of F-MTI to replace EHR or CPOE codes

	Drugs: SM vs DB	Drugs: SM vs Experts	Diagnoses: SM vs DB
Recall	37.4 % [33-42]	88.4 % [85-92]	26.7 % [21-32]
Precision	72.6 % [67-78]	88.4 % [85-92]	17.3 % [14-21]
F-measure	49.4 % [46-53]	88.4 % [85-92]	21.0 % [18-24]

SM=semantic mining, DB=database

ICD10 codes extraction:

When the F-MTI tool is compared with the spontaneous encoding process, which is essentially based on economic considerations, the results are not as good as when compared with an expert encoding based on the free-text documents:

- the overall Recall is **R = 0.27**,
- the overall Precision is **P = 0.17**,
- the F-measure is **F = 0.21**

Step 3- validation of the use of the Semantic Mining results for data-mining-based potential ADE detection

The comparison between Rouen and other hospitals datasets is performed on each rule separately. Rule n°53 is provided as a detailed example.

Rule N° 11: Vitamin K antagonist (VKA) & Antiepileptic → Appearance of too low an INR (International Normalized Ratio; risk of thrombosis)

In that example, no significant difference is observed between Rouen and other hospitals pooled together.

The same method is applied on the 245 validated rules. A significant difference between the pooled confidence and the Rouen confidence can be observed in 50 rules (20.4% of the rules).

Table 1 - Comparison between Rouen and other hospitals

Object	Rouen	Other hospitals
Stays matching both the conditions and the effect: VKA & antiepileptic & too low INR	2	43
Stays matching the conditions: VKA & antiepileptic & no too low INR	6	206
Confidence	33%	21%

Fisher's exact test: p value=0.61 (independence, α=0.05)

Discussion

The expert review before using the F-MTI is very time consuming, that's what the validation sets (50, 32) are small.

Predicting ICD10 codes is not an easy task when native data from the EHRs are used as the "gold standard" instead of an expert summary-based encoding. The ICD10 codes that are in the EHRs were most often encoded for economic objectives and include other information sources than the text documents. Moreover, the agreement between two experts is not so high [11].The results were coherent with the one obtained in a previous study [12].

Predicting ATC codes looks more successful although that task was performed on unstructured free text. Though mining the summaries poses problems. In discharge summaries, most often, only drugs previously taken by the patient and drugs prescribed at discharge are mentioned. In particular, some treatments only administered during the hospitalization (oxygen, pain killers, rehydration solutions, etc.) are never mentioned, which decreases the recall. Moreover the therapeutic information seems to be very rare when the patient has died during the hospitalization: there is no discharge treatment, and most often only clinical information is provided.

The F-MTI tool has to be improved. It encounters difficulties to recognize brand names in the discharge summaries due to identified problems that are currently being corrected. Some additional problems are linked with incorrect spelling of the names in the discharge summaries. Some brand names are written improperly with dash ("-") or underscore ("_") or with an incorrect space " " (e.g. *di-antalvic*, *diffu k*, *di hydan*, *cacit D*, *calcidose vit D*, *co renitec*). On the contrary, some brand names are written without dash ("-") or underscore ("_") or space (" "), as normally they should have to (e.g. *chibroproscar* instead of *chibro-proscar*; *bipreterax* instead of *bi-preterax*). Some other misspellings or mistyping are quite frequent (e.g. *triapridal* instead of *tiapridal*, *genopevaryl* instead of *gynopevaril*, *dextropropoxifene* instead of *dextropropoxyfene*, *piperacetam* instead of *piracetam*, *ketoderme* instead of *ketoderm*). For this type of mistakes, VIDAL team is now working on a phonemization algorithm to improve the system.

Some mistakes are redundant, e.g. the brand name is *cacit D3*. It is not automatically indexed and *cacit* is indexed instead of it. The same is occurring with *di-antalvic* & *antalvic* and *calcidose Vit D* & *calcidose*.

Some mistakes are more difficult to correct, as they refer to ambiguous terms. For instance in the lab results section of a discharge summary, *Albumin* refers to a lab result, while *Albumin* is also the brand name of a drug. This ambiguity will have to be handled. As FMTI is multilingual (French, English, Spanish, Portuguese and Danish), an extension of this study would be to index the discharge letters with the other 4 languages.

Conclusion

This validation task demonstrates that the F-MTI tool is able to identifying commercial and brand names of drugs in the free-text documents. The study allows identifying courses of action to improve the tool. A semantic mining tool is probably not able to automatically discover ADE prevention rules from previous hospital stays. It is not able to prevent ADEs as the discharge summaries and letters are always written after the end of the stay. Nevertheless, semantic mining of those documents can help to retrieve administered drugs in absence of CPOE in order to compute the confidence of potential ADE detection rules. Doing that, semantic mining of the free-text documents allows for potential ADE detection in former hospital stays.

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Aligning UniProt and MeSH – A Case Study on Human Protein Terms

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Abstract

Terminologies which lack semantic connectivity hamper the effective search in biomedical fact databases and document retrieval systems. We here focus on the integration of two such isolated resources, the term lists from the protein fact database UNIPROT *and the indexing vocabulary* MESH *from the bibliographic database* MEDLINE*. The generated semantic ties result from string matching and term set inclusion. We investigated the implicit terminological overlap between both resources in the domain of human proteins and evaluated our approach on a sample of 550 randomly selected* UNIPROT *entries that were manually mapped to their corresponding* MESH *headings. We achieved 90% precision and 79% recall (applying taxonomy-sensitive metrics). Fortunately, those proteins we were able to map to the* MESH *are ten times as frequently discussed in the literature as those on which we failed.*

Keywords:

Terminological Alignment, Interoperability of Terminologies

Introduction

Over the past years, MEDLINE – with now over 19M entries – has gained world-wide reputation as the most authoritative and often used bibliographic resource for biomedical literature search via the PUBMED interface.[1] Much of its retrieval power can be attributed to the Medical Subject Headings (MESH),[2] a terminology from which index terms are manually derived as content descriptions for MEDLINE records. The MESH not only covers a controlled vocabulary (of about 25,000 descriptors spanning various domains such as anatomy, diseases, chemicals and drugs) but excels in the provision of a multi-hierarchical taxonomic thesaurus structure (plus synonyms).

For bioinformatics, a comparably authoritative resource for protein and gene fact search has emerged through the UNIPROT KNOWLEDGEBASE (UNIPROTKB) [1]. In particular, UNIPROTKB/SWISSPROT, the curated part of UNIPROTKB, is a comprehensive, high-quality protein database which contains over 400,000 manually annotated proteins from various species. Unlike the MESH, UNIPROTKB does not offer any taxonomic links between terms, but (just as the MESH) contains synonyms of the gene and protein names in a specific protein entry, which are all lined up with their associated unique database identifier. Generally, UNIPROTKB describes proteins on a more specific level than the coarser grained MESH, the latter dealing with proteins in branch D (Chemicals and Drugs).

PUBMED, the retrieval interface to MEDLINE, allows users to search for documents about protein families, groups, or complexes by entering suitable MESH terms. However, literature on a specific protein can only be retrieved by running a free-text search. Yet, this search mode is known to suffer from several shortcomings because protein names are notoriously complex and ambiguous and thus hard to nail down by free-text expressions. A new breed of semantics-based search engines such as SEMEDICO [2] or IHOP [3] aim to cope with these problems by incorporating named entity recognizers (cf., e.g., SEMEDICO's gene name normalizer GENO [4]) which enrich plain documents with semantic metadata, including links to UNIPROTKB identifiers. If a protein name, e.g., **"**Heat shock protein HSP 90-beta", is entered in such a search engine, not only a set of documents matching this term is retrieved, but also a link to the corresponding UNIPROTKB entry (in this case HS90B_HUMAN) is provided which holds additional factual information about the protein under scrutiny.

Even such advanced search engines are incapable of searching for a specific protein and (if requested by the user), at the same time, generalizing to proteins belonging to the same protein group, family or complex. For example, if a document search for **"**Heat shock protein HSP 90-beta" were conducted, one might also be interested in documents about other members of the HSP90 heat shock protein family, or even about heat shock proteins, in general. One way to enable users to retrieve those additional documents would be to establish explicit links from the specific protein name to the appropriate MESH term, in this case "HSP90 Heat Shock Proteins", from where even more generic terms could be reached, such as its parent term "Heat Shock Proteins". To realize such a semantics-rich search strategy we aligned knowledge available from the UNIPROTKB with the taxonomic structure of the MESH, thus enabling new 'taxonomic' search strategies (see Figure 1).

[1] http://www.ncbi.nlm.nih.gov/pubmed
[2] http://www.nlm.nih.gov/mesh

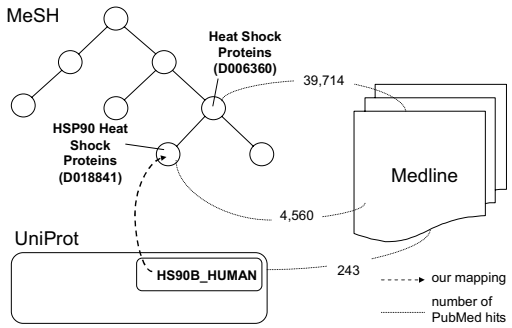

Figure 1- Linking UNIPROT and MESH for taxonomic search. The increasing number of hits (243 → 4,560 → 39,714) directly reflects the increasing conceptual generality of the search terms involved (HS90B_HUMAN → HSP90 Heat Shock Proteins → Heat Shock Proteins, respectively).

Materials and Methods

For our mapping study, we focused on the human subset of UNIPROTKB/SWISSPROT (RDF version from November 2008). Originally 20,328 entries were collected. In a subsequent cleansing step, we excluded those entries where the recommended name contained the phrase *"uncharacterized protein"* so that 19,052 human protein entries remained as input data for our mapping experiments. We also restricted the headings in the MESH thesaurus (MESH version 2008) such that permitted mapping targets were restricted to headings concerned with proteins and genes only, in the broadest sense though. This left us with all headings which belonged to one of the following MESH sub-hierarchies: D05 (Macromolecular Substances), D06 (Hormones, Hormone Substitutes, and Hormone Antagonists), D08 (Enzymes and Coenzymes), D09 (Carbohydrates) restricted to the Glycoproteins and Glycopeptides fraction, D12 (Amino Acids, Peptides, and Proteins), D13 (Nucleic Acids, Nucleotides, and Nucleosides), D23 (Biological Factors), and G14 (Genetic Structures).

We further utilized MESH's Supplementary Concept Records (SCR) as intermediate mapping target. SCR is a separate resource with rather specific, UNIPROT-like headings mainly concerned with chemicals and proteins. Each SCR heading comes with an explicit link to the closest possible MESH heading. Some SCR records are even linked to several MESH headings belonging to different classification axes. We exploited these links by mapping UNIPROT entries to SCR headings and then following the existing links to the associated MESH headings. Table 1 summarizes the sources of our mapping study.

Term Selection

For each UNIPROTKB entry we gathered all recommended and alternative protein names in their long form, as well as all gene names. In addition, for each entry we compiled a set of family and enzyme names based on three additional resources.

Table 1 - Quantitative data of terminological resources used for the mapping experiments

Source	Entries	Distinct Names
MESH protein	5,198	47,210
MESH SCR	182,890	462,673
UNIPROT human (cleansed)	19,052	90,920

We, first, extracted family names from the Similarity Annotation fields of UNIPROTKB entries, using simple regular expressions. A typical example for a Similarity Annotation is

"*Belongs to the protein kinase superfamily. TKL Ser/Thr protein kinase family. Pelle subfamily.*"

from the UNIPROTKB entry "IRAK3_HUMAN" ("Interleukin-1 receptor-associated kinase 3"). We here extracted the names "protein kinase", "TKL Ser/Thr protein kinase", and "Pelle".

Second, additional family names were harvested from INTERPRO,[3] a database of protein families and domains interlinked with UNIPROTKB. For the protein "KT81L_HUMAN" ("Keratin-81-like protein"), e.g., we followed the link to the protein family entry "IPR003054" from which we extracted the family name "Type II keratin".

Third, for entries coming with an Enzyme Commission (EC) number, this number was looked up in the Enzyme Nomenclature database,[4] to gather all attached enzyme names. For instance, UNIPROTKB entry "EYA2_HUMAN" ("Eyes absent homolog 2") is annotated with the EC number "EC 3.1.3.48". From the corresponding entry in the enzyme database we extracted the name "Protein-tyrosine-phosphatase".

While for MESH records, the heading itself and all associated entry terms were extracted, for MESH SCR records we considered the names of substances and all given synonyms.

Preprocessing of Terms

To cope with morphological term variations, we did not use a stemmer (that can be suspected to truncate many of the relevant domain-specific terms) but instead looked up each UNIPROTKB and MESH term in the UMLS Specialist Lexicon inflection file LRAGR.[5] If it is listed as a plural form of a noun, we extracted the corresponding singular form and added it to our term set. Then for all terms, punctuation marks were replaced by spaces, the task-specific stop words "gene", "protein", "family", "member", "domain", and "subunit" were removed from terms, and, finally, terms were lower-cased and tokenized, interpreting spaces as token boundaries.

A special preprocessing step was applied to MESH SCR terms. Many of these terms contain organism names, such as the substance name "IL2 protein, human" from record "C508594". These organism names were removed to make SCR terms compatible with UNIPROTKB terms that usually lack any kind of organism information (in UNIPROTKB, organism informa-

[3] http://www.ebi.ac.uk/interpro
[4] http://www.expasy.ch/enzyme/
[5] http://www.nlm.nih.gov/pubs/factsheets/umlslex.html

tion is kept in a separate field called 'Taxonomic Identifier'). We compiled a list of organism names from the NCBI taxonomy[6] and matched the names against all MESH / MESH SCR terms. If a name was found as substring of a MESH term, the organism-specific substring was removed from that term. However, we kept the NCBI taxonomy ID (TaxID), corresponding to the organism name that we removed, for later comparison with the TaxID associated with the UNIPROTKB entries. In our study on human proteins, this is only TaxID "9606" denoting "Homo sapiens (human)".

Term Mapping

In order to find for all human proteins in UNIPROTKB the closest related MESH heading we pursued a two-step approach. First, for each UNIPROTKB entry we matched all protein and gene names against all extracted MESH and MESH SCR terms. As matching criteria, we required, first, the MESH and the UNIPROTKB term to consist of the same tokens (their order was considered irrelevant) and, second, if a TaxID was associated with the MESH term, it had to match "9606" (human). Then for all these matches the corresponding MESH headings were selected as possible mapping targets for the UNIPROTKB entry. If no suitable MESH heading was found, in the second step, all enzyme and family names compiled for the UNIPROTKB entry were matched against all MESH / MESH SCR terms. Again the MESH headings corresponding to the successfully matched terms were selected as candidate mapping target for the corresponding UNIPROTKB entry. UNIPROTKB entries for which no target MESH heading was found after these steps were marked as *"not mapped"*.

In case several MESH / MESH SCR headings were found as possible mapping targets for a UNIPROTKB entry we determined the most suitable heading amongst the candidates with a LUCENE[7]-based ranking procedure basically relying on a fine-tuned TF-IDF weight (cf. Chapter 3.3 in [5]). In addition, our ranking mechanism took into account the type of terms that had matched. If, for instance, the recommended name of a UNIPROTKB entry matched a MESH term, we considered the associated MESH heading a better mapping candidate than a MESH heading of which a term matched an alternative name of a UNIPROTKB entry. If a UNIPROTKB entry was mapped to a MESH SCR heading, we followed the existing links to the corresponding MESH headings and selected them as mapping targets for the UNIPROTKB entry (only in this case several mapping targets were allowed per UNIPROTKB entry).

Mapping and Evaluation Results

In the first matching step (based on the comparison of protein and gene names from UNIPROTKB with MESH terms) our algorithm mapped 67% of all human protein entries to a MESH heading. In the second step (based on the comparison of family and enzyme names with MESH terms) mappings for additional 11% of the protein entries were found (see Table 2).

Table 2 - Results of the automatic mapping of human UNIPROTKB entries to MESH headings

Matching Step	Number of Matches (%)
Step1	12,691 (67%)
Step2	2,102 (11%)
Step1 + Step2	**14,793 (78%)**
Baseline	13,321 (70%)

As a baseline for comparison, we matched all protein and gene names of a UNIPROTKB entry to all MESH terms (terms were Porter-stemmed,[8] lower-cased, and punctuation marks were removed) and the MESH heading corresponding to the highest ranked match (cf. Section "Term Mapping") was selected as mapping target. Accordingly, mappings for 70% of all UNIPROTKB entries were found (see Table 2).

To assess the quality of automatically generated mapping results we compared them to a manually created gold standard. It consists of a random sample of 550 UNIPROTKB entries (drawn from the set of 19,052 entries) that were mapped by a domain expert to the closest related MESH heading(s). Since MESH is a multi-hierarchy, the expert was allowed to select more than one heading for each entry. A total of 58 entries (10.5%) were mapped to the general heading D011506 (Proteins). These entries were marked as *"not mapped"*.

As evaluation metric, we chose a relaxed precision and recall measure, *overlap proximity*, as introduced by Ehrig and Euzenat [6]. This metric pays tribute to the particularities of taxonomic hierarchies since, besides node-wise exact matches, it also incorporates the grounded intuition that even slightly more general or more specific matches within the taxonomic 'neighborhood' of a term are useful and reasonable matches, rather than treating them as absolute non-matches. Therefore, instead of taking the (strict) intersection of the set of automatically generated mappings (A) and the set of mappings in the manually created gold standard (G) as metrical criterion (as standard precision and recall metrics do), the relaxed variant takes the above considerations into account and measures the overlap proximity of the two sets with respect to a certain proximity function. Let M denote the matching between A and G ([6]) and σ be the proximity function between mappings a in A and g in G. Given the proximity ω

$$\omega(A,G) := \sum_{(a,g)\in M(A,G)} \sigma(a,g) \quad (1)$$

relaxed precision P_ω and recall R_ω are defined as

$$P_\omega(A,G) := \frac{\omega(A,G)}{|A|} \text{ and } R_\omega(A,G) := \frac{\omega(A,G)}{|G|} \quad (2)$$

We chose as proximity criterion for two mappings, $a = (u_a, m_a)$ and $g = (u_g, m_g)$, with u denoting a UNIPROTKB entry and m the MESH heading it was mapped to,

[6] http://www.ncbi.nlm.nih.gov/Taxonomy
[7] http://lucene.apache.org/
[8] http://tartarus.org/~martin/PorterStemmer/

$$\sigma(a,g) := \begin{cases} \dfrac{1}{p(m_a, m_g)} & \text{if } eq(u_a, u_g) \wedge (eq(m_a, m_g) \\ & \quad \vee s(m_a, m_g) \vee s(m_g, m_a)) \\ 0 & \text{otherwise} \end{cases} \quad (3)$$

with p denoting the length of the shortest path between two MESH headings (in terms of the number of nodes in the MESH taxonomy graph) plus one, such that $p(m, m) = 1$, eq denoting the equivalence and s the subclass relationship. As for standard precision and recall, a mapping in A that is also in G is scored '1'. Mappings in A where the predicted and the correct MESH heading are in a subclass relation to each other (hyponym relation, on the term level), are scored with the reciprocal value of the length of the shortest path between the correct and the predicted MESH heading. All remaining mappings are penalized with '0'.

Figure 2 illustrates the scoring logic for three automatically detected mappings. On the left, an exact mapping is shown, scored '1' (predicted and correct MESH heading are equal). In the middle, a too general mapping is shown. Since the predicted MESH heading is a direct parent of the correct heading, it is scored '0.5'. On the right, an incorrect mapping is shown where no subclass relationship holds between the predicted and the correct MESH heading, scored '0'.

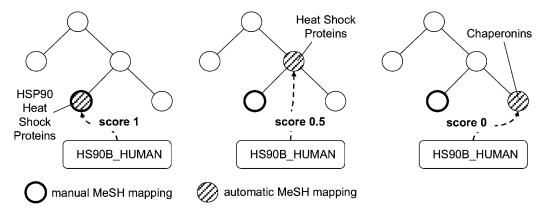

Figure 2 – Scoring of automatically computed mappings

As Table 3 reveals, when we apply the relaxed precision and recall measures we obtain 90% precision and 79% recall, resulting in 88% F-score, setting β to 0.5 in

$$F_\beta := ((1+\beta^2)PR)/(\beta^2 P + R) \quad (4)$$

in order to emphasize precision.

We also measured precision and recall for the constituent matching steps. Obviously, the first step based on matching protein and gene names to MESH terms results in more precise mappings (93% precision) than the second one based on looking up protein family names in MESH (73% precision). Still, adding the second step increases overall recall by 8 percentage points with a stable F-score of 88%. The mapping procedure outperforms the baseline (85% precision and 67% recall on the gold standard), in particular with respect to recall.

Table 3 - *Evaluation results in terms of relaxed precision P_ω, recall R_ω and F-score (values in %).*

Matching Step	P_ω	R_ω	F-score
Step1	93,0	70,7	87,5
Step2	72,7	8,0	27,7
Step1 + Step2	**90,2**	**78,5**	**87,6**
Baseline	85,3	66,6	80,8

This makes evident the value of the additional terms (e.g., from UNIPROTKB annotation fields and external databases like INTERPRO) for the mappings' outcome.

Discussion

For the evaluation of our approach we used a relaxed precision and recall measure and computed the F-score with emphasis on precision. Both decisions reflect requirements from the information retrieval scenario discussed in the beginning. The choice of the evaluation measure reflects our claim that even if the automatic procedure could not detect the fully correct MESH heading for a UNIPROTKB entry, detecting one of its parent or child headings would still enable the user to pass from UNIPROTKB to MESH and to correctly generalize / specialize the original search exploiting the MESH hierarchy. The emphasis on precision reflects our opinion that false mappings that would lead to the retrieval of irrelevant documents are worse than missing mappings due to the negligence of taxonomic relation that particular proteins share.

The terminological heterogeneity of protein and gene names might raise concerns about the size of our gold standard. To assess the plausibility of our evaluation based on this gold standard, let us assume that the random sample of 550 UNIPROTKB entries would have been drawn from an *infinite* set of entries, and the precision and recall estimates, resulting from the comparison of the automatically detected mappings with the gold standard, would be 0.5 (50%). Then the standard deviation of the estimates, ± 2.1, would be 'acceptable'. (In fact, the number is even an upper limit for the real standard deviation, since our sample was drawn from the finite set of 19,052 UNIPROTKB entries, and the determined precision and recall measures are 'far away' from 0.5.)

Still, about 20% of all human proteins in UNIPROTKB / SWISS-PROT could not be mapped properly to MESH headings by our algorithm, although based on the gold standard only 10% of non-matching entries should be expected. We tested two alternatives to increase our recall figures. First, we extended our procedure by a third matching step, again matching all UNIPROTKB terms (protein, gene, and family names) against all MESH terms. This time, we only required a partial token match and allowed for contradicting TaxIDs. Second, we considered additional UNIPROTKB name types for the mapping, *viz* short forms of gene and protein names, allergen names, CD antigen names, and the International non-proprietary names.

Although 1,267 additional UNIPROTKB entries (an increase of 7%) could be mapped, the overall effect (a decrease by 3 percentage points to 85% F-score) was negative due to decreasing precision (86%). The inspection of erroneously missed mappings revealed that many of the UNIPROTKB entries involved come with rather technical names such as "FAM75-like protein FLJ43859" ("YI020 HUMAN") that cannot easily be matched with MESH terms. Thus, we assume that only exploiting further annotations of UNIPROTKB entries (such as textual descriptions) might increase the number of correct mappings.

The good news is that our procedure deals satisfactorily with the most frequently occurring human protein names. We found that those proteins that we were able to map to MESH headings are mentioned, on average, in 10 times as many document as those on which we failed to map (111.3 documents, on the average, compared to 12.6).[9] In terms of precision, our procedure shows decent results. Still, we analyzed the false predictions and found that three-fourth of all incorrect mappings were due to the unresolved ambiguity of gene symbols.

Related Work

Biomedical ontologies and terminological resources are increasingly becoming important for knowledge management tasks in the life sciences [7]. This is witnessed by the rapid growth of single resources such as the GENE ONTOLOGY (GO)[10] which is massively used for the functional annotation of genes and gene products. Also large libraries of controlled vocabularies have emerged such as the UMLS[11] and OBO.[12] Efforts to foster interoperability have already been started, e.g., aligning GO with other OBO ontologies [8]. UNIPROTKB and the MESH have also been the target of deeper integration efforts. In [9], a procedure is described to link diseases mentioned in UNIPROTKB entries to the MESH disease terminology to make disease information in UNIPROTKB more easily accessible to clinical researchers. What has not been studied so far is the connection between protein entries in UNIPROTKB and MESH headings representing protein families, groups, or complexes, the goal of our investigation.

Conclusion

Despite the ever increasing number and size of single biomedical terminologies their usage for searching relevant facts and literature is currently hampered by a lack of semantic integration and interoperability. In this study, we proposed an automatic procedure to align human protein names in UNIPROTKB / SWISSPROT to suitable headings in the MESH.

The mappings we found were evaluated on a manually created gold standard of 550 match pairs resulting in 90% precision and 79% recall (with 88% F-score). Our approach outperformed a simple yet effective baseline by 7 percentage points F-score (5 and 12 percentage points in terms of precision and recall, respectively).

The mapping approach we propose can easily be applied to the whole of UNIPROTKB / SWISSPROT. A preliminary study on protein entries for a set of 29 important model organisms achieved promising results. For 78% of these entries mappings to MESH headings could be found. The research we have described is but a preparatory step for a more thorough evaluation that has to measure the effects of such alignments for the effectiveness of searches in real retrieval settings.

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[9] The numbers are based on analyzing 4M abstracts from MEDLINE's Molecular Biology journals (1990-2008), which were annotated with genes/proteins by the gene name normalizer GENO [4].

[10] http://www.geneontology.org/

[11] http://www.nlm.nih.gov/research/umls/

[12] http://www.obofoundry.org/

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Using SNOMED CT to identify a Crossmap between two Classification Systems: A Comparison with an Expert-Based and a Data-Driven Strategy

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Abstract

A crossmap between successive versions of classification systems is necessary to maintain the continuity of health care documentation. A reference terminology can serve as an intermediary to support this task. Within this study we evaluated the use of SNOMED CT to create a crossmap between two versions of an intensive care classification system. Firstly, the SNOMED CT crossmap was compared with an expert-based and a data-driven crossmap. Next, the influence of these crossmap strategies on the health care outcome was evaluated. For 50% of the analyzed cases, the three mapping strategies resulted in the same crossmaps. In other cases, there was an overlap between the SNOMED CT crossmaps and the crossmaps provided by one of the two other strategies. Differences in the crossmap results had however no significant influence on the health care outcomes. SNOMED CT can be used as an intermediary to solve the problem of crossmapping between versions of classification systems.

Keywords:
SNOMED CT, Classification, Intensive Care, APACHE II, APACHE IV

Introduction

In the healthcare setting, clinical encounters are increasingly documented using classification systems to serve purposes such as mortality and morbidity statistics or financial reimbursement. A classification system is defined as a systematic arrangement of objects or concepts based on their essential characteristics into groups of concepts, called classes [1]. As with all terminological systems, a problem with classification systems is the compatibility between two versions. The 9th revision of the International Classification of Diseases, ICD-9, for instance, was published in 1977 and has been succeeded by the 10th revision, ICD-10, in 1999. The ICD-10 was much more detailed than its predecessor and included alterations in the coding rules, the underlying classification, the number of disease and diagnostic codes, the code structure, and the naming of disease chapters and categories [2]. Health care settings use the ICD classification systems to compile health statistics and to monitor health spending and outcomes. Consequently, the versioning of the ICD has a direct impact on the health care systems in that the changes produce inconsistencies and discontinuities in the heath care statistics [3-5].

Versioning may also be a problem for domain specific classification systems. In the intensive care (IC), for instance, different versions of the APACHE classification system are used to code the reasons for IC admission, which is an important covariate in the APACHE prognostic models. The APACHE prognostic models (e.g. APACHE II and IV) are applied to calculate case mix (i.e. severity of illness, age, and the primary reason for IC admission) adjusted mortality in order to assess the quality of health care [6]. The APACHE IV prognostic model is almost backward compatible with its predecessor, the APACHE II prognostic model, meaning that covariates for APACHE II prognostic model are also used in the APACHE IV prognostic model. The covariate "reasons for IC admission" forms an exception in that it requires another classification system. Therefore, although the detailed registration of the reasons for admission in the latest APACHE IV classification system enables a more accurate prediction of mortality risks, to enable trend analyses, also the older APACHE II classification system is still concurrently applied.

In both the ICD and the APACHE example, a crossmap between the two versions of the classification systems is necessary to preserve the continuity and interoperability of health care documentation and to avoid double registration Yet, accurate 1-to1 crossmaps between (versions of) classification systems may be difficult because these systems have different levels of granularity and the mapping can be influenced by the structure and content of both systems [7, 8]. It has been argued that a reference terminology can serve as an intermediary to support the creation of a mapping between two (versions of a) classification systems [7]. Reference terminologies provide detail and precise meaning to data by formal concept definitions, required for complete and consistent coding of clinical data [9]. An advantage of using a reference terminology to create a crossmap is that once a mapping has been created between the target classification system and the reference ter-

minology, this mapping can be re-used to identify crossmaps between all other (versions of) classification systems which are also mapped to the reference terminology (dashed arrows in Figure 1).

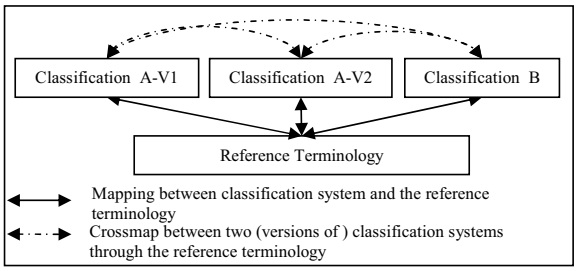

Figure 1- Using a reference terminology to identifying cross-maps between different (versions) of classification systems

SNOMED CT is regarded as the most comprehensive reference terminology for coding clinical data. Our goal within this study was to evaluate the use of SNOMED CT as an intermediary to create an n-to-1 crossmap between the two IC specific classification systems, i.e. from APACHE IV to APACHE II. Firstly, we compared the SNOMED CT crossmap with a manual expert-based and a data-driven crossmap. Secondly, the influence of these cross-map strategies on the calculation of case-mix adjusted mortality risks for quality of care assessment was evaluated.

Materials and Methods

SNOMED CT

The January 2008 release of SNOMED CT, which was used in this study, contains 284,777 active medical concepts associated with 737,695 active terms and interrelated by 860,865 active hierarchical (i.e. IS-A relationships) and non-hierarchical (i.e. Attribute relationships) relationships. SNOMED CT is a compositional terminology, i.e. it supports post-coordination, the use of composite expressions of concepts to define and refine (new) concepts.

APACHE classification systems

The APACHE classification systems are used to code the reasons for IC admission, one of the predictor variables in the APACHE prognostic models [6]. The APACHE II reasons for IC admission classification system is used in the APACHE II prognostic model and contains 54 diagnostic categories, each classified as nonoperative or postoperative, next by body system (e.g. cardiovascular disorder) and then by diagnosis (e.g. sepsis). The APACHE IV reasons for IC admission classification system is used in the APACHE IV prognostic model and contains 445 diagnostic categories, each classified as nonoperative or postoperative, next by body system (e.g. cardiovascular disorder) or a transplant or trauma-related category, and then by diagnosis (e.g. gastrointestinal sepsis). A residual "other" category is used in both classification systems for unlisted diagnoses within the main category (e.g. other listed diagnoses within the main category (e.g. other cardiovascular disorder).

Data

In 1996 the Dutch National Intensive Care Evaluation (NICE) foundation started collecting data on patients admitted to Dutch intensive care units (ICU) in order to monitor and improve the quality of care provided by the participating ICUs. For each ICU admission, the responsible intensivist or IC nurse collects the demographic, physiological and diagnostic variables required among others to calculate mortality predictions according to the APACHE II and IV prognostic models.

Since 2007, the APACHE IV variables can be recorded voluntarily and since 2008 all participants are obliged to record the APACHE IV reasons for ICU admission in addition to the APACHE II reasons for admission, which is recorded since 1996.

This study used a dataset from the NICE registry with data on all patients admitted to the Dutch ICUs between January 1, 2007 and July 1, 2009 for whom the APACHE II and IV variables were collected and who satisfied the inclusion criteria (e.g. excluding burns and re-admissions) of both the APACHE II and the APACHE IV prognostic models.

Data-driven crossmap

In the NICE database, for each IC admission, the reasons for admission have to be collected both according to the APACHE II and APACHE IV reasons for IC admission classification systems. To create the data-driven crossmap, a cross table was created with the APACHE IV categories against the APACHE II categories from the NICE database.

Expert-based crossmap

We used an expert-based crossmap that had been created for the NICE registry. Two intensivists, both experienced in the APACHE II and APACHE IV classification systems, independently mapped each APACHE IV category to exactly one related APACHE II category. The final map was based on consensus between the two intensivists.

SNOMED CT crossmap

As part of a larger study, we first created a manual mapping from the APACHE II and APACHE IV categories to SNOMED CT concepts (Figure 2 I). Each APACHE category was aligned with one or more SNOMED CT concepts. The categories were first matched to pre-coordinated concepts. In case no pre-coordinated match was available, a post-coordinated match was searched for. Concepts that did not exist in SNOMED CT were eventually matched to the appropriate superordinates [10]. To generate the crossmap between the APACHE IV and the APACHE II classification system, for each SNOMED CT concept that did not directly map to a APACHE II or IV category, first the closest superordinate with a pre-coordinated APACHE II mapping and the closest superordinate with a pre-coordinated APACHE IV mapping was identified (Figure 2 II).

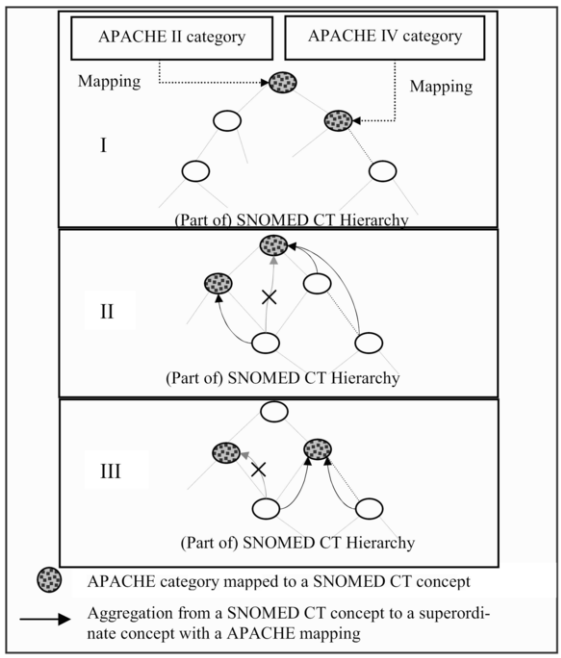

Figure 2- I:Mapping from APACHE categories to SNOMED CT concepts, II: Aggregation from a SNOMED CT concept to the closest superordinate with a pre-coordinated APACHE mapping, III: Aggregation from a SNOMED CT concept to the closest superordinate that results in highest mortality risk.

In case of multiple matches, the superordinate with a pre-coordinated APACHE II or APACHE IV mapping that resulted in the highest predicted mortality were selected in order to achieve a unique match (Figure 2 III). Next, the matched SNOMED CT conceptIDs from the previous step were used to generate a cross table with the APACHE IV categories against the APACHE II categories to identify the crossmap. Table 1 provides an example of such a crossmap through SNOMED CT.

Table 1 – An example of a crossmap between APACHE IV and APACHE II categories through SNOMED CT

SNOMED CT concept	APACHE II category	APACHE IV category
Urosepsis|371093006	Sepsis	Urosepsis

Analysis

Comparison of the mapping strategy

The SNOMED CT crossmap was compared to the expert-based manual crossmap and the data-driven crossmap. To this end, for each APACHE IV category, the matched APACHE II categories were identified according to the three crossmap strategies.

Influence of the crossmap strategy on the outcome

To evaluate the influence of the crossmap strategy on the mortality risk predictions, for all included admissions from the NICE database, an APACHE II predicted mortality was calculated based on the APACHE II categories from the NICE database and the APACHE II categories derived from the expert-based mapping and the SNOMED CT mapping. The predicted mortality risks were then compared for the three crossmap strategies. To this end, mortality risks were expressed as mean ±SD. T-test statistics was used for the comparison and a p-value of 0.05 was defined as statically significant.

Results

Data

From January 1st 2007 to July 1st 2009, 41,211 patients were recorded in the NICE registry who met the general inclusion criteria for the APACHE II and APACHE IV model and for whom an APACHE II and an APACHE IV reason for admission were recorded.

Not all APACHE IV categories occur frequently in the Dutch ICUs. Therefore, although for all APACHE IV categories a crossmap was developed, in here we will analyze and discuss the results for the most frequently occurring pre-coordinated postoperative and non-operative categories in each body system, transplant- or trauma-related class.

Comparison of the crossmap strategies

Table 2 provides the results of the three crossmap strategies For some APACHE IV categories more than 1 match was available in the data-driven crossmap and SNOMED CT crossmap (i.e. expressed in "Number of different APACHE II matches"). For 10 APACHE IV categories, the three crossmap strategies resulted in the same APACHE II categories. In case of disagreement, generally, there was an overlap between the SNOMED CT matches and the matches provided by the two other strategies. An exception was the APACHE IV category "Genitourinary surgery", which was matched to APACHE II category "Renal surgery" in the SNOMED CT crossmap and to "Cardiovascular surgery" in the other crossmap strategies.

Influence of crossmap strategy on predicted mortalities

The mean (±SD) predicted mortality risk was 0.158 (0.18) for the data-driven crossmap, 0.154 (0.18) for the expert-based crossmap, and 0.158 (0.17) for the SNOMED CT crossmap. For categories where more than 1 match was available, the predicted mortalities represent a weighted average score based on the different matches as shown in Table 2. No significant differences were found in the predicted mortalities for the three crossmap strategies.

Discussion

To preserve the continuity of health care documentation and to avoid registration inefficiency, e.g. double registration, a crossmap between successive versions of classification systems is necessary.

*Table 2 – * indicates >= 80%. The APACHE II categories are: CD: Cardiovascular disorder, CS: Cardiovascular surgery, DK: Diabetic ketoacidosis, DO: Drug overdose, GIB: Gastrointestinal bleeding, GID; Gastrointestinal disorder, HD: Hematological disorder, HT: Head trauma, KTRP: Kidney transplantation, MD: Metabolic disorder, MS: Metabolic surgery, MT: Multiple trauma, ND: Neurological disorder, PE: Pulmonary embolus, PVS: Peripheral vascular surgery, RD: Respiratory disorder, REND: Renal disorder, RENS: Renal surgery, RI: Respiratory infection, RIAS: Respiratory insufficiency after surgery, RS: Respiratory surgery, SCCD: Surgery for chronic cardiovascular disease, SEP: Sepsis, SGID: Surgery for GI disorder, SGIN: Surgery for GI neoplasm, SHD: Surgery for hematological disorder, SHS: Surgery for hemorrhagic shock, SND: Surgery for neurological disorder, SMT: Surgery for multiple trauma, TSN: Thoracic surgery for neoplasm: TRP: Transplant.*

				Data-driven		Expert-based	SNOMED CT	
	APACHE IV main category	Most frequently occurring APACHE IV category	Number of cases in the NICE database	Number of different APACHE II matches	APACHE II category (occurrence % (>5%))	APACHE II category	Number of different APACHE II matches	APACHE II category (occurrence % (>5%))
Non-operative	Cardiovascular	Vascular disorder	122	15	CD (*)	CD	10	CD (*)
	Gastro-intestinal	Upper GI bleeding	574	9	GIB (*)	GIB	2	GIB (*)
	Genitourinary	Acute renal failure	214	11	REND (*)	REND	3	REND (*)
	Hematology	Hematological disorder	21	2	HD (*)	HD	4	HD
	Metabolic	Diabetic ketoacidosis	367	5	DK (*)	DK	1	DK
	Musculoskeletal	Cellulitis and soft tissue infections	47	8	SEP (55) CD (13) MD (9) RD (9)	SEP	7	HT (24) RD (17) RI (17) GID (10) CD (7)
	Neurologic	Sedatives, hypnotics, antipsychotics, benzodiazepines overdose	893	10	DO (*)	DO	2	DO (*)
	Respiratory	Bacterial pneumonia	715	20	RI (*)	RI	2	PE (86) RI (14)
	Transplant	Kidney transplant	5	3	RD (60) CD (20) TRP (20)	CD	1	REND
	Trauma	Chest/thorax trauma	238	12	RD (61) MT (23)	MT	7	ND (41) CD (25) RD (22)
Post-operative	Cardiovascular	Abdominal aortic aneurysm	2096	15	PVS (76) CS (22)	PVS	1	CS (*)
	Gastro-intestinal	Gastrointestinal Surgery	834	10	SGID (70) SGIN (11)	SGID	2	SGID (*)
	Genitourinary	Genitourinary surgery	374	17	CS (43) SMT (19) RS (10) RIAS (7) SHS(6)	CS	3	RENS (*)
	Hematology	Hematological surgery	8	2	SCCD (75) SHS (25)	SHD	1	SHD (*)
	Metabolic	Thyroidectomy	132	4	MS (74) RS (16) CS (5) RIAS (5)	MS	2	SGID (50) RS (50)
	Musculoskeletal	Orthopedic surgery	352	22	CS (47) RS (12) SHS (6) MS (5)	CS	6	SGID (45) RS (31) SND (18)
	Neurologic	Neurological surgery	215	8	SND (*)	SND	4	SND (*)
	Respiratory	Respiratory surgery	546	8	RS (68) TSN (11) RIAS (9)	RS	2	RS (*)
	Transplant	Kidney transplantation	92	1	KTRP (*)	KTRP (*)	1	KTRP (*)
	Trauma	No pre-coordinated APACHE IV category	-	-	-	-	-	-

Our goal within this study was to evaluate the use of SNOMED CT as an intermediary to create a crossmap between two versions of an IC-specific classification system, i.e. from APACHE IV to APACHE II. For 50% of the most frequently occurring APACHE IV categories, the three mapping strategies resulted in the same APACHE II categories. In other cases, there was an overlap between the SNOMED CT matches and the matches provided by one the two other strategies. Differences in the crossmap results had however no significant influence on the predicted mortalities.

Although there are no differences in the outcome, the crossmap strategies do differ. This might have a large influence on e.g. selection of patient groups based on reason for IC admission. Each of the crossmap strategies has its own drawbacks. Data-driven crossmapping is highly dependent on the amount and the quality of the underlying data, and on the correct classification by clinicians. For rare clinical encounters, for instance, it is not possible to generate a reliable crossmap. Expert-based crossmapping is time consuming and labor intensive, especially for large classification systems. Furthermore, the reliability of the crossmap depends on the skills and knowledge of the experts. Automated tools might be used to assist this task, however, these tools are usually domain and language specific, and, if not available, costly to build. Besides, manual review is required to validate and complement the output of the automated crossmaps [11]. The SNOMED CT crossmap encloses the same problems as the Expert-based crossmapping, as first a (manual or automated) mapping needs to be created from the source classification systems to SNOMED CT. However, the advantage of using SNOMED CT crossmapping is that once the mapping is generated with the target classification system, it can be re-used to identify crossmaps to all other classification systems that are already aligned to SNOMED CT. E.g. for five classification systems, the use of SNOMED CT as intermediary requires the creation of 5 mappings from these target systems to SNOMED CT, possibly by shared effort, to create the 10 crossmaps. Otherwise, each classification system pair (n=10) needs to be crossmapped separately.

When crossmapping two versions of a classification system, an important issue is the relationship between their categories. In general, for the purpose of interoperability, a 1-to-1 crossmap is required. However, a 1-to-1 crossmap between two versions of a complex classification system might not be possible, as the two successor systems not only differ in the level of granularity, but also in the coding rules and structure. In these cases, a n-to-n mapping is generated which requires an additional decision to select the appropriate target links [11].

A key characteristic of classification systems is that they generally serve a specific purpose. DRG-like classification systems for instance are used to generate reimbursement overviews, while classification systems such as the ICD are used for generation of mortality and morbidity statistics [12]. Consequently, the same information is often recorded in multiple systems resulting in multiple registration. Although within this study we focus on the problem of version compatibility of a classification system, our results are also generalizable to settings in which multiple classifications are used for different purposes. Also in these cases, SNOMED CT can serve as an intermediary to support the creation of crossmaps in order to preclude double registration [7]. However, to rule out registration inefficiency completely, clinical information should preferably be captured on a detailed level in daily practice using a reference terminology such as SNOMED CT which holds the promise to (retrospectively) aggregate clinical encounters compatible to different classification systems. Further research is needed to gain insight in the use of SNOMED CT for data collection to serve this purpose.

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An Automated Approach to map a French terminology to UMLS

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Abstract

Background: CCAM is a French terminology for coding clinical procedures. CCAM is a multi-hierarchical structured classification for procedures used in France for reimbursement in health care, which is external to UMLS . Objective: The objective of this work is to describe a French lexical approach allowing mapping CCAM procedures to the UMLS Metathesaurus to achieve interoperability to multiple international terminologies. This approach used a preliminary step intended to take only the significant characters used to code CCAM corresponding to anatomical and actions axes. Results: According to the 7,926 CCAM codes used in this study, 5,212 possible matches (exact matching, single to multiple matching, partial matching) are found using the French CCAM to UMLS based mapping, 65% of the corresponding anatomical terms in the CCAM code are mapped to at least one UMLS Concept and 37% of the corresponding action terms in the CCAM code are mapped to at least one UMLS Concept. For all the exact matches found (n=200), 91% were rated by a human expert as narrower than the mapped UMLS Concepts, while only 3% were irrelevant.

Keywords:

Coding system, Mapping, Ontology, Semantic interoperability, Terminology

Introduction

Retrieval and exchange of information from multiple health terminologies and databases becomes increasingly useful. UMLS appears as a powerful candidate for supporting interoperability among all biomedical terminologies. Mapping terminology for coding clinical procedures to UMLS is essential for international case mix comparison between data and practices in different Electronic Health Record systems**.** This mapping will achieve semantic interoperability between CCAM and every international terminology through UMLS, especially SNOMED International ("procedure" axis) and ICD10. All these French health terminologies are integrated into a Health Multi-Terminology server [1]. However, translating information from one terminology to another is not very easy because of their heterogeneity, due to the different scope, points of view, and level of abstraction and detail of each health terminology.

The process of terminology mapping consists of identifying identical (or approximately identical) concepts or relationships between terminologies [2]. A number of algorithms and approaches have been proposed to create an automatic mapping between health terminologies [2-6]. For example, Rocha et al [3] and Cimino et al. [4] both proposed a frame-based approach to perform mappings between health terminologies. Other approaches were proposed using UMLS (Unified Medical Languages Systems) [7] as a knowledge resource to perform mappings between terminologies. For example, Fung and Bodenreider [5] described an algorithm [6] to map between any two terminologies in the UMLS making use of synonymy, explicit mapping relations and hierarchical relationships. However, approaches using the UMLS are limited to the biomedical terminologies already incorporated into UMLS.

The objective of this work is to describe a mapping method to be used by any biomedical terminology in French not yet included in the UMLS, to be subsequently included in this metathesaurus. The mapping approach has been used and evaluated in this work to map the CCAM terminology (Classification Commune des Actes Médicaux) for procedures to UMLS Metathesaurus. This terminology is not yet included in the UMLS.

This work takes place in a more global InterSTIS project, funded by the French National Agency. Semantic interoperability inter and intra terminology is the main objective of InterSTIS. This current work was funded mainly by the InterSTIS project grant.

Materials

CCAM is a multi-hierarchical structured classification mainly for surgical procedures used in France, for reimbursement and policy making in health care. Several terminologies for procedures exist and are used in different countries. For example,

the CPT (Current Procedural Terminology) [8] developed by the American Medical Association and since 2001, selected by the Department of Health and Human Services (HHS) as the standard code set for reporting health care services in electronic transactions. The NOMESCO Classification of Surgical Procedures (NCSP) used by all the 5 Nordic countries [9].

The 10th version of the CCAM covers about 7,926 procedure codes. Each procedure is described by a code using "CCAM Basic Coding System", which consists of coding: (1) body system/anatomical site or function, (2) action and (3) approach/method.

The concatenation of the codes for these axes results in a multiaxial code with 7 alphanumeric characters, which gives a "synthetic" procedure description, based on the code/definition tables of the CCAM Basic Coding System. (See Figure 1).

The construction of the CCAM associated the traditional expertise and ontology-driven terminological tools provided by GALEN (Generalised Architecture for Languages, Encyclopedias and Nomenclatures in Medicine) [10,11] with the constraint of being compatible with the European standards [12]. This process allowed checking the conformity of the label with the significant concepts of medical knowledge. Therefore, CCAM has been the main source of inspireation for the classification procedure in Australia (ICHI) [13] and Germany [14]

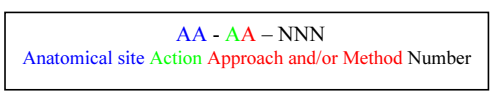

Figure 1- CCAM code structure

UMLS: the "Unified Medical Language System" is a repository of biomedical vocabularies developed by the US National Library of Medicine. Currently, the UMLS integrates over 5 million names of over 1,270,000 concepts from more than 140 biomedical terminologies, classifications, and ontologies, as well as 13 million relations among these concepts. Each concept isolated from terminologies has a concept unique identifier (CUI) in the Metathesaurus. This means that the same concept appearing in various terminologies, perhaps with various names and synonyms, has a unique entry in the Metathesaurus.

Methods

One automated mapping method was used to map CCAM codes to UMLS Concepts. This method is based on the structure of the CCAM code described in the previous section. However, it is impossible to assign one or more specific UMLS concepts using only CCAM label. This is mainly due to the length of CCAM labels. Indeed, there are 85% of CCAM labels equal or with more than 5 words vs. only 5% of the MeSH descriptors equal or with more than 5 words. The approach using the coding structure for mapping to UMLS was also used in [15] to allow the LOINC (Laboratory Observation Identifier Names and Codes) [16] integration to UMLS.

In this approach, only the significant first three characters composing the CCAM code according to the anatomic (two characters) and action (one character) axes are mapped to the UMLS Metathesaurus. For example: The CCAM code "NCCA010" with the label: "*Osteosynthesis of tibial diaphysis fracture by external fixing*", is represented according to the significant three first characters with:

- "*Bones of the leg*" corresponds to "NC" characters (anatomic axis)
- "*Osteosynthesis*" corresponds to the "C" character (action axis)

French natural languages processing tools and mapping algorithms were developed by the CISMeF team to map between French health terminologies. These tools were used in previous works [17, 18] and extended to link terms in multiple French health terminologies.

This approach allows for a given term (obtained by the concatenation of the resulting terms of the preprocess step according to the two axes (anatomic and action) to find a UMLS Concept with French terms that are lexically the most similar to it. Thus, to overcome some problems like account inflections, stop-words, etc., basic natural language processing is necessary beforehand:

1. Remove stop words: frequent short words that do not affect the phrases such as "a", "Nos", "of", etc; are removed form all terms in all terminologies (CCAM and French terminologies of the UMLS).
2. Stemming: we use a French stemmer "Lucene" which proved to be the most efficient for the F-MTI automatic indexing tools using several health terminologies [17], as compared to the stemming tools developed by the CISMeF team and the stemming tools in [18].

The mapping used by this approach provides three types of matches between all terms in source terminologies and the French terms in the UMLS metathesaurus. These levels of matching are inspired in most cases by the "ISO 5964", which is an ISO standard for the establishment and development of multilingual thesauri [19]. Relation types may be also represented in SKOS language [20]. SKOS language is also used to represent French health terminologies into the French Health Multi-terminological Server [1], which intends to integrate the main health terminologies available in French, including those not yet mapped to the UMLS (e.g. CCAM, ATC, Orphanet).

The three types of matching are:

Exact matching

One CCAM term and one French term in UMLS are in "exact matching" if all the words composing the two terms are exactly the same. Thus, according to this matching there is at most one UMLS Concept corresponding to all the significant characters of the CCAM code (see Table 1). Formally, in this type of matching the label obtained by the concatenation of the two terms according to the two axes, is considered as a one and unique term, an

"exact matching" between this term and one French term in UMLS.

Single to multiple matching

One CCAM term and at least two French terms from UMLS are in a "Single to multiple matching" when the CCAM term cannot be matched by one exactly French term in UMLS, but can be expressed by a combination of two or more French terms in UMLS. In this "Single to multiple matching", the CCAM term is mapped to at least two UMLS Concepts.

Partial matching

This type of matching is the less accurate one. In this type of matching only a part of the CCAM term will be mapped to one or more UMLS Concepts. Table 1, list some examples corresponding to the three types of matching described above.

Evaluation

The evaluation was performed on all the types of matching from the "exact" set matching type and for only 100 from the "Single to multiple" set matching type. We chose only 100 matching instances because in most cases the same codes with the same three firsts characters were mapped to the same UMLS concepts (HLHH003, HLHH004...).

The qualitative evaluation was performed by a physician (PM), expert in CCAM and in UMLS. The following terms were used to rate the quality of each matching result: (a) "equivalent" the UMLS concept corresponded exactly to the CCAM code; (b) "BT-NT" when the CCAM code was rated as broader than the UMLS concept according to the label of the CCAM and the preferred terms (PTs) in the UMLS concepts; (c) "NT-BT" the CCAM code was rated as narrower than the PTs in the UMLS concept, (d) "incomplete" when the UMLS concept only reflected some part of the CCAM label and (f) "irrelevant" when the matching was considered by the expert as incorrect.

For example, the matching between the CCAM code "BFGA003" (label: "*manually extraction of lens without intraocular lens implant*") and the UMLS concept C0007389 (preferred term: "*cataract extraction*") was rated as NT-BT because the UMLS concept is narrower and less accurate than the CCAM label. However, for the "Single to multiple" set, the expert performed the evaluation in two steps: 1) each pair (CCAM axe, UMLS concept) was evaluated independently. 2) the matching between the CCAM code and the combination of the UMLS concepts was then evaluated in this second phase. For example, to evaluate the matching between the CCAM code "AAFA003" and the two UMLS concepts: C006104 (preferred term: *"Brain") and C0919588 (*(preferred term: *"Exeresis").* First, the expert evaluated each axis with the corresponding UMLS ((Brain, C006104) =equivalent and (Exeresis, C091958) =equivalent)). Second, the expert evaluated the matching between the label and the combination of the two UMLS concepts: (AAFA003, (C006104, C091958) =NT-BT).

Table 1- Examples of the three types of matchings using the French based UMLS matching

CCAM code	Anatomic axis	Action axis	UMLS concepts	Typeof matching
BDHA001	Cornea	biopsy	C0197417 (Biopsy cornea)	Exact
AAFA003	Brain	exeresis	C0006104 (Brain) and C0919588 (Exeresis)	Single to multiple
DGFA013	Aorta	laparotomie	C0003483 (Aorte)	Partial corres-pondance

Results

Using this approach, there were 5,212 (65%) CCAM codes out of the 7,926 CCAM codes used in this study that provided possible matching between the CCAM and the French terms in the UMLS. The results of each type of matching are displayed in Table 2.

There were 2,210 (27.5%) matches regarding the anatomical and action axes. On the other hand, there were 1,716 (21%) matches regarding only anatomical and 1,286 (16%) matches regarding only the action axis. Overall, 65% of the matching "anatomical terms" in the CCAM codes were matched to at least one UMLS Concept and 37% of the matching "action terms" in the CCAM codes were matched to at least one UMLS Concept.

Table 2- Results of each matching type

Type of matching	Number of matches
Exact	200 (2.5%)
Single to multiple	2,010 (25%)
"Exact**"** Partial matching	3,002(37.8%)

For the set of exact matching (n=200), 182 (91%) of matches between CCAM codes and UMLS concepts were rated as NT-BT and only in nine cases, the matches were rated as equivalent (see Table 3).

Table 3- Evaluation results of the "exact" set matchings type

Equi-valent	BT-NT	NT-BT	Incomplete	Irrelevant	Total
9 (4.5%)	0 (0%)	182 (91%)	3 (1.5%)	6 (3%)	200

For the set of single to multiple matchings (n=100), 61 and 44 of the anatomic and action axes respectively were equivalent to at least one UMLS concept. According to this type of matching, 27 (27%) matches between CCAM code and at

least one UMLS concept were rated as exactly equivalent, when 54 matchings were rated as NT-BT (see Table 4)

Table 4- Evaluation results of the "Single to Multiple" set matching type (n=100)

Single to multiple matching (100)	Equivalent	BT-NT	NT-BT	Incomplete	irrelevant
Anatomic	61	1	29	9	0
Action	44	0	49	1	6
Combinaison	27	0	54	10	9

Discussion

The CCAM is an important French terminology external to UMLS. The objective of this work is to partially map the CCAM to the UMLS. Because the CCAM terms are quite verbose (85% with strictly more than 4 terms), this task is difficult. Our approach using French NLP tools allows mapping 65% of the CCAM. In most of the cases, the qualitative evaluation has shown a NT-BT (narrower than) relation between a CCAM term and an UMLS concept. This result is easily explainable because terms the anatomic and action CCAM axes, which are mapped to the UMLS Metathesaurus, are generally broad terms (e.g. cornea for anatomy and resection for action).

Some fine-tuning of the method is possible. The use of the existing manual mapping between CCAM and MeSH performed by one author of this paper [21] can help find some matches with the UMLS. The impacts of the matching between UMLS and CCAM are: (a) possible matching with other terminologies (e.g. ICD10 used in French DRGs with CCAM); (b) querying PubMed from a CCAM code with a MeSH query (using CCAM-MeSH mapping)

Two main perspectives are identified: (a) the method presented here could be used with the MetaMap tool [22-23] in order to map the CCAM, and then compare our results with those obtained in [24];(b) to map CCAM to the "procedure" axis of the SNOMED International.

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Implementing rules to improve the quality of concept post-coordination with SNOMED CT

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Abstract

The use of SNOMED CT as a standard reference terminology enables interoperability between clinical systems. This reference tool provides a method for creating post-coordinated terms by users according to local needs. While the creation of these terms is free, there are a number of rules, as defined in the user manual of SNOMED CT that must be followed.The Hospital Italiano of Buenos Aires has a Terminology Server that encodes medical terms, using SNOMED CT as the reference vocabulary. An interoperability analysis performed with the Nebraska Medical Center in 2006 found a high error rate (26%) in post-coordinated terms. Therefore, we implemented an automatic system of rules within the Terminology Server as defined in the user manual.
Following rules implementation, the error rate decreased from 26% to 2%.

Keywords:

Medical records systems, Vocabulary controlled, Systematized nomenclature of medicine, Terminology, Information systems, SNOMED CT.

Introduction

SNOMED CT has been proposed as a standard terminology in many countries, with an appropriate coverage of medical vocabulary [1]. Development standards are currently maintained by a multinational organization but local implementations often require content extension to address specific requirements. For this reason SNOMED International identifies and promotes mechanisms for post-coordination.

The Electronic Medical Record of the Hospital Italiano in Buenos Aires initially allowed physicians free text entry of problems and procedures. After a period of four years, we analyzed data and migrated this information into a specialized server. Then, a local interface terminology for physicians was developed, where they could choose a more accurate description for a given problem or a procedure [2]. This online terminology interface was created from items originally entered by individual physicians as free text.

The online interface consisted in 21,000 unique concepts, which were related to SNOMED CT as equivalent concepts or as post-coordinated expressions (in those cases where a direct equivalence could not be found). The creation of a post-coordinated expression was necessary for 16,000 of the 21,000 concepts (76.19%). This is a very high proportion of concepts requiring post-coordination, which is related to an implementation decision, by which all concepts recorded for at least 10 times in the problem list repository were included. These included highly specific concepts having a large number of modifiers, such as severity, laterality, clinical course, etc.

There are no specific tools for modeling SNOMED CT logics-dependant vocabularies. Programs such as Apelon or Protégé have been used in the past for modeling ontological standards. However, the specific rules of concept modeling and creation of logical definitions according to SNOMED International and published in SNOMED CT guides had not been tested or reinforced by these programs. The "in house" modeling tool designed and developed in the Hospital Italiano initially did not include rules for controlling modeling logics.

In 2006, an interoperability test was jointly developed and conducted between the Hospital Italiano of Buenos Aires and the Nebraska Medical Center in the United States. It evaluated SNOMED CT features by merging and comparing SNOMED-encoded problem lists from primary care sites in Nebraska and Argentina. Both problem lists showed small differences in semantic content, but differed substantially in the percentage of post-coordinated content. A classification using SNOMED Normal Forms effectively identified semantic equivalence in 65.2% of the reviewed cases. The most common reason for post-coordination failure was non-observance of SNOMED's guidelines (28.8% of remaining 34.8%) [3].

There were also approach differences among users who model post-coordinated expressions [4-6].

After these tests were completed, a new quality assurance tool was added in order to improve the quality of local post-coordinated expressions. This gave users the ability to review, evaluate and correct concept errors online. The system shows a red alert when a rule is broken.

Objective

Our purpose was to test the effectiveness of control modeling rules for concept post-coordination.

Background

The definition of post-coordinated expressions follows the same structure as any concept in SNOMED CT. Concepts included in the current distribution of SNOMED CT and defined by its authority are called pre-coordinated. New concepts defined by local users are called post-coordinated. The User Guide specifies the SNOMED CT post-coordination rules for new concepts. This is the Semantic Model of SNOMED CT [7].

The purpose of post-coordination is to incorporate new concepts into SNOMED CT, building these from existing ones and following their semantic model. The creation of post-coordinated expressions to represent new concepts must follow 2 steps:

- The first one is to define one or more supertypes for the new concept. The supertypes are in this case, more general concepts of SNOMED CT related to the current distribution. The proper assignation of supertypes defines the hierarchy of the concept[1].
- The second step is to incorporate attributes and differentiate the new and more specific concept from its SNOMED CT's supertype included in SNOMED CT. Each attribute is defined as a relationship with other SNOMED concept.

A concept that is fully explained and completely defined by its attributes and by those inherited from its supertypes is called "Fully defined". On the other hand, concepts, which meaning cannot be fully explained or with some different attributes, are "Primitive".

Hospital Italiano's SNOMED CT modeling tool, provides the users utilities for modeling new SNOMED CT concepts created in the local extension. The modeling process includes adding new relationships for describing supertypes and attributes. The creation of a new defining relationship in SNOMED CT consists in the selection of 3 values:

- Source concept: the concept that is being modeled with the relationship
- Relationship type: it can be a "is a" relationship for supertype definition (parent concepts) or any other attribute, like "finding site", "severity", "laterality", etc.
- Target concept: points to the parent concept in "is a" relationships, or to the attribute value, for example in the case of the relationship type "finding site" a usable value can be "lung structure".

According to the semantic model, different types of relationships are valid in different hierarchies, but only a pre-defined proportion of SNOMED CT concepts is a valid target for these relationships. For example, "Severity" attribute is a valid concept of the hierarchy "Clinical Finding", but not for concepts located in the "Procedure" hierarchy. The opposite occurs with the attribute "Direct Device", which is valid for "Procedure" but not for "Clinical Finding".

[1] Relationships: page 10, SNOMED CT User Guide, July 2008

Materials and Methods

Semantic model rules are encoded in a relational database model using tables of valid relationship types. This hierarchical table identifies high-level concepts and a target chart, defined once again by the top level concept of the group of valid target concepts.

The Hospital Italiano vocabulary is also stored in a relational database, including its concepts, descriptions and relationships [8]. A procedure developed using PL / SQL checks if each post-coordinated expression is in accordance with SNOMED's semantic model restrictions.

The following rules were entered to the Terminology server using SNOMED's user guide:

- The concept must belong to only one hierarchy.
- The hierarchy of a given concept cannot be different from the domain hierarchy
- If one relationship depends on the existence of another one, this one must be present.
- The relationship type must be appropriate for that hierarchy.
- Relationship target concepts must be valid.

"In house" Created:

- Only one "IS A (mapping)" relationship can exist
- If the relationship used is "IS A (mapping)" the concept cannot be "Primitive".
- There must be at least one "is a" or "IS A (mapping)".relationship
- There is also a warning if coders use an "entire body structure".

In order to verify the effectiveness of the modeling control system, two samples of post-coordinated terms were selected from the Hospital Italiano vocabulary.

The first one took place in 2006, after Nebraska Medical Center testing and before the implementation of the rules system. The sample included 34,253 post-coordinated terms.

The second sample was assessed in 2008, after the implementation of the rules system (August 2007) and included 9,015 terms.

Post-coordinated concepts included concepts in all domains from the clinical information systems, as well as those included in the list of problems, procedures, drugs or devices.

Each list of concepts was reviewed by an expert that rated the concepts into "right" or "wrong" categories according to the standards of SNOMED post-coordination detailed in the User Guide. A more detailed error description was given for concepts rated as "wrong".

Errors were classified as follows:

- Error in hierarchy definition: The concept is not assigned to the correct hierarchy, e. g. a procedure in the hierarchy of problems (appendectomy as a problem), or a disposable in procedures (as a stent entered as a procedure, etc.).

- Error in the relationship type: a not allowed relationship type used for a given hierarchy, e. g. finding site used in procedure hierarchy.
- Error in relationship target: the target concept is out of the valid range for the relationship type. The relationship is correct, but the target is wrong, e. g. relationship "laterality" with "right knee" as a value, when the proper value should be "right" (otherwise, a "finding site" relationship should have been used).
- Inappropriate use of an anatomical structure as an entire structure: The target concept is a subtype of the concept Entire anatomical structure (body structure), as when the concept "entire leg" is used instead of "leg structure".
- Other errors: those not included in the previously mentioned categories.

The expert also assessed the accuracy of representation; post-coordinated expressions may fulfill the SNOMED CT standards, but not accurately describe the meaning of the concept. Using a 5-point Likert scale, the expert rated meaning representation from the best possible representation to a completely wrong representation.. This measurement will be useful to identify quality control components for the terminology interface, i.e. which parts should be automated and which ones would always require manual review.

Statistical analysis of both samples was performed using a null hypothesis test and power was analyzed. In order to identify a statistically significant difference (0.050), 50 randomly selected terms from each sample had to be analyzed to attain a power of 80.9% in order to obtain a statistically significant result. This estimate assumes that the difference in proportions is 0.20 (specifically, 0.25 versus 0.05).

The sample size also allowed us to report the difference between both samples with an accuracy of approximately 0.13 points (confidence level 95%).

Specifically, a difference of 0.20 would have a confidence interval of 0.07 to 0.33.

Table 1- Examples of post-coordination errors

Physician text	Post-coordination coder error	System Alert	Proper post-coordination
Lobectomy of right lung	is a: Lobectomy of lung Side: Right	The relationship type must be appropriate for that hierarchy	is a: Lobectomy of lung Procedure site - Direct: Right lung structure
Pain in right buttock	is a: Pain in buttock Side: Right	If one relationship depends on the existence of another one, this one must be present	is a: Pain Finding site: Buttock Side: Right
Implantation of cardiac pacemaker	IS A (mapping): Implantation of cardiac pacemaker (Primitive)	If the relationship used is "IS A (mapping)" the concept cannot be "Primitive"	IS A (mapping): Implantation of cardiac pacemaker (Fully defined)
Fracture of tibia and fibula	IS A (mapping): Fracture of tibia IS A (mapping): Fracture of fibula	Only one "IS A (mapping)" relationship can exist	is a: Fracture of tibia is a: Fracture of fibula
Thoracic aorta atheromatosis	is a: Atherosclerosis of aorta Finding site: Entire thoracic aorta (body structure)	Warning of use an "entire body structure"	is a: Atherosclerosis of aorta Finding site: Thoracic aorta structure
Stent (in Precedure Domain)	is a: Stent (in Procedure Domain)	The hierarchy of a given concept cannot be different from the domain hierarchy	is a: Stent (in Device Domain)
Hematoma of left leg	Finding site: Leg Side: Left	There must be at least one "is a" or "IS A (mapping)".relationship	is a: Hematoma of leg Finding site: Leg Side: Left

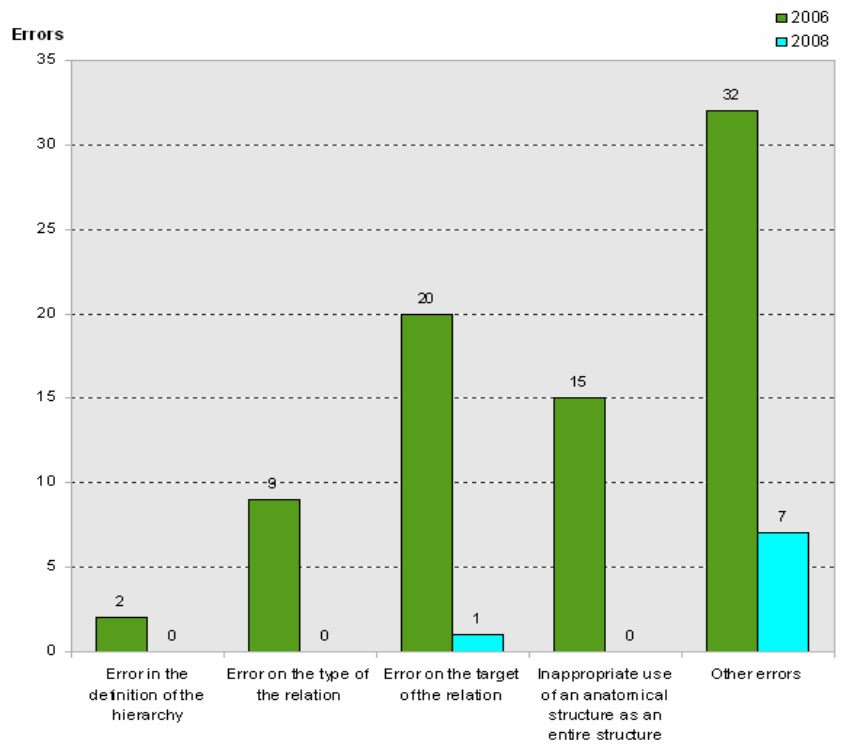

Figure 1- Number of errors grouped by category

Results

In the first sample, we analyzed 300 out of a total of 34,253 concepts; 74% showed no errors. The remaining 26% was distributed as follows: 0.67%, error in hierarchy definition; 3%, error in relationship type; 6.67%, error in relationship target; 5%, improper use of "entire part", and 10.67%, other errors.

In the second sample we analyzed 300 out of a total of 9,015 concepts. No errors were found in 97.3%. The remaining 2.7% consisted in: 0.3% error in relationship type and 2.4%, other errors (Figure 1).

The first sample in the accuracy performance analysis showed that 77% of the terms were adequately represented (points 1 and 2 on the Likert scale), 10.67% were poorly represented (points 4 and 5) and 12.3% could not be determined.

The second sample completed in 2008 showed that 96.33% of terms were properly represented, 2% were poorly represented and 1.67% could not be determined (Figure 2).

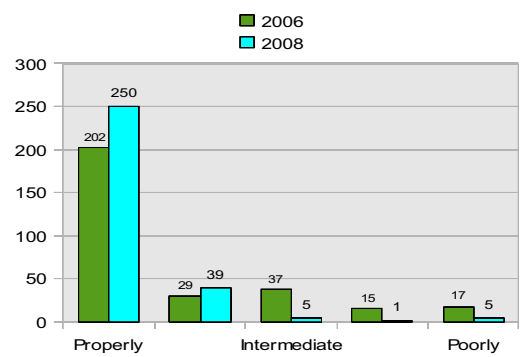

Figure 2- Quality performance

Conclusion

The implementation of an automatic system of rules for concept post-coordination, improves their representation, by enabling the proper use of SNOMED CT relationships, as well as the adequate representation of medical concepts.

Clearly, a system of rules will improve interoperability with other health centers, allowing better results than those achieved in 2006 with the Nebraska Medical Center.

It also has a positive impact in educational settings, by improving the training of users (coders) in charge of concept modeling, who should follow consistent rules to enhance concept representation.

This system of rules may reduce inter-user (coders) variability at the time of interpreting meaning and generating post-coordinated expressions, increasing consensus.

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A Unified Framework for Biomedical Terminologies and Ontologies

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Abstract

The goal of the OBO (Open Biomedical Ontologies) Foundry initiative is to create and maintain an evolving collection of non-overlapping interoperable ontologies that will offer unambiguous representations of the types of entities in biological and biomedical reality. These ontologies are designed to serve non-redundant annotation of data and scientific text. To achieve these ends, the Foundry imposes strict requirements upon the ontologies eligible for inclusion. While these requirements are not met by most existing biomedical terminologies, the latter may nonetheless support the Foundry's goal of consistent and non-redundant annotation if appropriate mappings of data annotated with their aid can be achieved. To construct such mappings in reliable fashion, however, it is necessary to analyze terminological resources from an ontologically realistic perspective in such a way as to identify the exact import of the 'concepts' and associated terms which they contain. We propose a framework for such analysis that is designed to maximize the degree to which legacy terminologies and the data coded with their aid can be successfully used for information-driven clinical and translational research.

Keywords:

Ontology, Terminology, Mapping.

Introduction

Familiarly, biomedical information is published using multiple different sorts of terminologies, classifications and coding systems. This diversity produces silo effects, which reduce the value of annotations created on the basis of such systems by making data both difficult to access and resistant to integration. Ontologies such as the Gene Ontology, in contrast, seek to overcome these problems by providing corridors of semantic interoperability between distinct information resources [1]. The idea is that, if multiple bodies of relevant information can be annotated using common, non-redundant sets of categories with definitions formulated in some common logical language, then the information they contain will thereby be more easily accessible and more readily capable of being integrated together computationally. This strategy is now increasingly being applied also in the field of human health. [2] Unfortunately, many of the ontologies being employed in specific life science disciplines and in associated clinical specialisms are still built by groups working independently or with no resort to common ontological standards.

Increasingly, one or other version of description logic such as OWL 2.0 is being used in their development. However, the use of a logical representation language alone is clearly not enough to ensure the high quality of an information resource [3], and even ontologies employing the same formal language are often not combinable into a single resource because of incompatibilities between the ways this language is used by different groups. [4]

The goal of the OBO (Open Biomedical Ontologies) Foundry is to counter such tendencies by promoting the creation of a single, expanding family of ontologies designed to be interoperable and logically well-formed and to incorporate accurate representations of biological reality. Ontologies are admitted into the Foundry, and to its on-going process of review, only if their developers commit to an evolving set of common principles [2], of which the most important for our purposes are:

1. that terms and definitions should be built up compositionally out of component representations taken either from the same ontology or from more basic feeder ontologies;
2. that for each domain there should be convergence upon exactly one Foundry ontology; [5]
3. that ontologies should use upper-level categories drawn from Basic Formal Ontology (BFO) [6] together with relations unambiguously defined according to the pattern set forth in the OBO Relation Ontology (RO) [7].

The concept orientation

Concept-based terminologies such as SNOMED CT consist of groups of terms, each such group being linked to a 'concept' that is said to define the meaning of the corresponding terms. We have argued that the inconsistent interpretations of the word 'concept' embraced by the creators and users of such terminologies have given rise to multiple distinct modeling practices, which in turn have given rise to inconsistent representations. [8-9]

Our identification of these problems – which are now acknowledged also by other experts in the field [10-11] – does not, however, imply that we dismiss traditional terminology resources as being without value. On the contrary, it is clear that the majority of these systems will continue to play an im-

portant role in the information-driven clinical and translational science of the future, and this for at least two reasons.

First, huge quantities of clinical and research data have already been annotated (and in some cases compiled *ab initio*) in their terms, and it cannot be expected that these data will be annotated a second time using OBO Foundry ontologies created *de novo*.

Second, where Foundry ontologies seek to represent the entities on the side of reality, traditional terminology systems are designed to reflect the ways language is used by clinicians and others in reporting (for example) patient encounters. This closeness to the needs of clinicians and healthcare institutions suggests that concept-based systems may still be in common use in the future.

The problem must be addressed, however, that the data resulting from such annotation efforts, precisely because they stay so close to the language used in specific disciplinary communities, and because they are affected by the multiple modeling paradigms associated with the orientation around 'concepts', are marked by the detrimental effects of silo formation.

The widespread adoption of SNOMED CT would diminish such effects. But as long as SNOMED CT itself does not use a consistent ontological approach [12], we believe that the data expressed with its aid, too, will involve too high a degree of redundancy and of inconsistent coding [13].

SNOMED's structure does not as yet provide a consistently accessible and reliable representation of the reality on the side of the patient as this reality changes through time. Moreover, SNOMED in its current form will not be able to do justice in consistent fashion to the changes in our knowledge of this reality which will be brought by advances in translational science [14]. To address these problems we need a strategy to map legacy terminologies such as SNOMED CT to OBO Foundry ontologies in such a way as to ensure that both can contribute to the creation of the non-redundant common framework for data integration and exploitation that will be needed in the future.

Objectives

The underlying idea is that both terminology artifacts and ontologies contain representational units (such as single words) and combinations thereof (such as compound word phrases and whole sentences) – together called 'representations' in what follows. The goal is to subject such representations to careful inspection of a sort which can allow terminological representations organized around 'concepts' to be mapped to appropriate ontological counterparts. To this end, we must provide a framework for ontological analysis of terms in legacy terminologies that will support adequate mappings especially for those terms that, because they are declared as 'synonyms', are associated with single 'concepts' under the terminological view. Such terms must be mapped separately wherever they refer – on face value – to entities of different types.

Methods

Our framework rests on three principal distinctions: (1) between *generic* and *specific portions of reality (**POR**s)*, (2) between the various purposes that can be served by *definitions*, and (3) between three distinct levels of reality.

Generic versus specific portions of reality

The first distinction separates *generals* from *particulars*, or in other words it separates *generic* (***GPR***) from *specific portions of reality* (***SPR***). While this distinction, like the remaining proposals outlined in this section, can be applied to both *continuants* (such as cells and organisms) and *occurrents* (such as lives and deaths), we shall concentrate here exclusively on the case of continuants.

Amongst the generic portions of reality are *universals* (***UNV***) and what we shall call *generic configurations* (***GCO***).

Universals are denoted by general terms such as 'human being', 'president', 'nation', 'population'. Universals are *instantiated* by particulars such as President Obama, the USA, the inhabitants of Buffalo. [15]

Generic configurations are configurations formed by *generic portions of reality* (***GPR***) that stand in some relation to each other that can be represented by some statement. An example is the portion of reality represented by the statement '*cell membrane part_of cell*'. Here '*part_of*' represents the generic *part_of* relation as described in the Relation Ontology. [7] Another example is the portion of reality represented by the sentence '*clinicians are human beings*'. Here the word '*are*' denotes what we shall call the *subgroup* relation, which holds between *clinicians* and *human beings*.

Amongst the *specific portions of reality* (***SPR***) are, analogously, *particulars* (***PAR***) and *specific configurations* (***SCO***).

PARs are entities that exist only once and are confined in space and time. Examples are: Mary, Buffalo, and the World Health Organization (WHO). Some ***PAR***s are what linguists would describe as 'named entities', but the majority – a liver cell in Mary, the fracture in her leg, and so forth – are not.

Both specific and generic configurations are represented by statements. Each ***SCO*** involves at least one ***PAR*** that stands in some relation to something else, for example to another ***PAR***, as in the specific configuration represented by the statement '*Mary's left leg part_of Mary*'. If Mary's left leg is amputated, then the two ***PAR***s involved in this ***SCO*** may survive the amputation, but the ***SCO*** itself will cease to exist.

Particulars can be divided into *atomic particulars* (***APA***) and *groups* (***GRP***). An atomic particular is a ***PAR*** that constitutes a unity in the sense that it has a complete, spatially connected external boundary. Examples, again, are: Mary and Mary's left leg. '*Atomic*' is here not to be understood as implying that the entity in question is not further decomposable. If Mary's left leg is amputated, then it may still exist, though not any more as part of Mary. Nor is it to be understood that anatomic particulars cannot themselves contain parts which are atomic (for example Mary herself contains parts which are her cells).

GRPs are entities denoted by generic terms such as 'limb of vertebrate', 'limb of human being', and even 'limb of Mary'. Although the latter example will likely not be found in a terminology or ontology, terms of the same sort do occur, examples being 'citizen of the United States', 'Nobel Prize winner', 'veteran of the Second World War'. Terms denoting ***GRP***s are typically formed via combination of smaller terms which themselves denote universals, particulars, or other ***GRP***s.

If Mary is a healthy human being, the entity denoted by the noun phrase 'Mary's limbs' is an example of a group (***GRP***). Each of healthy Mary's limbs is at the same time a *part* of Mary and a *member* of the corresponding ***GRP***. All members of a ***GRP*** at any given time are such as to exist at that time.

Among ***GRP***s, we distinguish further between, *bona fide groups* (***BGR***), *fiat groups* (***FGR***) and extensions (***EXT***) [16]. While these distinctions are by no means trivial, their correct understanding is important if we are to find coherent ways to manage the large families of terms (for example in SNOMED CT the family consisting of terms such as 'absent leg', 'amputated leg', 'withered limb', 'absent bone in leg', 'limb amputee', 'amputation of lower limb', 'amputation of limb'), whose meanings are otherwise difficult to capture in a coherent way.

A bona fide group (***BGR***) is a group whose members are homogeneous, are causally linked together, and which is maximal in the sense that all causally linked entities of the relevant sort are members of the group. Examples are: Mary's limbs, Mary's cells, Mary's molecules.

A fiat group (***FGR***) is a group that is demarcated by fiat, such as: left lungs of people currently in Buffalo, the left lungs of all the people now participating in clinical trial #77639.

At any time at which the ***BGR*** constituted by healthy Mary's 4 limbs exists, a cognitive being may explicitly recognize the simultaneous existence of any combination of two or more of her limbs. Some of these combinations, for instance any group of 3 of her limbs, are distinct ***FGR***s, since they fall short of being maximal. The groups formed by her two arms and by her two legs, in contrast, are ***BGR***s. The relation between fiat subgroups of the bona fide group that is formed by Mary's limbs is analogous to the relation between some proper part of Mary that is demarcated by fiat and Mary as a whole. There is a fiat boundary between healthy Mary's left arm and the rest of Mary's body in the region of her left shoulder.

To each continuant universal corresponds a group, called its *extension* (***EXT***), formed by all and only those particulars that are instances of that universal at any given time.

The purposes of definitions

Our second distinction recognizes three purposes which a *definition* of a representational unit may serve:

P1: to specify the conditions that must be satisfied for a term to be an acceptable designator for a given entity in some given community. An example would be:

chronic pain =def. *a pain that has been present for more than 3 months*

P2: to specify what is characteristic of particulars that instantiate a certain universal, for instance:

disorder =def. *a part of an organism which serves as the bearer of a disposition to pathological processes* [17]

P3: to demarcate groups and classes by specifying characteristics that their members or elements must exhibit.

P1 definitions are essentially a matter of terminological decisions. The definition given as example excludes the use of the term 'chronic pain' for pains lasting less than 3 months. This does not mean, however, that a pain in a specific patient that has already lasted for 90 days *becomes* a chronic pain one day later. It was, in fact, a chronic pain already from the very beginning, even though this fact was unknown to any observer.

P2 and P3 definitions help in determining whether a given particular is to be classified in a given way. P2 does this at the level of universals, while P3 does it for ***GRP***s and as further explained, classes.

First-order entities versus representations

The third distinction concerns the *level of reality* at which the referent of some representation exists. Of importance here is the distinction between

1. *first-order entities* such as patients, disorders, families,
2. *beliefs* in people's minds (including beliefs putatively about objects such as unicorns which do not in fact exist), and
3. *representations* in some publicly accessible medium, for instance a term in an ontology.

Applying the framework

When a terminology has been selected as one that needs to be mapped to OBO Foundry ontologies, each of its representational units should be inspected to identify, in terms of corresponding representations in Foundry ontologies, what sorts of ***POR***s it is able to denote. A problem is that terms from concept-based terminologies often denote multiple distinct sorts of ***POR***s, for example because of asserted subtype relationships, as in SNOMED CT, whose concept 'Finger structure' subsumes the concepts 'entire finger' (a ***UNV*** under a realist framework) and 'all fingers' (a ***GRP***) (though SNOMED does not specify whether the latter means: 'all fingers in the world', 'all fingers of a given patient', 'all fingers on a given hand').

To address this problem, we introduce an intermediary layer made up of *classes* (***CLA***), understood as arbitrary totalities of elements which are either (i) defined through some descriptor referring to ***POR***s of any of the sorts described thus far (for example: 'the disorders in all the patients treated by Dr. McX'), or (ii) totalities whose elements are themselves so defined, or (iii) combinations of (i) and (ii).

Classes under (i) thus carve out ***POR***s in ways which go far beyond ***GRP***s as defined in the foregoing. Classes under (ii) and (iii) allow simultaneous reference to entities associated together in ways which have no counterpart ***POR***, for example

when we wish to assert heritability relations between Mary and certain of her ancestors who died many years before she was born.

Defined classes

Where groups have *members*, classes have *elements.* A *Defined Class* (***DCL***) is a class all of whose elements are specified by some class description. In the simplest case, this will be of the form '*ξ which stands in R to λ*', where '*ξ*' names some universal, for example 'person born in Belgium', which defines what we shall call a *Specifically Defined Class* (***SDC***), or 'patient who has tuberculosis', which defines a *Generically Defined Class* (***GDC***), each of whose elements enjoys the same relation (*exemplifies*) with instances of the single universal: tuberculosis. In more complex cases the definition will be of a logically more complex form, such as '*ξ* **has duration** *which stands in R to λ*', for example in the ***GDC*** *chronic pain*, where *ξ* is the universal: pain, *R* is the relation *longer_than* and *λ* is the temporal interval: 90 days. Many of the terminological definitions distinguished under P1 above will define terms which refer to ***GDC***s in the outlined sense.

For each ***GDC*** and for each ***SDC*** there is some universal from whose extension all its elements are drawn. An *Ad Hoc Class* (***AHC***), in contrast, is a ***CLA*** formed through combinations of ***GDC***s and ***SDC***s which is such that there is no such overarching universal. An example is, again, the SNOMED CT concept '*finger structure*', since among the entities that can be denoted by this term are both ***GRP***s and ***APA***s

Among ***AHC***s, too, we can distinguish both *Generic* (***GAC***) and *Specific Ad Hoc Classes* (***SAC***). An example of a ***SAC*** is the class whose elements are the clinical signs exhibited by some specific patient with tuberculosis [17]. An equivalent ***GAC*** would be the class whose elements are the clinical signs exhibited by all tuberculosis patients assigned to the control group of a given clinical trial.

Solving the semantic proximity problem

In its January 2009 version SNOMED CT associates the concept '*Fractured nasal bones (disorder)*' with the following synonyms: 'Fractured nasal bones' (S1), 'Broken nose' (S2), 'Fractured nose' (S3), 'Fracture of nose' (S4), 'Fracture of nasal complex' (S5), and 'Fracture of nasal bones' (S6). One consequence of the multiple interpretations that are given to the term 'concept' both inside [12] and outside [8] of SNOMED CT is that it is difficult to understand precisely how this 'association' is to be understood. In practice, what it means is that SNOMED is here acknowledging the different ways language users capture nasal bone fracture-related information when entering patient data into a record, and providing an aid to translating the corresponding bodies of data into SNOMED form. As realist ontology (and common sense) would suggest, however, it can be assumed that when a study nurse enters the term 'fractured nasal bones' into a patient record, then what he means thereby is not a *nose of a certain (fractured) sort* but rather a certain *group of bones.* If, accordingly, we are to devise a strategy for translating the resultant SNOMED data into the OBO Foundry framework, then our mapping will need to take account of the mentioned 'associations' in a more careful way than is possible when all the mentioned synonyms are treated *en bloc*. It is for this reason that we introduce the machinery of ***CLA***s and ***GRP***s in the above. This machinery is designed to make apparent the unarticulated complexity of SNOMED's synonymy relation by allowing each synonym to be treated separately in a way which at the same time allows formulation of the needed mappings to the corresponding OBO Foundry terms.

Human bones and noses are represented in the FMA Anatomy Ontology [18] by means of representational units denoting the universals *bone* and *nose* respectively. Fractures, in contrast, would be included in an ontology of disorders [17]. To realize our proposed strategy, now, scholars developing a mapping from SNOMED CT to OBO Foundry ontologies would have to decide, in collaboration with the SNOMED authors, what precisely the synonymous terms (S1–6) mentioned in our list above should properly be understood as denoting. In the framework here proposed, for example, S2 and S3 would both denote a ***GDC*** that is a subgroup of the extension of the universal *nose*. S1 would denote, according to further context, either a ***GRP*** which has *nasal bones* as members or a ***GDC*** denoted by the plural term 'bones of the nose'.

Another advantage of our strategy is that it helps us to understand the structure of the *is a* hierarchy in SNOMED CT. 44 concepts in SNOMED CT are described as being *is a* parents of *Fractured nasal bones (disorder)*. Where all of the synonyms referred to above denote first-order entities on the side of the patient, this is not the case for all 44 of the parent concepts listed. '*Disorder by body site (disorder)*', for example, reveals itself upon inspection to denote not a disorder at all but rather the way the representational units about disorders are further organized.

Another problematic case is '*Finding by site (finding*)': fractured nasal bones cannot, in our terms, be a (type) of finding, since something can only be found – and hence give rise to a finding – if it pre-exists, and is thus independent of, the corresponding act of observing. On our strategy, in fact, finding data would be mapped, not to bones directly, but rather to the corresponding datable observations.

Conclusion

It has been stated that '*Terminologies should not be developed by reference to a system of preferred terms, rather they should be developed in such a way that their individual nodes and* [the] *relations amongst these nodes are modeled on an underlying formal ontology, where the linguistic content of these nodes will be filled in based on a system of terms and synonyms (from many different languages) that is associated with each node based on the intended ontological interpretation of that node'*. [19] Few, if any, existing biomedical terminologies exhibit these characteristics. The framework we propose is designed to promote progress in this respect, with the goal, not of developing an underlying formal ontology for these terminologies themselves, but rather of achieving appropriate mappings to OBO Foundry ontologies. The approach provides a tool for terminologists to detect ambiguities and conflations in

the conceptual structures they have designed and to determine the correct handling of terms proposed as synonyms; it also forces developers of realism-based ontologies to be more precise about what exactly the representational units in their artifacts denote. Certainly there is a long way to go. We acknowledge that the proposed approach is not easy to apply because of the subtle distinctions it requires, distinctions which are perhaps not easy to understand especially for adepts of the concept-based approach. We believe, however, that the approach promises significant benefits, both practical and theoretical, in the long run.

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Enhancing a Taxonomy for Health Information Technology: An Exploratory Study of User Input Towards Folksonomy

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Abstract

The U.S. Agency for Healthcare Research and Quality has created a public website to disseminate critical information regarding its health information technology initiative. The website is maintained by AHRQ's National Resource Center (NRC) for Health Information Technology. In the latest continuous quality improvement project, the NRC used the site's search logs to extract user-generated search phrases. The phrases were then compared to the site's controlled vocabulary with respect to language, grammar, and search precision. Results of the comparison demonstrate that search log data can be a cost-effective way to improve controlled vocabularies as well as information retrieval. User-entered search phrases were found to also share many similarities with folksonomy tags.

Keywords:

Classification, Information retrieval, Internet, Health informatics

Introduction

Since September 2004, the U.S. Agency for Healthcare Research and Quality (AHRQ) has invested over $266 million in its health information technology (health IT) initiative. The goal of AHRQ's investment is to develop and disseminate health IT evidence and evidence-based tools to support AHRQ's overall mission of improving the quality, safety, efficiency, and effectiveness of health care for all Americans. A major component of AHRQ's health IT initiative is the National Resource Center (NRC) for Health IT, initially created by AHRQ to assist its grantees and contractors. Today the NRC is a public resource for those interested in implementing and using health IT. The main point of interaction with the AHRQ NRC is through its website[1].

Since its launch in 2006, the NRC has strived to continuously improve the website. To accomplish its goal, the NRC routinely captures usage metrics and user feedback, considered a best practice in the industry [1]. The metrics and feedback are used to identify website performance and usability issues. In addition, the data are used to identify content gaps. The NRC website supports a large, heterogeneous group of informatics practitioners and researchers, including novice providers just starting down the path towards implementation, adoption, and usage of health IT applications.

During the past two years, the NRC has focused on supporting these novice users in their quest to find knowledge resources to support local implementation and adoption of health IT. Part of this support involved the creation of a controlled vocabulary to describe the diverse content available on the site. The taxonomy of health IT terminology was used to organize web pages and index items made available through a search function. However, initial usability testing revealed that the taxonomy was confusing to novice users who did not use the same language and grammar as that used by the experts who created the taxonomy [2]. Based on the results of the usability testing, the NRC team removed the taxonomy from the site's outward facing information architecture but continued to use it for categorizing knowledge resources on the back-end.

The initial emphasis on users' ability to effectively browse the website, or click through the various pages to find information and knowledge resources, resulted in a lower priority for improvements to the search function. This changed in 2008 when usability testing revealed that many users, both novice and experienced, were frustrated with the website's search function. Furthermore, usability testing results showed that experienced site users tend to use search first, rather than browse through a site's information architecture.

To improve the site's search function, the NRC focused on enhancing its taxonomy. Best practice in information retrieval calls for the use of domain specific, controlled vocabularies to index the content made available through the search function [3]. Since the NRC already employed a controlled vocabulary to index its content, efforts focused on enhancing the taxonomy to improve search queries.

Recent information science literature has described the use of a folksonomy, in addition to or in place of, a controlled vocabulary to improve the user experience for searching. A folksonomy involves the use of open-ended, collaboratively generated metadata (or tags) for categorizing a site's content [4]. Folksonomies are further referred to as social bookmarking, social tagging, and social classification based on the fact that users typically create metadata tags for themselves and then

[1] http://healthit.ahrq.gov

share the content and tags with others. Common folksonomy websites include Digg, Delicious, and CiteULike.

Whereas taxonomies are top-down, controlled vocabularies, created and maintained primarily by librarians or domain experts, folksonomies are bottom-up, uncontrolled vocabularies that utilize familiar, accessible, and shared concepts created and maintained by a community of users [3,4]. In addition, folksonomies may have several advantages over taxonomies. First, folksonomies have been described as dynamic and forward looking with the capacity to categorize unforeseen subject matter, including emerging technologies [5]. Second, folksonomies may be a less expensive alternative to the development, maintenance, and enforcement of a tightly controlled vocabulary [5,6]. Finally, folksonomies may have a gentler learning curve for novice users [6]. These advantages may be attractive to a publicly funded program with limited resources for long term site development and maintenance.

Creating the ability for users to develop and share folksonomy tags on the NRC site would be difficult. U.S. Government policies restrict agencies from collecting users' names and other identifying information without strong oversight [7]. Before the NRC could ask for permission to enable users to login to a personal profile, create folksonomy tags, and view other users' tags, the Web team desired to explore the use of user-generated language and grammar to enhance the search function. In this paper, we outline our methods for approximating a folksonomy with user-generated search queries and present the results of an exploratory study in which user-centered language and grammar is compared with the expert-created taxonomy. We further suggest how folksonomies and other forms of user-entered concepts can be used to improve taxonomies as well as search functionality.

Materials and Methods

The AHRQ National Resource Center website utilizes the social networking plug-in AddThis (www.addthis.com). This application enables users to share web pages and content items with others via third-party Web 2.0 applications, including Twitter, Delicious, and Digg. Although these third-party applications make sharing easy for users by leveraging existing infrastructure, they do not allow AHRQ to easily review the content tags assigned to the items shared by users. Attempts to retrieve public folksonomy tags via Delicious and Digg for AHRQ pages and content did not yield substantive results. Nearly all of the users utilizing these services are storing the links and tags as private, perhaps sharing them with a limited number of peers or using them as personal bookmarks. This prevented a direct evaluation of folksonomy tags associated with NRC information and knowledge resources.

Therefore we approximated user-generated concept tags by utilizing an available data source, the maintenance logs of the NRC website. These logs contain many data on anonymous users' interactions with the site, including search phrases and keywords automatically captured each time users perform a query. The logs are comprehensive, and they are routinely used for other performance and usability monitoring.

Our hypothesis was that user-entered search phrases and keywords, extracted from queries, would exhibit the same characteristics as folksonomy tags. When testing the NRC site's taxonomy, we observed that users typically searched for information using concepts and phrases from their language and grammar. These concepts did not always overlap with the highly controlled vocabulary used in the first version of the site's taxonomy [2]. So in our search to identify an alternative, practical source for pilot data to evaluate the potential use of a folksonomy, we hypothesized that user-entered search terms may reflect users' language and grammar in a similar way to that of folksonomy tags.

We examined twelve months worth of search logs ranging from July 1, 2008 through June 30, 2009. The logs from December 2008 were corrupt, so they were excluded from the final analysis. A total of 34,816 user-entered search phrases were extracted from the logs and analyzed.

Three analytical methods were employed to review the search phrases and determine their appropriateness as a source of quality improvement data. First, the occurrence of each search phrases was counted, and the top 100 phrases were analyzed for patterns and trends. Our belief was that the search phrase patterns and trends would be similar to those observed of folksonomies by previous information science researchers.

Second, the top 100 phrases were mapped to the National Resource Center's taxonomy [1] to qualitatively evaluate its robustness and identify gaps. The mapping was also performed to examine the search phrases. We believed that the phrases would represent health IT concepts in the natural language and grammar of the end users.

Third, a non-random sample of five search phrases from the top 100 was selected for additional qualitative review. Each original search phrase and its mapped taxonomy concept were used to execute independent searches of the website. The search results were then examined for relevance. The search results were evaluated using 10-*Precision* method as described by Pera [8] and defined in Equation (1). This 10-*Precision* equation produces a precision value for the top 10 search results for a given query (*Q*).

$$10\text{-}Precision = \frac{\#_{of_{Retrieved_{Relevant_{Records}}}}}{10} \quad (1)$$

Precision values for the five user-generated search phrases and repeated, independent searches using the mapped taxonomy concepts were calculated. The values were then compared and contrasted. We hypothesized that the mapped concept precision values would be higher for each of the 5 paired queries. We further hypothesized that precision values for the mapped concept queries would be 1.0 since the taxonomy was engineered to facilitate precise information retrieval.

Results

Top 100 User-Entered Search Phrases

The 34,816 log records contained 8,574 unique search phrases. The number of occurrences for each unique phrase was counted for analysis. When sorted in descending order, the search phrases reveal an inverse logarithmic relationship as

shown in Figure 1. The curve begins to level off after the fifth most popular phrase, and just 30 phrases were entered more than 100 times in the eleven month period. These top 30 phrases were entered 12,707 times, which represents 36.5% of the total phrases observed over the 11 month period. The top search phrase, "health information technology," was entered 2,650 times and accounted for 7.6% of the total queries.

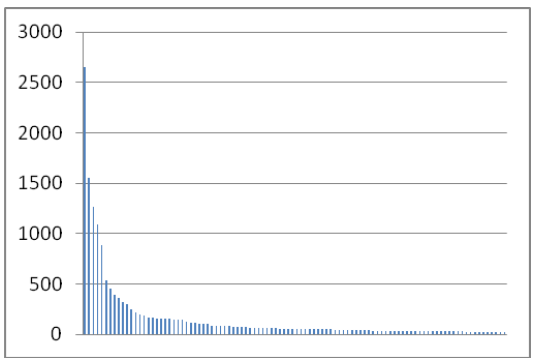

Figure 1- Distribution of the Top 100 User-Entered Search Phrases for http://healthit.ahrq.gov

Mapping User-Entered Search Phrases

Ninety-three of the top 100 search phrases were successfully mapped to existing taxonomy concepts. Thirty-three percent of the mapped terms pertained to just four political/administrative concepts: the Office of the National Coordinator for Health Information Technology, the Health IT Policy Committee, the Health IT Standards Committee, and the American Health Information Community.

The seven phrases that could not be mapped to existing taxonomy concepts are presented below in Table 1. The "knowledge library" concept refers to the area of the site where searches are executed, but the concept itself is not represented in the taxonomy. The concept "betaa" appears to be a misspelling. Two concepts (medical home, medical home model) are related, and they represent a health care delivery concept frequently discussed in the American medical community. The remaining three concepts appear to be terms invoked by robots scanning the site for downloadable content.

Table 1 – User-Entered Phrases for Which No Taxonomy Concept Existed

Search Phrase
knowledge library
default_collection
medical home
Saleslogix
xml_no_dtd
medical home model
betaa

User-Entered Search Phrases versus Taxonomy Concepts

Five unique search phrases from the top 100 were non-randomly chosen for additional analysis by the primary author. The author selected phrases that did not pertain to overly general concepts, such "health information technology," and phrases were further selected to represent a range of concepts.

For each phrase, two searches were performed. First, the original, user-entered phrase was used. Second, the mapped taxonomy concept was used. A total of 10 queries were independently performed. For each query, the authors examined the search results and calculated a 10-*Precision* value using Equation 1.

The selected search phrases and their 10-*Precision* values are summarized in Table 2. The original, user-entered phrases are listed first, followed by their 10-*Precision* values. Next the mapped taxonomy concepts are listed, followed by their 10-*Precision* values. The results show a general trend in which the taxonomy concepts performed as well or slightly better than the user-entered phrases.

Table 2 – Selected Search Phrases and Their Precision Scores

User-Entered Phrase	10-*Precision*	Mapped Taxonomy Concept	10-*Precision*
system implementation	0.9	Implementation	0.9
emr readiness assessment	0.2	Readiness Assessment	1.0
snomed	0.9	Coding Standards -> SNOMED	0.9
cpoe systems	0.6	Systems -> Computerized Provider Order Entry	0.9
time and motion study pdf healthcare	0	Workflow Impact -> Efficiency of Care	0.4

Discussion

Proponents of folksonomies suggest that they should replace traditional controlled vocabularies given the latter's limitations and expense [9]. Others in the information retrieval community view folksonomies as potential supplements to taxonomies, enhancing knowledge management practices with input from users [3,6]. Based on our review of the literature and exploratory study, we believe that folksonomies may be able to play a supporting role. We further assert that there are other sources of user input that can enhance information retrieval and knowledge management, namely search logs.

When we originally sought to enhance the NRC taxonomy, we looked towards a folksonomy. Because U.S. Government website policies do not favor private user accounts that collect

identifiable information [7], we turned to an alternative source of user input we believed would exhibit the same characteristics as folksonomy tags. Our exploration of this data source confirmed our hypothesis, revealing that user-generated search phrases indeed share characteristics with folksonomy tags.

Similarities between Folksonomy Tags and Search Phrases

User-generated search phrases are like folksonomy tags in the sense that they are uncontrolled. Folksonomies have been described as lacking rigor in their use of spelling, parts of speech, and use of plurals [4,6,10]. For example, the concepts "cat" and "cats" are typically unique concepts in a folksonomy, even though more structured vocabularies would relate the concepts to one another.

We found similar patterns within the search logs. For example, users varied in their use of "cost" versus "costs" when searching for information on the "typical cost" of a computerized provider order entry (CPOE) system. Thus one can imagine that if users were asked to tag a study on the "costs and benefits" of health IT [11], some users would use a "cost" tag while others would use a "costs" tag.

Also, like folksonomy tags, user-generated search phrases tended to be broad and less specific than the NRC taxonomy. Previous studies have shown that when users tag content when contributing to a folksonomy, they often choose the cognitive path of least effort [12]. The example described by Munk and Mørk involved an article by Milton Friedman in the *New York Times*. Folksonomy users tended to label the article with very broad tags, such as "business," "economics," and "politics," whereas the article dealt primarily with the concept of corporate social responsibility.

We found that many of the top 100 search phrases exhibited similarly broad concepts. The top search phrase, accounting for 2,650 (7.6%) of the 34,816 total phrases, was "health information technology." Other broad phrases in the top 100 included: "hit standards," "it tools," and "data reporting." These labels would likely apply to many of the articles, white-papers, and other information resources found on the AHRQ Health IT website, making them generally unhelpful to users seeking more narrow concepts such as EHR adoption, standard clinical vocabularies, and project management tools.

Search phrases are like folksonomy tags in the sense they both follow inverse logarithmic or power law distributions. Folksonomy tag distributions are the subject of several detailed analyses [10,12]. Each analysis revealed a general trend whereby a handful of so-called "power tags" are very popular followed by the long tail of tags used sparsely.

We observed a similarly long tail of unique search phrases, accounting for nearly two-thirds of all search phrases. However, the caveat is that we did not apply any intelligence to the raw search phrases, matching them to similar concepts or attempting to relate them to each other in any fashion. It could be that many of the phrases overlap in semantic meaning and, as a result, there may be a shorter tail than these data would otherwise indicate.

Synonymy is another similarity between folksonomies and search phrases. Folksonomies are described as possessing large semantic overlap between tags [5,6,12]. Often this is a function of the folksonomy platform. Delicious, for example, does not permit spaces in tags. Therefore "New_York_City" and "NewYorkCity" are distinct tags with no relationship. In a controlled vocabulary, the synonymy of these two concepts would be managed by content experts.

When reviewing the top 100 search phrases, we observed quite a bit of semantic overlap. Twelve of the top 100 phrases conveyed the broad subject of "health information technology." If these variants were used as distinct, unrelated tags in a folksonomy, they would likely not improve the precision of the search function. Users would instead need to execute 12 queries, one for each variant of "health IT," to retrieve all items tagged with the various synonyms of "health IT."

Enhancing Taxonomies and Information Retrieval

Folksonomies have been described as forward thinking, meaning that they keep pace with changing language, grammar, and trends in society (e.g., emerging technologies and concepts) [6,9,10]. This benefit is one of many reasons that many web managers and information system designers are looking towards folksonomies to enhance or complement controlled vocabularies. Our exploratory study of user-entered search phrases revealed not only that search log data are similar to folksonomy tags but that search phrases can be used in a similar manner to enhance controlled vocabularies and improve information retrieval within a web site or application.

Proactive monitoring of search log data to enhance controlled vocabularies yielded three main benefits. First, the review of search phrases identified users' evolving language, grammar, and search behavior. Consider the 12 variants of "health IT." Using the search logs, additional variants of this concept were identified and mapped as synonyms of the general term "health information technology." This process expands and enhances the controlled vocabulary and will likely to lead to search function improvements, since users could enter any of the 12 variants and, once the synonyms are linked within the taxonomy, and receive a very similar list of precise search results.

We further identified a concept that was not yet in the taxonomy: medical home. Although medical home is not a core informatics concept, much of the discussion in the U.S. surrounding medical home development and maintenance has involved the use of health IT systems to enable efficient and effective coordination of care among a diverse set of providers. Therefore this concept is an important, related concept that should be represented in a controlled vocabulary designed to encompass the field of health IT.

We also noted unanticipated patterns of users' search behavior. Consider the search phrases for four government entities, the Office of the National Coordinator for Health Information Technology (ONC), the Health IT Policy Committee, the Health IT Standards Committee, and the American Health Information Community (AHIC), which accounted for a significant number of searches. Three of these four concepts are non-permanent government committees, which raises the issue of whether currently popular labels should be included within the controlled vocabulary or incorporated in other ways (e.g., folksonomy tags, related terms).

Second, enhancing the taxonomy using user-entered search phrases improved the precision of the site's search function.

The 10-*Precision* values associated with mapped taxonomy concepts were greater than or equal to the values associated with the original search phrases. If the controlled vocabulary was routinely enhanced to reflect users' behavior and language, then the search function should significantly improve over time. Furthermore, we learned that the fifth term, "Workflow Impact -> Efficiency of Care," yielded a low precision value and should therefore be modified. User data might therefore benefit taxonomies beyond just the identification of synonyms and new terms.

Finally, the use of search phrases can be cost-effective. The search logs used to collect the data were already a foundational component of the website. They worked in the background, logging queries. The process of extracting the search phrases from the logs was quick and simple. Loading the phrases into an application for review and analysis also took less than a half a day. In total, less than one business day per quarter could be devoted to active review of search logs for new phrases and patterns of usage.

Other sites and applications that host controlled vocabularies could benefit from this study. For example, the Medical Subject Headings (MeSH) vocabulary maintained by the U.S. National Library of Medicine (NLM) currently does not contain concepts for health information exchange (HIE) and personal health records (PHRs). Reviewing search logs would probably reveal a number of queries for these concepts, which could prompt NLM to add them more rapidly to the MeSH tree than through the usual process of search term development. EHR and PHR applications might also benefit from collecting and analyzing user search data, which could aid in the retrieval of patients' health information or relevant evidence-based medicine knowledge.

Limitations of the Study

There are several limitations of this study. First, the study was exploratory in nature. The data were gathered from just one website, and they were not cross-checked with similar data from other websites. Second, only one expert was involved in reviewing the data and mapping search phrases to taxonomy concepts. Third, the sample used for analyzing precision was small. Finally, the study did not take advantage of natural language processing (NLP) techniques which could be utilized to perform automated scanning of the data to find new patterns and trends. NLP methods might also help us understand the structure of search phrases, which in turn may help to develop new methods for enhancing the search function interface and the way queries are formed by novice and intermediate users.

Conclusion

Website and application search logs contain user-generated phrases and keywords that exhibit similar characteristics to folksonomy tags. Using user-entered search phrases and keywords to enhance controlled vocabularies can be a cost-effective strategy for improving information retrieval. It may also be an effective complement to approaches, including folksonomies. Health informatics websites and applications should consider this technique to improve information retrieval and the overall usability of end-user products.

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The DebugIT Core Ontology: semantic integration of antibiotics resistance patterns

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Abstract

Antibiotics resistance development poses a significant problem in today's hospital care. Massive amounts of clinical data are being collected and stored in proprietary and unconnected systems in heterogeneous format. The DebugIT EU project promises to make this data geographically and semantically interoperable for case-based knowledge analysis approaches aiming at the discovery of patterns that help to align antibiotics treatment schemes. The semantic glue for this endeavor is DCO, an application ontology that enables data miners to query distributed clinical information systems in a semantically rich and content driven manner. DCO will hence serve as the core component of the interoperability platform for the DebugIT project. Here we present DCO and an approach thet uses the semantic web query language SPARQL to bind and ontologically query hospital database content using DCO and information model mediators. We provide a query example that indicates that ontological querying over heterogeneous information models is feasible via SPARQL construct- and resource mapping queries.

Keywords:

Ontology, Knowledge sharing, Antibiotics, Semantic heterogeneity, Systems integration, Information storage and retrieval

Introduction

After fifty years of unreflected and abundant use of antibiotics, the emergence of resistant and potentially untreatable pathogens has led to increased healthcare costs and patient risks. Comparison of antimicrobial resistance data across Europe led to the discovery of a wide diversity in practices. For instance, in Urinary Tract Infection (UTI) by uropathogenic E.coli, Trimethoprim is used as first line medication, while Fluoroquinolones are preserved as backup for patients with contraindications, allergies and where first line drugs fail. Although increasingly widespread use of Fuoroquinolones will promote bacterial resistance, an uncontrolled prescription can be observed in some areas. While resistance to Fluoroquinolones averages 5% in Europe, it can be as high as 24% in Spain [1].

The **DebugIT** project (**D**etecting and **E**liminating **B**acteria **U**sin**G** **I**nformation **T**echnology, http://www.debugit.eu/), a large scale data integration project funded within the 7th EU Framework Program, intends to analyze these practices and their outcomes across Europe and to exploit this knowledge to detect patient safety related patterns in hospital data, i.e. to discover indicators for better treatments and antibiotics resistance prevention.

In this project, a semantic infrastructure allowing bidirectional communication between locally distributed Clinical Data Repositories (CDR) and the DebugIT knowledge mining services is being built[1]. Most of the required semantics are provided by the DebugIT Core Ontology (DCO), which represents the formal and explicit computer-interpretable meaning throughout the project using semantic web technologies. DCO focuses on patients, diseases, pathogens, their analyses and medications.

We present DCO's current state of development and demonstrate how DCO is used within DebugIT to bridge the semantic gap between two heterogeneous clinical information systems. In order to do so, we briefly introduce some core aspects of the DebugIT interoperability platform which enables the semantic query integration over different hospital CDRs via DCO. The overall DebugIT knowledge mining architecture is described in [2].

Materials and Methods

Querying within the DebugIT interoperability platform

In order to understand how DCO is used for building cross-hospital queries, we here describe the query building process and the involved modules:

1. A data miner receives a clinical question and determines the needed datasets in the list of different hospital CDRs by iterating through steps 2 to 4 for each of the targeted CDRs. Soon the system will eventu-

[1] D. Teodoro, R. Choquet, E. Pasche, J. Gobeill, C. Daniel, P. Ruch, C. Lovis, Biomedical Data Management: a Proposal Framework. MIE 2009

ally possess a large battery of solved questions and their queries, which in turn give rise to the needed datasets for certain type of questions, therefore simplifying any subsequent query making process.

2. Previously stored SPARQL[2] dataset queries for the selected CDR are searched in order to be reused. Also partially matching queries may be used.
3. If no adequate query is found, a new SPARQL query is created (or an existing one adapted) by the data miner. We bridge the gap between the different CDRs by linking the specific CDR concepts via the DDO to DCO classes in a SPARQL query.
   a. First the **CONSTRUCT** clause is created using DCO according to a graph pattern template that specifies how results of the query should be returned. This CONSTRUCT clause can be reused for further CDR SPARQL queries the data miner is building and can be the same for all of the CDRs.
   b. Then the **WHERE** clause is created using an RDF file mediator called 'DataDefinitionOntology', DDO, expressing the information model and the mapping between its local concepts and DCO. The data miner needs to build a SPARQL query for each targeted CDR, because they are independent storage systems and normally have different DDOs. If a DDO concept is missing, the local CDR maintainer is notified who should fill this gap by defining the missing concepts.
4. The SPARQL query is sent to the targeted CDR and the returned RDF result is analysed to determine if it provides the needed data to solve the clinical query. If this is not the case, steps 2 to 4 are repeated to refine the SPARQL query. If the result is adequate the steps are repeated for the next selected CDR.
5. Finally, the SPARQL queries are sent to all distributed hospital SPARQL endpoints[3] to access their CDRs. The results are then aggregated into one RDF data result set, which can be exported to different formats, depending on the needs of the used data mining approach.
6. The constructed dataset SPARQL queries can be stored together with the RDF result and additional metadata in a knowledge repository for later reuse.

The gap between the different CDRs is bridged by linking the specific CDRs to DCO concepts in a mapping SPARQL query. In the query process described, we apply two kinds of ontologies to communicate between different modules of the interoperability platform. DCO classes and relations are used for formulating a hospital independent clinical query using SPARQL. It is mapped to the local IM via an RDF converted database schema[4], the DDO, acting as a query mediator to the proprietary hospital CDR. The physical IM was converted into RDF syntax by a syntax conversion tool to render it accessible to the SPARQL WHERE clause.

DCO design principles

We subscribe to a realist perspective towards biomedical ontologies as detailed in [3], however this is not in conflict with integrating information entities (see footnote 6).

Whereas according to [4] domain ontologies describe the vocabulary for a generic domain (medicine) and task ontologies describe a generic task or activity (e.g. diagnosing), DCO has to be classified as an application ontology according to this system, because DCO describes terms depending both on a particular domain (infectious disease) and task (data mining). From an engineering standpoint, we apply the normalization approach of [5] and use single asserted parenthood throughout the taxonomy. This will facilitate the orientation in the taxonomy and its maintenance. A reasoner infers multiple parenthood from the formal restrictions.

Ontology builders and users root their modeling decisions and interpretations into upper-level assumptions, whether they make it explicit in an upper-level ontology or not. We build DCO as an extension of the already existing upper level ontology BioTop [6], which renders the meaning of classes and relations explicit and less ambiguous. It helps to ensure a rigid modeling view and eases modeling decisions by providing basic constraints on a high level that can readily be exploited. To allow non-ontologist biomedical experts to view and check parts of the ontology we apply user-friendly ontology visualizations as generated by the OwlPropViz Protégé plugin[5] (see Figure 1).

Scope delineation

In order to maintain the ontology manageable and not to fall into "analysis paralysis", a restriction of the representation to an area of more immediate interest is mandatory. The top requirement for DCO is the coverage of the conceptual space for the detection of harm patterns and the exchange of clinical information, focused on infectious diseases. We decided to model the full circle for a concrete application and querying scenario first, rather than going for broad coverage. This will result in a better idea of how time series of events and branching within processes can be handled and it will contribute to test where the DCO upper level model needs to be updated in order to capture all information in the different CDRs.

Use Case and Competency questions (CQs)

A simple and common scenario, the antibiotic therapy of UTI with the most commonly used drugs Fluoroquinolones and Trimethoprim/Sulfametoxazol (TMP/SMX), has been chosen as the core of our first modeling iterations. We first look at a prototypical 'treatment course' of patient urine sample collection, culturing and antibiogram testing with and without intro-

[2] Simple Protocol and RDF Query Language, http://www.w3.org/TR/rdf-sparql-query/
[3] E.g. http://debugit1.spim.jussieu.fr/ for the Paris hospital
[4] E.g. a DDO with a PREFIX inserm: http://debugit1.spim.jussieu.fr/resource/vocab/ as in example query
[5] http://protegewiki.stanford.edu/index.php/OWLPropViz

ducing empirical therapy with TMP/SMX. The result of the antibiogram can then influence the empirical therapy (adaption) or directly result in a targeted antibiotic therapy.
To be able to verify whether DCO is sufficiently complete to represent our use case, we have collected a set of ten competency questions [7] from clinicians. The ontology needs to contain a necessary and sufficient set of axioms to represent these questions. As such, they will later serve as benchmarks for the DCO evaluation.

From the full set, we choose CQ #5 that we want DCO to be able to answer in the DebugIT prototype. We will use this in all examples in the remainder of this article: "select all Patients that have UTI caused by E. Coli and that are Trimethoprim resistant" The abstract formulation of this CQ is: "Select patients with treatment courses, where disease x caused by agent y, and agent y has a certain quality z (i.e. has susceptibility test result: resistant)". The formalization of this CQ in DCO is illustrated in the DCO query example below.

Term harvesting to populate DCO

We have chosen a data-driven approach in order to acquire a first set of terms for the ontology. Whereas the project seeks to reuse existing ontologies, major parts had to be built from scratch. To gain input for DCO development we harvest terms via the following channels:

- harvesting the set of CQs and abstractions thereof
- harvesting the partners hospitals' CDR schemata
- harvesting concepts of terminologies already in use in the clinical domain (e.g. SNOMED CT)

Concepts from the 'information artefact' realm were integrated via a so called information model ontology (IMO) that was build by 'ontologization' of a semiautogenerated RDF model of an HL7 v3 based information model[6]. IMO mainly amends DCO with 'information entity' concepts found in HL7.
These sources permitted a first representational scaffold to represent the domain, which since then has been incrementally refined.

Ontology modularization and imports

Besides BioTop, for which bridges to all major top level ontologies exist, the following external domain ontologies are aligned with DCO:

An Image mining Ontology IRON.owl has been created[7], which also describes an approach to handle numeric values in owl-DL.

We use an ontology of medical evidence to allow application users to choose between different sources of evidence (e.g. patient records, clinical trials, data mining results). This ontology also describes data exchange concepts like 'request' and 'response' to facilitate interoperability in message exchange systems, e.g. for querying. These operational feature descriptors will soon be factored out into a separate task ontology.

[6] A paper describing this approach has been accepted for MEDINFO 2010 by D. Ouagne et al.
[7] http://www.cs.ucy.ac.cy/itab2009/ (paper accepted)

Mapping to external vocabularies

Whereas DCO follows strict architectural guidelines it is devised to co-exist with less expressive ontologies by some of our collaborators. Specifically, we agreed to re-use the following external vocabularies within the DebugIT project:

- For **diseases** we will re-use and adapt the SNOMED CT finding hierarchy. Currently about 2/3 of the present DCO classes are mapped to matching SNOMED CT terms.
- For **anatomical entities** needed to describe disease and specimen locations we are re-using and adapting portions of the Foundational Model of Anatomy.
- For **bacteria** we are reusing the NEWT taxonomy.
- For **drugs**, we are using the WHO ATC codes.

DCO administration and access

DCO is maintained using a shared Subversion (SVN) repository[8] that allows easy detection of work progress using the log files and allows for file revision history tracking, revert to previous file states and a diff function to detect atomic changes made in single files. All more immediate exchange of ideas and progress monitoring is realized via weekly teleconferences along the SCRUM[9] project management methodology.

Administrative and editorial metadata schemes

We have developed a metadata schema optimized to the project's needs via a self-standing owl file that contains all necessary annotation properties[10]. This allows us to use the RDF:comment field for its intended purpose of capturing comments as well as action items for all entities.

To keep track of abundantly used core entities, we use the bookmark plugin[11] in Protégé 4. This helps in the selection process of ontology modules, especially for repeated evaluations and visualizations of certain views.

To ease DCO development and to foster a common view on use case relevant subsets of classes we have created a DebugIT specific Protégé Tab that shows

- the Bookmark view on selected DCO classes
- the OWLPropViz view to see a graph of DCO nodes linked via edges representing relations
- a cloud view on DCO classes, that displays them according to their subclass count or other criteria.

Results

The DCO ontology and the DebugIT Protégé 4 Tab are available in the project SVN. To access the ontology conveniently in a web browser, we have set up an owlDoc generated HTML serialisation[12].

[8] http://www.greeninghealthcare.org/repository/debugit/trunk
[9] http://www.scrum.org/scrumguides/
[10] http://purl.org/imbi/ru-meta.owl#
[11] http://code.google.com/p/co-ode-owl-plugins/wiki/Bookmarks, A selected set of entities is saved along with the ontology annotations for future reference
[12] http://www.imbi.uni-freiburg.de/~schober/dco_owlDoc/

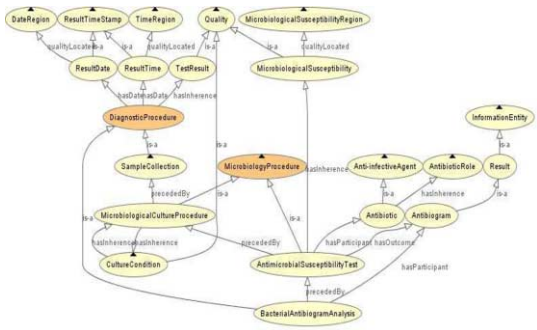

Figure 1- Graph based view on a DCO module

Figure 1 displays a use case relevant view on DCO as a graph created by the OwlPropertyViz plugin. A simple timeline of Processes, starting with the 'Bacterial Antibiogram Analysis' is shown along the *preceded_by* relation allowing for a simple model of relative time flow.

DCO Metrics

The current description logic expressivity is SRIQ(D). We are using the Hermit DL reasoner[13], which takes ~4 seconds to classify DCO including BioTop on an average PC. Table 1 illustrates the metrics of DCO and BioTop.

Table 1- Ontology metrics at submission time

Ontology Idiom	Count (all)	DCO	BioTop
Classes	1029	686	343
Object Properties (relations)	82	21	61
Datatype Properties	5	5	0
Subclass Axioms	1162	779	383
Equivalent Class Axioms	123	40	83
Disjoint Axioms	75	1	74
Sub Object Property Axioms	44	1	43
Transitive Object property Axioms	14	0	14
Object property Domain Axioms	28	0	28
Object property Range Axioms	28	0	28

DCO in a SPARQL mapping query - an example

SPARQL endpoints (see footnote 3) have been implemented in three hospitals. Mappings between the information models of local data repositories and DCO have been performed in order to run SPARQL queries. To illustrate how a mapping SPARQL query links DCO concepts to IM schema elements, we look at competence question CQ #5, which has been exemplarily modelled using DCO and BioTop concepts in the CONSTRUCT clause and entities of a particular hospitals IM schema in the WHERE clause:

```
PREFIX dco:    <http://www.debugit.eu/ontology/1.0/dco.owl#>
PREFIX inserm: <http://debugit1.spim.jussieu.fr/resource/vocab/>
CONSTRUCT {

          _:therapy             a dco:TreatingUrinaryTractInfection;
                                  biotop:hasPatient _:patient.
          _:urineSampling       a dco:UrineSampleCollection;
                                  biotop:hasParticipant _:patient;
          dco:hasOutcome _:urineSpecimen.
          _:culturing           a
dco:MicrobiologicalCultureProcedure;
                                  biotop:hasParticipant
_:urineSpecimen;
                                  dco:hasOutcome [ a dco:Result;
biotop:encodes _:bacteriaName ].
          _:bacteriaName        biotop:qualityLocated [ a
biotop:SpeciesEscherichiaColiRegion ].
          _:susceptibilityTest1 a
dco:AntimicrobialSusceptibilityTest;
                                  biotop:precededBy _:culturing;
          dco:hasParticipant [ a dco:Trimethoprim ];
          dco:hasOutcome [ a dco:Result; biotop:encodes
?susceptibility1 ] .
          ?susceptibility1      a dco:MicrobiologicalSusceptibility;
                                  biotop:qualityLocated [ a ?result1
].
          _:susceptibilityTest2 a
dco:AntimicrobialSusceptibilityTest;
                                  biotop:precededBy _:culturing;
          dco:hasParticipant [ a dco:CoTrimoxazole ];
          dco:hasOutcome [ a dco:Result; biotop:encodes
?susceptibility2 ] .
          ?susceptibility2      a dco:MicrobiologicalSusceptibility;
                                  biotop:qualityLocated [ a ?result2
].
}
WHERE {
          GRAPH<http://debugit.eu/inserm-map.n3> {
                    ?antibiotic1 a dco:Trimethoprim.
                    ?bacteria    a
biotop:SpeciesEscherichiaColiRegion.
                    ?r1          a ?result1.
?uti           a dco:UrineSampleColleciton.
?result1 rdfs:subClassOf dco:MicrobiologicalSusceptibilityRegion.
                    FILTER (!sameTerm(?result1,
dco:MicrobiologicalSusceptibilityRegion))
          }
          GRAPH<http://debugit1.spim.jussieu.fr/resource> {
                    ?susceptibility1 a inserm:CultureResults;
                                       inserm:culture_id ?culture;
                                           inserm:bacteria_analyzed
?bacteria;
                                       inserm:antibiotic_tested
?antibiotic1;
                                       inserm:antibiotic_RESULT ?r1.
                    ?culture         a inserm:culture;
                                       inserm:culture_sample_type
?uti.
          }
}
```

Challenges

The pursued SPARQL mapping approach requiring a mediation layer is still experimental. It depends on novel formats and tools, which challenges the stability of such a complex project. Considering the large data volumes performance might become a problem[14], and it is still an open question whether the whole setup will be scalable and well-performing. The on-the-fly IM schema to RDF conversion and SPARQL querying over DDO-DCO mappings is slow on certain constructs[15].

The mapping between an ontology and a clinical data repository is not trivial as the recording of clinical data blends ontological with epistemological, pragmatic and contextual aspects. The difficulty will be to find a metamodel that can consistently deal with the rather different implicit top level assumptions in the heterogeneous information models (see footnote 6). Time modeling will be another complex problem in the near future. DCO currently includes a relation 'preceded

[13] http://hermit-reasoner.com/

[14] The clinical data from George Pompidou hospital in Paris (of a year period of time) was migrated into the clinical data repository corresponding to 59000 patients, 89000 stays, 170000 episodes of care, 28000 culture results and 9800 antibiograms.

[15] http://www.w3.org/2007/03/RdfRDB/papers/d2rq-positionpaper/

by' to link processes and allows to model relative time flows (see Figure 1). To allow for absolute time modelling we have to include date-time stamps, e.g. using xsd:dateTime.

Conclusion

Whereas earlier attempts tried to integrate CDRs via purely syntactical integration, e.g. via XML schemata as in [8], recent approaches acknowledge the benefit of a computer interpretable formally defined semantics [9,10]. Not only are the requirements for medical data integration ontologies well investigated [11], recent projects have shown their usefulness in healthcare data integration settings [12]. As in the Advancing Clinico-Genomic Trials on Cancer (ACGT) project [13], which aims at improving Post-genomic clinical trials by providing seamless access to integrated clinical, genetic, and image databases, we use IM model-derived mediator artefacts and SPARQL to resolve syntactic and semantic heterogeneities when accessing wrapped databases. Along these lines DebugIT adopts a federated data warehouse model approach for clinical data integration as described by [14].

Although it seems too early to evaluate the full potential of DCO as core communication channel for the DebugIT interoperability platform, few preliminary properties can already be evaluated. Of the four properties of an ontology that may be quality-assured [15] philosophical validity, compliance with meta-ontological commitments, fitness for purpose and content correctness, we will primarily concentrate on the latter two, because an ontology compliant with all current philosophical theories, following all necessary ontological commitments, and with entirely 'correct' content, may be too complex to be directly usable. The next steps will be identifying and fixing coverage gaps for additional competence questions. We will continue to add logical definitions for at least all bookmarked classes in order to make these accessible to automatic reasoning. We believe the application of CQs and the example given illustrates DCOs 'fitness for purpose' and its 'content correctness' has been ensured via the application of consistency checks and automated reasoning. DCO has reached a level of completeness and formality to start to interoperate data queries across clinical sites as a proof of concept. We have provided a working example for a successful query execution of a query expressed using DCO answering one given competence question.

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Mapping BFO and DOLCE

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Abstract

Upper level ontologies are key technology for integrating heterogeneous information coming from different sources. DOLCE and BFO, are the favorite candidates which propose rigorous foundational principles to model any domain. The objective of the AKENATON project is to improve alert management and to support patient-centered medical decision in telecardiology. This requires to integrate information transmitted by implantable cardiac devices with clinical data extracted from patient health records. To achieve this goal, we have designed an ontology of telecardiology based on DOLCE. In order to integrate ontologies based on BFO such as FMA, we have developed a framework for mapping BFO and DOLCE categories in terms of equivalence and subsumption between categories.

***Keywords*:**

Upper level ontologies, BFO, DOLCE, Ontology, Mapping, Telecardiology

Introduction

Upper level ontologies (ULO), also called top ontologies or foundational ontologies describe very general concepts (e.g. *substance*, *physical object, event, quality*) and relations (e.g. *parthood, participation*) that are common to all domains. They are key technology for integrating heterogeneous knowledge coming from different sources [1]. DOLCE (Descriptive Ontology for Linguistic and Cognitive Engineering) [2] and BFO (Basic Formal Ontology) [3], are the favorite candidates which propose rigorous foundational principles to model any domain. These ontologies were elaborated in the context of the WonderWeb project [2], whose ultimate aim was to build a library of foundational ontologies, and to establish the foundations enabling the "negotiation of meaning" between agents. In the biomedical domain, several projects rely on BFO as a foundational ontology, e.g. [4, 5] while others use DOLCE, e.g. [6,7, 8].

In the AKENATON[1] project, we have designed an ontology of telecardiology in order to enrich and classify automatically alerts coming from Implantable Cardiac Device (ICD). The goal is to integrate clinical information from the patient health record (e.g. *diseases, prescriptions, procedures*) together with information provided by the ICD. The objective is to help physicians to assess their relevance and emergency level and to support patient-centered medical decision in telecardiology. The AKENATON ontology is based on DOLCE as it appears that DOLCE offers a better support for representing temporal qualities (e.g. *heart rate, atrial fibrillation duration*) and cognitive entities (e.g. *prescriptions, diagnosis, therapy plan*). However, our choice of DOLCE as framework should not hinder the future reuse of ontologies aligned to BFO (e.g. FMA, Foundational model of anatomy [9]). Conversely, it should not be an obstacle to ensure interoperability between the AKENATON ontology and ontologies based on BFO. Therefore, we investigated the compatibility between BFO and DOLCE. In this paper, we propose a mapping between BFO and DOLCE categories, in terms of equivalence and subsumption relationships between their respective categories.

[1] http://resmed.univ-rennes1.fr/akenaton/

Material and method

Several authors have proposed methods for mapping or merging ontologies, including lexical methods, structural methods, logical and semantic approaches based on models such as propositional satisfiability (SAT) and modal SAT techniques or description logic based techniques [1]. Contrary to domain ontologies and application ontologies, top ontologies would not benefit from these mapping techniques. ULOs adopt different philosophical perspectives that guide their defining of formal categories. Consequently, we generated the mappings between BFO and DOLCE categories, by analyzing and comparing their respective formal, textual definitions, with a focus on constraints and characteristics as well as examples of each category provided by authors. We focused on *equivalence* and *subsumption* relations. For each category of BFO (respectively DOLCE) we determined relations of equivalence or of subsumption considering the constraints of their DOLCE (respectively BFO) counterpart, and their philosophical approach.

BFO

BFO adopts a *realistic* approach. According to the modes of existence in time of the entities populating the world, BFO subdivides the reality into two orthogonal ontologies: SNAP and SPAN.

SNAP: SNAP ontology (Figure 1) is an ontology of *Continuants* (also called *Endurants*), which are entities that have continuous existence and fully exist in any instant of

time at which they exist. SNAP entities are separated into three main categories:

1. `bfo:Substantial entities` subsumes the categories of substances, their fiat parts, their aggregates, their boundaries and sites.
   - `bfo:Substances` are maximal connected substantials which they have the following main features: *i)* not depend entities, *ii)* bearers of qualities, *iii)* preserves their identity *iv)* located in space *v)* they are self-connected wholes with bona fide boundaries. Examples are organism and organ such as *human* and *heart*.
   - `bfo:Fiat parts` are part of `bfo:Substances`, on which they depend. `bfo:Fiat parts` cannot have their own complete bona fide exterior boundary, e.g. some body part such as *leg* and *nose*.
   - `bfo:Aggregates of substances` are mereological sums comprehending separate substances as parts. They may be scattered and thus have non-connected boundaries. Examples include *groups of human beings*.
   - `bfo:Boundaries` are lower-dimensional parts of spatial entities. Examples are *surface of skin* and *external surface of heart*.
   - `bfo:Sites` are holes, cavities and similar entities. They are generally filled by a medium such as air or water. Examples are *atrial cavity*.
2. `bfo:SNAP dependent entities` are continuant entities that depend for their existence on the `bfo:Substances` which are their bearers. However, if endurance and dependence are necessary conditions for `bfo:SNAP dependent entities`, they are not sufficient conditions. The distinguishing feature of these entities is that they *inhere in* `bfo:Substances`. They include particularized `bfo:Qualities` (e.g. *blood pressure, blood glucose level*), `bfo:Functions` (e.g. *function of heart to pump blood*), `bfo:Roles` (as *patient*, as *physician*).

`bfo:Spatial regions` are continuants, such that other SNAP entities can be located at or in them.

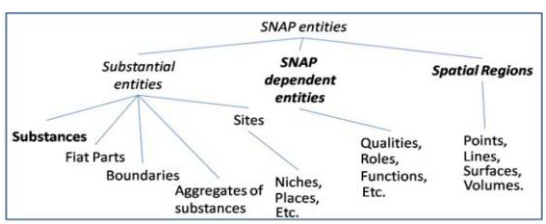

Figure 1-Top SNAP entities from BFO

SPAN: SPAN ontology (Figure 2) is an ontology of *Occurrents* (also called *Perdurants*), which are entities that occur in time and they unfold themselves through a period of time. The SPAN entities are divided into three separate categories:

1. `bfo:Processual entities` are entities that happen in time**,** they involve participants of a kind of `bfo:Substantial entities`. They are dependent on their participants, and occupy spatiotemporal regions. Conversely to `bfo:Substantial entities`, `bfo:Processual entities` do not have qualities [10]. Five main categories are subsumed by `bfo:Processual entities`:
   - `bfo:Processes` are those extended `bfo:Processual entities` which are self-connected wholes, they have beginnings and endings corresponding to real discontinuities, which are their bona fide boundaries. Examples are *blood circulation*, *course of disease*, *life*.
   - `bfo:Fiat parts of process`. All the proper parts of a process share the same level of granularity (e.g. *first phase of blood circulation*, and *metastasis phase of cancer*).
   - `bfo:Events` are instantaneous boundaries of processes and instantaneous transitions within processes. Examples are *birth, death, stroke, cardiac arrest*.
   - `bfo:Aggregates of Processes`. Examples include the aggregate of *all episodes of atrial fibrillation* in a given year; and the aggregate of *all surgical procedure* in a given period.
2. `bfo:Temporal region`, *Time*, the maximal temporal region, is an occurrent, and thus a SPAN entity. A `bfo:temporal region` is a part of *Time*.
3. `bfo:Spatiotemporal region` the totality of spatiotemporal regions reflects the totality of possible fiat demarcations of that maximal region, called *spacetime*.

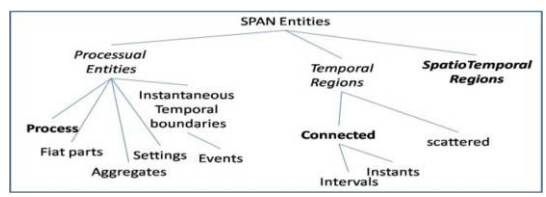

Figure 2-Top SPAN entities from BFO

DOLCE is a foundational ontology of *Particulars* which adopts a *Descriptive/Multiplicative*[2] approach and has a clear *cognitive bias*. Entities are classified into four separate categories, depending on their modes of existence (Figure 3):

1. `dol:Endurants` are entities that "are wholly present in time". Among `dol:Endurants`, and according to whether the entity has direct spatial qualities, `dol: Physical Endurants` (e.g. *heart, lung*) are distinguished from `dol:Non-Physical Endurants` (e.g. *prescriptions*, *diagnosis*), which cover social and cognitive entities. Furthermore, based on the unity criterion discussed in [11], `dol:Physical endurants` are divided into:
   - `dol:Amount of Matter` are `dol:Endurants` with no unity (according to [11], none of them is an essential whole). Examples are *some blood, some gas, and some water*.
   - `dol:Physical Objects` are `dol:Endurants` with unity. `dol:Physical Objects` change some of their

[2] A multiplicative ontology allows for different entities to be *co-localized* in the same space-time. This case is often presented through the problem of the vase and the clay it is made of [2].

parts while keeping their identity. Examples are *humans*, and *pacemakers*.

- `dol:Features` whose typical examples are "parasitic entities" such as *holes*, *boundaries*, *surfaces*, or *stains*, which are generically constantly dependent on `dol:Physical objects` (their hosts). Examples are *lesions*, *interior surface of coronary artery*, and *edema*.

2. `dol:Perdurants` are entities that "occur in time" in which `dol:Endurants` *participate* (e.g. *disease cours*). Among `dol:Perdurants`, `dol:Statives` are distinguished from `dol:Events` according to whether the `dol:Perdurants` are *cumulative*[3] or not. `dol:Events` are divided into `dol:Achievements` (e.g. *death*, *cardiac arrest*) and `dol:Accomplishments` (e.g. *scan session*, *clinical studing*) according to whether they are *atomic* or not. `dol:Statives` are divided into `dol:States` (e.g. *setting*) and `dol:Processes` (e.g. *pumping blood*, *coagulation*) according to whether they are *homeomerous*[4] or not.

3. `dol:Qualities` are neither `dol:Endurants`, nor `dol:Perdurants`. They are dependent entities which are *inherent in* either `dol:Endurants`, `dol:Perdurants` or `dol:Qualities`. `dol:Qualities` are entities that we perceive and/or measure. Examples are *blood pressure*, *blood glucose level*, and *duration of atrial fibrillation*.

4. `dol:Qualities` take "values", called `dol:Quales` (e.g. *120/80 mmhg*, *1.12 g/l*, *10 min*) within associated `dol:Region`.

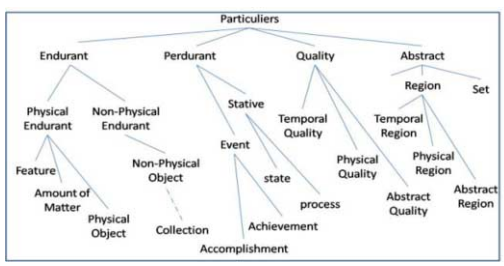

Figure 3-An excerpt from DOLCE's top-level taxonomy.

Mapping result

The result obtained when mapping an ontology O_1 to O_2 is a set of triples $C_1 R C_2$ where `C1`(resp. `C2`) is a concept of O_1 (resp. O_2) and `R` is a relation which is either *equivalence* or *subsumption*.

100% of BFO categories were successfully mapped to DOLCE resulting in 6 equivalence relations and 13 subsumption relations (Figure 4). However, 81% of DOLCE categories were successfully mapped to BFO, and we obtained 6 equivalence relations and 13 subsumption relations. 3 categories in DOLCE did not have any correspondence in BFO, such as the `dol:Temporal qualities`, and `dol:Abstract qualities`, because of BFO *realistic* approach.

Mapping snap entities (see Figure 4):

- `bfo:Substantials entities` is a general category. We map its five sub categories:
  - `bfo:Sites` are defined by examples such as *holes*, *cavities* or *places* depend on physical hosts. These same examples are given by DOLCE for the `dol:Feature` category, whose entities also depend on physical hosts. The `dol:Feature` category also subsumes other categories which are not `bfo:Sites`. Therefore `dol:Feature` *subsumes* `bfo:Sites`.
  - `bfo:Boundaries` are defined as lower-dimensional part of spatial entities, depend on entities they bound, as part depend on wholes. DOLCE gives boundaries as typical examples of `dol:Feature` entities (e.g. *surface of skin*) which also depend and are part of their hosts. Then, as `bfo:Sites`, `bfo:Boundaries` is also *subsumed by* `dol:Feature`.
  - `bfo:Fiat parts` are defined as parts of `bfo:Substances`, on which they depend. BFO distinguishes them according to their boundaries, and considers that each entity with no complete boundaries is a kind of `bfo:Fiat parts` (e.g. *noses*, *hands*). DOLCE is based on identity and unity criteria to determine the kind of entities which are parts of physical entities. Thus, for DOLCE, the body parts such as *legs* and *hands* are kind of `dol:Physical objects` because they keep their identity, even if they are detached from the body. Then, if this position is considered to hold in DOLCE, `bfo:Fiat parts` *are subsumed by* `dol:Physical objects`. If it is rejected, `bfo:Fiat parts` *are subsumed by* `dol:Features`. In our case, we chose the second proposition.
  - `bfo:Aggregates of substances` are defined as mereological sums comprehending separate substances as parts. In DOLCE, a new category called `dol:Collection` was introduced to represent the notion of aggregation [12]. `dol:Collection` is a category defined to manage entities such as *groups*, in which `dol:Endurants` are members. Thus, the *aggregate of humans* of BFO is a *group of humans* in DOLCE where the *humans* are the members. Then `bfo:Aggregates of substances` *are subsumed by* `dol:Collections`.
  - `bfo:Substances` category corresponds to the union of `dol:Physical objects and dol:Amount of matter`, which are based on unity and identity criteria. Unlike BFO, DOLCE distinguishes entities such as *some blood*, *some water* (entities with no unity (**~U**), which change their identity when they change their parts) from objects (entities with unity (±U) which can change some of their parts while keeping their identity). Thus, according to

[3] An occurrence is cumulative if its corresponds to the mereological sum of two of its instances

[4] An occurrences is homeomerous if each part of the instance stay belong the same occurrence. eg: each part of an instance of *setting* is a *setting*

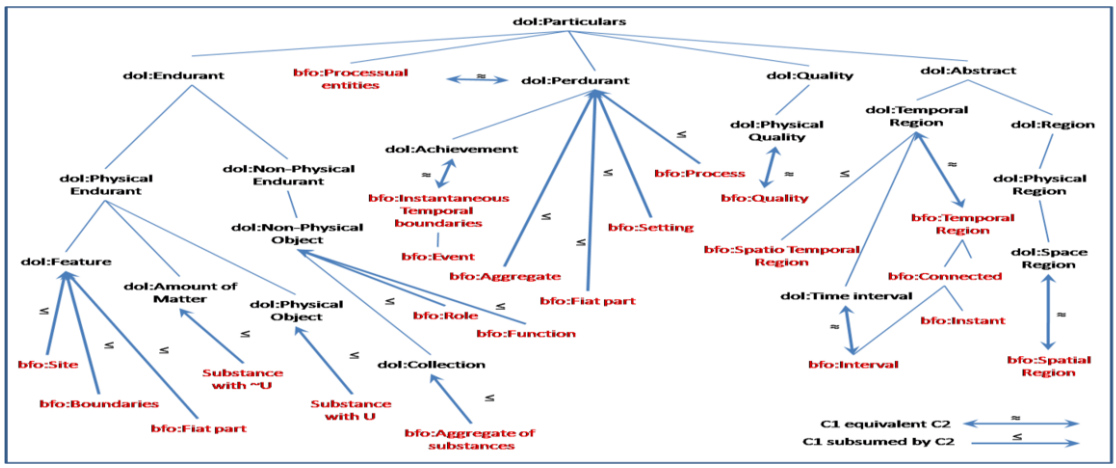

Figure 4- Mapping BFO to DOLCE

DOLCE distinctions, we subdivided `bfo: Substances` into two categories: `Substances with ±U` *subsumed by* `dol:Physical objects` and `Substances with ~U` *subsumed by* `dol:Amount of matter`.

- Except `bfo:Qualities` all categories subsumed by `bfo:Dependent entities` such as `bfo:Functions`, `bfo:Plans` and `bfo:Roles` are in DOLCE *subsumed by* `dol:Non-physical objects`, which are defined also as dependent entities with no spatial location. Concerning `bfo:Qualities`, because BFO considers only qualities for substantial entities, `bfo:Qualities` *are equivalent to* `dol:Physical qualities`.
- `bfo:Spatial Region` *is equivalent to* `dol:Space region`.

Mapping span entities (see Figure 4):

`bfo:Processual entities` are equivalent to `dol:Perdurants` in DOLCE. Moreover, DOLCE distinguishes `dol:Perdurants` according to three criteria: *cummulativity*, *homeomerousity,* and *atomicity.* However, often designers find these criteria elusive and not very intuitive. Therefore, we suggest that categories subsumed by `bfo:Processual entities` are directly *subsumed by* `dol:Perdurants`.

Actually, we cannot map directly in DOLCE the category `bfo:Processes` which are defined as `bfo:Processual entities` with unity criterion and with a beginning and an ending. Indeed, an entity, which is a kind of `bfo:Processes` may be either a kind of `dol:Process` (e.g. *cardiac rhythm*), or `dol:State` (e.g. *waiting*) or `dol:Accomplishment` (e.g. *scan session*). All of these examples have an unity criterion and have a beginning and an ending, but according to DOLCE *cardiac rhythm* is a `dol:Process` because it is *cumulative* and non *homeomerous*; *waiting* is a `dol:State` because it is *cumulative* and *homeomerous;* and *scan session* is an `dol:Accomplishment` because it is non *cumulative* and non *atomic*. Furthermore, at the same level of granularity, `bfo:Fiat part` of a `dol:Process` is a `dol:Process`, and `bfo:Fiat part` of a `dol:State` is a `dol:State`. However, `bfo:Events` defined in BFO as instantaneous temporal boundaries *are equivalent to* `dol:Achievements`. Because they are instantaneous, they satisfy the atomicity criterion. Otherwise, if designers want to adopt the DOLCE distinctions criteria of `dol:Perdurants`, they must examine the DOLCE criteria for each new subcategories of `dol:Perdurants` which may require to split one category into several categories. `bfo:Temporal region` as a part of *time is equivalent to* `dol:Temporal region` of DOLCE. However, the notion of `bfo:Spatiotemporal region` is not represented in DOLCE but can be easily added as a new specialization of `dol:Region`.

Mapping DOLCE categories to BFO (see Figure 5).

As we did with BFO categories, we now map the DOLCE categories to BFO with respect of BFO philosophical approach. Some categories are mapped without difficulties: such as: *i)* `dol:Feature` (union of `bfo:Sites`, `bfo:Boundaries`, and `bfo:Fiat parts`) *is subsumed by* `bfo:Substantial entities`, *ii)* `dol:Physical objects` and `dol:Amount of matter` *are subsumed by* `bfo:Substances`. *iii)* `dol:Physical qualities` *are equivalent to* `bfo:Qualities`. Although BFO does not accept the notion of `dol:Non-physical objects`, we find that categories such as `bfo:plans`, `bfo:functions`, `bfo:roles` subsumed by `bfo:Snap dependent entities`, *are subsumed by* `dol:Non-physical objects` in DOLCE. Hence, `dol:Non-physical objects` *are subsumed by* `bfo:Snap dependent entities`.

Furthermore, we have to be careful that all subcategories satisfy the constraints. For example, `dol:Collections` can be either collection of `dol:Physical objects` or `dol:Non Physical objects` in DOLCE. Since in BFO, `bfo:`

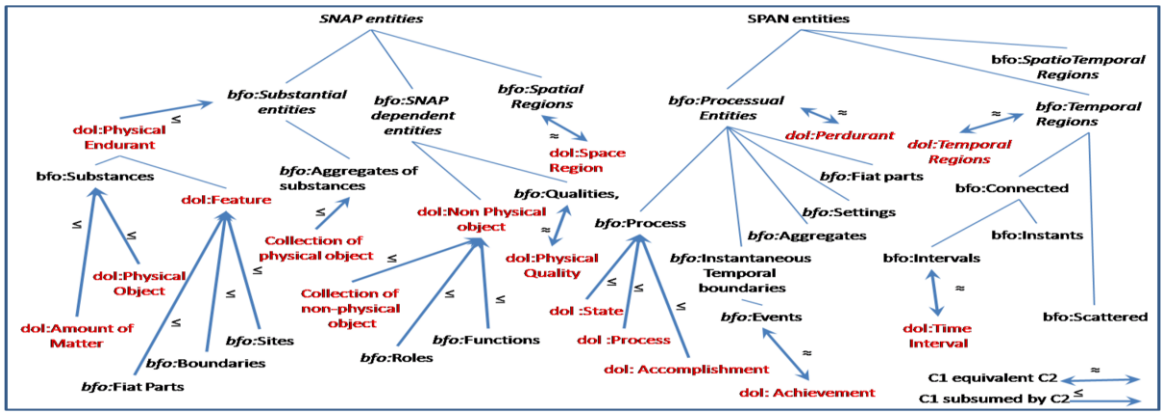

Figure 5-Mapping DOLCE to BFO

`Aggregates of substances` are kind of substantial, we divide collections into `Collections of physical objects` *subsumed by* `bfo:Aggregates of substances`, and `Collection of non physical objects` *subsumed by* `bfo:Snap dependent entities`.

Discussion

Grenon compared informally the main DOLCE and BFO categories. He presented similarities and differences between them, and gave some indications to do the mapping [10]. To our knowledge, no effective mapping between these foundational ontologies has been made available. However, this mapping is a crucial preliminary step to address interoperability issues. In this work, the goal is not to approve a particular model or to discuss philosophical choices, but rather, to give an opportunity to those who chose to use DOLCE (respectively BFO) as a framework, to reuse ontologies designed under BFO (respectively DOLCE). We have developed this mapping with respect to the philosophical approach inherent of foundational ontologies. There are aspects in DOLCE, e.g. qualities for perdurants, that are no recognized in BFO, because of the *realistic* approach of BFO. In fact, it is not yet clear how one can represent notions such as, *duration*, and *heart rate* in BFO. It is then difficult to give a satisfactory mapping for this kind of entities. This work proposed a mapping between the DOLCE and BFO upper-level ontologies, where their respective *realistic* and *cognitive* could be reconciled. We have developed and evaluated the mappings in the AKENATON project. The expected outcome is to support future mappings between a domain ontology based on DOLCE and another one based on BFO in other biomedical projects.

Acknowledgments

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Using the Abstraction Network in Complement to Description Logics for Quality Assurance in Biomedical Terminologies - A Case Study in SNOMED CT

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Abstract

Objectives: To investigate errors identified in SNOMED CT by human reviewers with help from the Abstraction Network methodology and examine why they had escaped detection by the Description Logic (DL) classifier. Case study; Two examples of errors are presented in detail (one missing IS-A relation and one duplicate concept). After correction, SNOMED CT is reclassified to ensure that no new inconsistency was introduced. Conclusions: DL-based auditing techniques built in terminology development environments ensure the logical consistency of the terminology. However, complementary approaches are needed for identifying and addressing other types of errors.

Keywords:

Systematized nomenclature of medicine, Comparative study, Quality assurance, Description logics, Abstraction network.

Introduction

SNOMED CT is one of the largest clinical terminologies in the world. The most recent release (July 31, 2009) comprises more than 289,000 active concepts and 1.5 million relations (hierarchical and associative). SNOMED CT concepts are organized into 19 hierarchies, such as **"**Procedure"**, "**Clinical finding" and **"**Body structure."

Modern terminologies including SNOMED CT and the NCI Thesaurus are created with the support of Description Logics (DL), which ensures the logical consistency of the terminological assertions. However, due to its sheer size and complexity, it is almost unavoidable that SNOMED CT should contain errors, such as inaccurate or incomplete logical definitions (e.g., errors in the nature or in the target of asserted relationships, as well as missing relations).

A number of techniques have been developed for auditing SNOMED CT, based on lexical, structural, and ontological principles. Lexical approaches have been used by [1-2] to suggest missing and erroneous relations based on the compositionality of biomedical terms. Additionally, [2] exploited formal ontological principles. Formal Concept Analysis was employed by [3] to analyze semantic completeness. Based on various structural approaches, [4] detected improper assignment of relationships, redundant concepts, and omission of relationships. Finally, [5] identified redundant and underspecified concepts by detecting equivalent concept definitions. In summary, these approaches applied computational method to the identification of potential errors. This automated process is designed to facilitate the work of human editors (subject matter experts) and it contributes to the quality assurance of biomedical terminologies.

The objective of this paper is to investigate errors identified in SNOMED CT by human reviewers, with help from the Abstraction Network methodology. More specifically, we examine why such errors could not be identified by a Description Logics classifier and propose a strategy for using the Abstraction Network in complement to DL-based techniques for the quality assurance purposes. The contribution of this paper is not to propose novel approaches to identifying errors in SNOMED CT, but rather to tease out differences between existing approaches based on several cases of errors thoroughly investigated.

Background

Description Logic

Description logics (DL) are a family of knowledge representation formalisms often used as ontology languages [6]. Not only does DL provide support for defining concepts, but it also provides methods for reasoning about concepts and their instances. DL reasoning services are carried out by DL classifiers.

The basic inference on concept expression is subsumption, i.e., comparing two classes and checking whether one class is more general than the other. For example, "brain disorder" is more specific than (i.e., subsumes) "disorder," because "brain disorder" is defined as a "disorder" located to the brain. Another important inference is concept satisfiability. A class is deemed unsatisfiable (i.e., inconsistent) if it cannot possibly have any instances. For example, nothing can be at the same time a procedure and an anatomical structure. If a class "C" were defined as a subclass of both "Procedure" and "Body structure," while "Procedure" and "Body structure" are defined to be disjoint, a DL classifier would identify "C" as unsatisfiable. The interested reader is referred to [6] for additional details about DL.

There are, however, many different dialects of DL in terms of the set of constructors they offer, resulting in different levels

of expressiveness for what can be defined. The expressiveness of the DL also determines the kinds of inference a DL classifier is enabled to perform and the kinds of logical inconsistency it is able to identify. The dialect of DL natively used by SNOMED CT is "EL", whose expressiveness is relatively limited. For example, EL does not allow disjunction to be stated between classes and the example of unsatisfiability presented earlier could therefore not be identified by the DL classifier used for the creation of SNOMED CT.

From the perspective of error identification in ontologies, two major types of errors can be distinguished. Type I errors are the logical inconsistencies in concept expression that can be detected by DL classifiers (assuming the DL dialect used is expressive enough to state the circumstances under which concepts would be inconsistent, e.g. disjointness). In contrast, Type II errors are those content errors (e.g., wrong relations, missing relations) that would not generate logical conflicts in the DL system. Quality assurance processes in SNOMED CT ensure that all Type I errors have been identified and corrected before the terminology is released to users. All the errors under investigation in this study are therefore Type II errors. (Here, Type I and Type II errors are defined in reference to the level of expressiveness of the EL dialect of DL).

In practice, several views of SNOMED CT are provided to users. The main view is the inferred view, in which all inferences are precomputed and redundant relations removed. The inferred view is automatically derived from the asserted view by a DL classifier. In this work, we analyze the inferred view, but, unlike most users, we also modify the asserted view and use a DL classifier in order to check any suggested changes for consistency.

Abstraction Network

The Abstraction Network (AN) is a structural methodology developed for reducing the complexity of large biomedical terminologies [7]. The AN methodology is based on the associative relationships and their inheritance patterns in the hierarchies of the terminology. It has been applied to auditing SNOMED CT. Here, we give a brief description of its underlying principles and review its application to SNOMED CT. Our examples focus on the "Specimen" hierarchy of SNOMED CT.

AN provides an abstraction of the hierarchical and associative relations of concepts in a SNOMED CT hierarchy. The idea is to partition such concepts into structural uniformity groups (strUGs), and then to refine the partition into semantic uniformity groups (smtUGs). A detailed description can be found in [7-9][1].

A "structural uniformity group (strUG)" is the group of all concepts with exactly the same set of associative relationships. In a graph structure, we use a node to represent a strUG. The label for the strUG node is the set of associative relationships in which its concepts participate.

Five different associative relationships are introduced to the concepts of the "Specimen" hierarchy; they are ***substance***, ***morphology***, ***procedure***, ***topography***, and ***identity***[2]. For example, the concept "Surgical excision sample" has one relationship ***procedure*** pointing to a concept "Excision" (from the "Procedure" hierarchy). Therefore, the concept "Surgical excision sample" is in the strUG{***procedure***}. Similarly, the concept "Abscess swab" has two relationships ***procedure*** and ***morphology*** pointing to "Taking of swab" and "Abscess morphology" (from the "Procedure" and "Body structure" hierarchy, respectively). Thus, "Abscess swab" is in the strUG{***procedure***, ***morphology***}. Note that strUGs do not overlap, because, by construction, one given concept belongs to one and only one strUG corresponding to its relationship pattern. Therefore, the entire set of strUGs forms a partition of the concepts in a given hierarchy of SNOMED CT.

StrUGs can be organized into a graph structure. Hierarchical relations between strUGs are determined by the inclusion of the sets of relationships they represent. For example, the strUG{***procedure***} subsumes the strUG{***procedure***, ***morphology***}. Figure 1(a) shows a portion of the graph of strUGs for the "Specimen" hierarchy. Each colored box represents a strUG. The boxes are color-coded to differentiate the levels. Each level corresponds to the number of relations in the strUG. The concepts in the strUG Ø have no associative relationships.

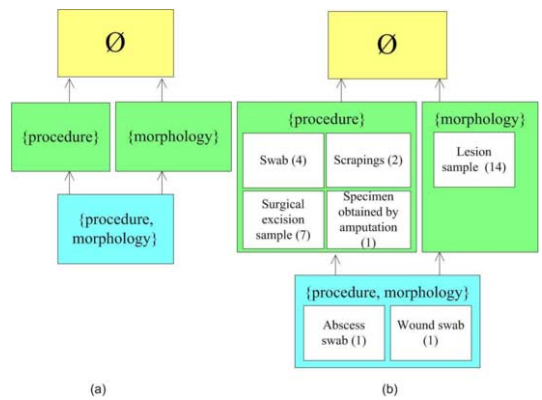

Figure 1- (a) Portion of the graph of StrUGs for the "Specimen" hierarchy (b) Corresponding portion of the graph of smtUGs

A "semantic uniformity group (smtUG)" is a group of concepts within a structural uniformity group sharing the same lowest common ancestor (LCA). In other words, the smtUG groups concepts with the same associative relationships by hierarchical relations. The label for the smtUG is the LCA from which all other concepts in the smtUG are descendants. A strUG may have more than one LCA, and thus more than one smtUGs. The smtUGs form a semantic subdivision of the strUG, but not necessarily a subpartition of it, since a concept may have more than one LCA.

[1] In our previous work, *structural uniformity group* is referred to as *area*, while *semantic uniformity group* is referred to as *partial-area.*

[2] The full name of these relationships is ***specimen substance***, ***specimen source morphology***, ***specimen procedure***, ***specimen source topography***, and ***specimen source identity***, respectively.

The graph of strUGs in Figure 1(a) can be refined with the smtUGs contained within each strUG, as shown in Figure 1(b). For example, the strUG{*procedure*} contains the four smtUGs: smtUG("Swab"), smtUG("Scrapings"), smtUG("Surgical excision sample") and smtUG("Specimen obtained by amputation"). The number in the parentheses indicates the number of concepts within a smtUG. For example, in the smtUG("Surgical excision sample"), there is a total of seven concepts. The six hidden concepts are all subsumed by "Surgical excision sample."

The strUGs and smtUGs form a graph structure called abstraction network (AN), which hides some of the complexity of the terminology. This abstracted view has proved a useful auditing tool for manual review of biomedical terminologies by subject matter experts.

Auditing Method based on Abstraction Network

Several strategies have been devised to help subject matter experts review parts of SNOMED CT based on the Abstraction Network methodology.

Group-based auditing takes advantage of the grouping of concepts in semantic uniformity groups [7]. All concepts from a given group are reviewed at the same time, making it easier for experts to identify discrepancies among concepts expected to be both structurally and semantically similar. Errors exposed via "group-based auditing" include redundant concepts, erroneous relationships, incorrect ***IS-A*** assignments, and other content errors.

Auditing "complex" concepts focuses on those concepts within a structural uniformity group, which belong to several semantic uniformity groups because they have ancestors in several smtUGs [9]. Errors found in such complex concepts include missing child and incorrect parent.

Error concentration based auditing is predicated on the fact that small semantic uniformity groups are more likely to contain errors, because small sets of similar concepts might have received less modeling attention, compared to larger sets (e.g., based on a concept model). The correlation between small smtUG size and error concentration was assessed in [8].

Case study

We selected two of the errors detected in SNOMED CT by subject matter experts with help from the Abstraction Network methodology and reported to the International Health Terminology Standards Development (IHTSDO)[3], the organization in charge of SNOMED CT. Our objective in this paper is to investigate these cases and examine how they escaped detection by the DL classifier used to check the logical consistency of SNOMED CT.

DL reasoners are stand-alone tools that point out logical inconsistencies in an ontology. In contrast, the Abstraction Network methodology helps organize the workflow of subject matter experts, in order to focus their attention to parts of the ontology where errors are likely and by grouping the concepts to be audited according to the principles described earlier.

[3] http://www.ihtsdo.org/

The two errors under investigation were identified in the "Specimen" hierarchy of SNOMED CT. In the first one, "amputation", it was argued that two sibling concepts actually stand in a subsumption relation. The issue is thus a missing ***IS-A*** relation between these two concepts. The second case, "leukocyte", highlights two concepts that are arguably equivalent, but stand in a ***IS-A*** relation.

In addition to discussing the errors, we also want to test the remediation suggested to the IHTSDO. Toward this end, we loaded the asserted version of SNOMED CT in OWL DL into the ontology editor Protégé[4] and tested the suggested changes with the DL classifier Fact++[5]. Our goal is to verify that the proposed changes did not introduce any inconsistencies to SNOMED CT. Classification was performed on a standard desktop machine with the 64-bit Microsoft Windows operating system and 4 GB of RAM. The classification of the OWL version of the SNOMED CT takes about 17 minutes.

Case 1: Amputation

This error was identified by the subject matter expert while examining a group of concepts from the "Specimen" hierarchy corresponding to one particular structural uniformity group, namely the strUG{*procedure*}. By construction, the concepts naming the smtUGs within a strUG are not expected to stand in any kind of hierarchical relation. The assumption for the subject matter expert reviewing the concepts from a strUG is that they are all expected to be siblings. Therefore, reviewing these concepts as a group makes it easy to identify errors including missing or incorrect parent/child relations, for example.

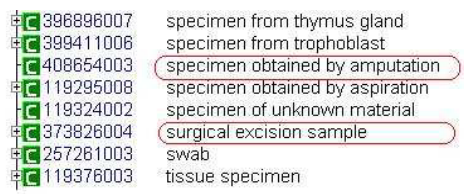

Figure 2- "Specimen obtained by amputation" and "Surgical excision sample" displayed in the CliniClue browser

Figure 2 shows a portion of the inferred view of the SNOMED CT displayed in the CliniClue browser[6]. The two concepts circled in red, "Specimen obtained by amputation" and "Surgical excision sample", are siblings. Both of them are in the "Specimen" hierarchy under the root concept "Specimen." The corresponding target concepts with the relationship *procedure* are "Amputation" and "Excision," respectively, in the "Procedure" hierarchy, under the parent concept "Surgical removal" (not shown in the figure). The four concepts "Specimen obtained by amputation", "Surgical excision sample," "Amputation" and "Excision" are fully defined.

The subject matter expert determined that "Specimen obtained by amputation" is, in fact, a kind of "Surgical excision sample." The fact that the two concepts were grouped in the

[4] http://protege.stanford.edu/
[5] http://owl.man.ac.uk/factplusplus/
[6] http://www.cliniclue.com/

strUG{*procedure*} made it easier for the expert to identify this error. Of note, there was no logical inconsistency in the concept expression and the DL reasoner failed to detect the missing subsumption relation because its absence did not create any kind of conflict in the terminology. One particular reason why no conflict could be identified is because there was a parallel error on the target side. The target concepts "Amputation" and "Excision" are siblings (descendants of "Surgical removal"), while amputation is actually a kind of excision. Because of a missing ***IS-A*** relation in parallel on both sides of the *procedure* relationship, there was no logical error that could be identified by the DL classifier.

From the perspective of the Abstraction Network, both smtUG("Surgical excision sample") and smtUG("Specimen obtained by amputation"**)** are in the strUG{*procedure*} (see Figure 1(b)). But the existence – indicated by the expert – of an ***IS-A*** relation between these two concepts within the same strUG{*procedure*} violates the principles under which the strUG was constructed.

Figure 3 shows the comparison before and after addition of the missing ***IS-A*** relations. As a result of this modification, "Specimen obtained by amputation" is now subsumed by "Surgical excision sample", and the smtUG("Surgical excision sample"**)** has gained a new member.

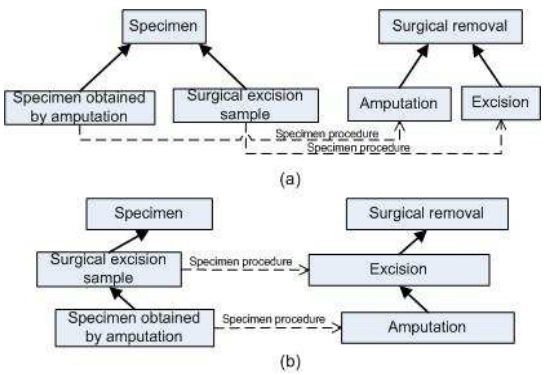

Figure 3- Parent-child error with "Surgical excision sample" and "Specimen obtained by amputation" (a) Before correction (b) After correction

We modified the target hierarchy ("Procedure") by making "Surgical Excision" the super class of "Amputation" in our copy of SNOMED CT in Protégé, while leaving the source hierarchy ("Specimen") unchanged. After reclassification, we saw that the classifier had used the changes we made to the target hierarchy ("Procedure") to automatically make parallel changes to the source hierarchy ("Specimen"), where "Surgical excision sample" has become the super class of "Specimen obtained by amputation" (Figure 3(b)).

Case 2: Leukocyte

This error was identified by the subject matter expert while examining a group of concepts from the "Specimen" hierarchy corresponding to one particular semantic uniformity group, namely the smtUG("White blood cell sample"). By construction, concepts within a smtUG are expected to stand in an ***IS-A*** relation with the lowest common ancestor after which the smtUG is named. The assumption for the subject matter expert reviewing the concepts from a strUG is that they are all expected to be distinct and descendants of "White blood cell sample". Therefore, reviewing these concepts as a group makes it easy to identify duplicate concepts, for example.

As shown in Figure 4, "Leukocyte specimen" is one of the children of "White blood cell sample." The subject matter expert determined that "Leukocyte specimen" and "White blood cell sample" are, in fact, duplicate concepts. The fact that the two concepts were grouped in the smtUG("White blood cell sample") made it easier for the expert to identify this error.

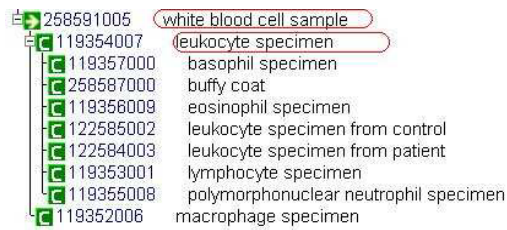

Figure 4 – "Leukocyte specimen" and "White blood cell sample" displayed in the CliniClue browser

In DL, concepts exhibiting the same logical definitions are treated as equivalent concepts by the classifier. In this case, the DL classifier did not identify these two concepts as equivalent, because the logical definitions were actually slightly different. "Leukocyte specimen' is a primitive concept, whereas "White blood cell sample" is fully defined. Because the definition of "Leukocyte specimen" is underspecified (primitive), the DL classifier cannot recognize it as equivalent to the fully defined "White blood cell sample."

From the perspective of the Abstraction Network, there is no difference between primitive and defined concepts. Only the set of relationships is taken into account during the creation of the groups.

We modified the definition of "Leukocyte specimen" in our copy of SNOMED CT in Protégé, so as to make it fully defined instead of primitive. After reclassification, "White blood cell sample" and "Leukocyte specimen" were indicated as being equivalent concepts.

Discussion

Strengths and limitations of each approach

The main advantage of DL is that it identifies errors completely automatically, while the Abstraction Network (AN) methodology only constrains the workflow of subject matter experts in such a way that it facilitates their work and improves their chances of identifying errors by reducing the complexity of the terminology and by organizing the concepts to be reviewed in small groups, with assumed relations among concepts within and across groups.

Unlike the DL classifier, AN does not rely on defined concepts, but simply takes advantage of the structural properties of concepts, i.e., their sets of relationships. Unlike AN, the DL classifier processes the terminology as a whole and can address remote inconsistencies, whereas experts tend to focus on a small portion of the terminology and may not foresee the consequences of local changes to distant parts of the terminology.

Finally, DL classifiers are limited to the identification of logical inconsistencies. Moreover, they are limited in the type of logical inconsistencies they can identify by the level of expressiveness of the dialect of DL used for creating the ontology [10]. In contrast, subject matter experts guided by the Abstraction Network methodology can address a wider range of issues (i.e., beyond logical inconsistencies) and identify content errors, such as inaccurate and missing relations.

Auditing strategy

The DL classifier is used for detecting logical inconsistencies at the time the terminology is built. The performance of the classifiers has improved tremendously in the past few years and the editors of large terminologies will soon enjoy real-time classification. We recommend the use of the Abstraction Network methodology for targeted auditing, as a possible alternative to dual editing. However, multiple auditing strategies combining lexical, structural and ontological methods are required for quality assurance of large, complex terminologies such as SNOMED CT.

Current developments and future work

One of the limitations of the Abstraction Network methodology is that it relies heavily on the structure of relationships of the concepts and is therefore not applicable to concepts with few or no relationships. In order to address this limitation, we have developed the converse abstraction network [11].

Conclusions

In this study, we examine the differences between two approaches to identifying errors in large biomedical terminologies such as SNOMED CT. On the one hand, Description Logics classifiers can automatically identify logical inconsistencies in the terminology. On the other, the Abstraction Network methodology helps experts perform targeted manual reviews of the terminology by reducing its complexity and grouping the concepts by their structural and semantic properties. We illustrate the differences between the two approaches through two cases of errors identified in SNOMED CT.

Acknowledgments

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Information-Content-based Measures for the Structure of Terminological Systems and for Data recorded using these Systems

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Abstract

Terminological systems such as SNOMED CT play an increasingly important role in contemporary record keeping. This drives the need of assessing the content of these systems, as well as the content of medical records captured using these systems. In this paper, the use of information content as a measure for the structure of terminological systems and the content in medical records is explored. Two complementary information-content-based measures for terminological systems are proposed: the proportion of concepts with zero information content, and the average information content. The measures are applied to the latest releases of SNOMED CT. The measures are useful as an indicator of the overall structure of terminological systems or parts thereof. Furthermore, two measures are described which can provide an estimate for the content of medical records that is captured using a terminological system. Information content is shown to provide a useful basis for assessing the structure of terminological systems and the content of medical records.

Keywords:

Terminology, SNOMED CT, Information theory.

Introduction

Medical terminological systems provide a systemized representation of medical knowledge. A large number of terminological systems have been developed over the last decades. Whereas these systems originally were small lists or hierarchical systems, contemporary systems are large and complex.

The increasing size and complexity of terminological systems raises a number of challenges. First, the need arises for automated ways to assess their quality, as the effort of doing this manually becomes too high, and because maintenance of terminological systems increasingly becomes a team effort, which further increases the need for structural and reproducible methods[1]. Recently, a special issue of the Journal of Biomedical Informatics was fully dedicated to the auditing of terminological systems in medicine [2].

Second, the adequate use of terminological systems becomes increasingly intricate. Traditionally, terminological systems focused on the task of classification, i.e., determining the most appropriate category or "label" for a patient. Classification brings the challenge of adequately applying the classification rules to determine which category is the most appropriate. In contemporary compositional terminological systems, where the emphasis shifts from mere classification to structured and detailed coding of information, the user needs guidance not only on determining the most appropriate concept, but also on providing necessary and relevant detail. For example, the 2007 release of the 10th edition of the International Classification of Diseases (ICD-10) distinguished 12 categories of viral meningitis, and 4 residual categories (i.e., "other" or "unspecified"). The July 2009 release of the Systematized Nomenclature of Medicine – Clinical Terms (SNOMED CT) [1] contains 29 types of viral meningitis and 4 residual categories (which are likely to be removed from SNOMED CT shortly). As another example, ICD-10 contains 4 categories of acute myocardial infarction, and 2 residual categories; SNOMED CT distinguishes 49 types and 3 residual categories.

Using SNOMED CT for capturing patient information enables multiple uses of the data. For this purpose it is required that data is captured with maximal detail. Consequently, rather than resorting to a generic concept such as acute myocardial infarction, the user must be supported to provide any available detail, while having the possibility of being less specific when information is not (yet) available. In order to assess the amount of detail provided, metrics are needed.

In this paper, the use of information content is explored to measure both the structure of terminological systems as well as the content of records captured using these systems. As an example, these measures are applied to SNOMED CT.

Background

Terminological systems have a variety of structural aspects that influence their quality. Generally, metrics such as number of concepts and number of relationships are presented, but these do not necessarily correlate with quality. Other metrics which related more closely to quality are for example: number of superordinate concepts, subordinate concept, and roots, and number and nature of differentiae [3].

[1] http://www.ihtsdo.org/

Information content is applied to biomedical terminological systems, for example to investigate semantic similarity of concepts in the Gene Ontology [4, 5].

A benefit of these measures is that they can be calculated automatically. However, in the case of number of super- or subordinate concepts, averages or frequencies need to be analyzed to summarize the quality of a terminological system. In the case of the semantic similarity measures, a GO-specific measure was developed, which provides concept-based measures and can not be applied to other terminological systems.

Materials and Methods

SNOMED CT

Today, SNOMED CT is among the largest clinical healthcare terminological systems. The most recent release, of July 2009, contains about 290,000 active concepts. SNOMED CT provides formal definitions for these concepts using about 430,000 IS_A relationships and some 700,000 attribute relationships such as finding site, method, and associated morphology. These relationships serve three purposes: making semantics explicit; automated classification; and allowing post-coordination. SNOMED CT content is organized in a number of categories, such as clinical finding, body structure, and procedure.

Information content

The information content of a concept is a numerical measure of the information that is represented by the concept [6]. The information content of a concept c can be quantified as negative the log likelihood, -log p(c). Generally any base of the logarithm can be used (e.g., 2, e, or 10). In this paper, the $\log_2$ will be used.

For example, when tossing a fair coin, the probability of coming up heads is 0.5, and the information content thereof is 1. Likewise, when throwing a fair die, the probability of throwing 2 is 1/6, and the information content thereof is 2.58. So, a lower probability corresponds to higher information content.

As the above examples show, information content is determined based on actual probabilities. Suppose one has a manipulated die that always results in throwing 6, the information content of a throw is 0, as the probability of throwing 6 is 1.

The fact that information content depends on actual probabilities is a drawback when attempting to determine the information value of concepts in a terminological system. As terminological systems can be used in a broad range of situations, the actual information content may differ. For example, the probability of a person to be of female gender may be about 0.5 in the general population, 0.1 in the army, and 1 in a gynecology department, in which cases the respective information content is 1, 3.3, and 0. To get round this, the probability of coordinate concepts will be regarded as equal, i.e., when a concept has 4 subordinate concepts, each is regarded as having a probability of 0.25, and an information content of 2.

The information content of concepts is used in various ways to provide measures for a terminological system. First, two de-

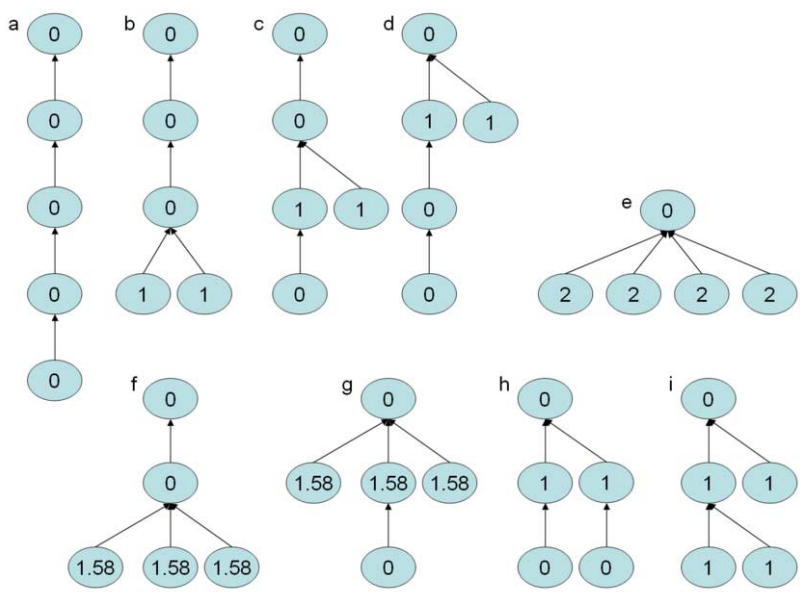

Figure 1- Possible configurations of a rooted mono-hierarchical terminological system with 5 concepts. Arrows denote Is_A relations, ovals denote concepts, and the numbers indicate the information content of the individual concepts.

rived measures for terminological systems are defined which are illustrated by a small example, consisting of 5 concepts, as shown in Figure 1. Then, the use of information content for data in a medical record will be addressed. Finally, the measures will be applied to SNOMED CT. Calculation of these measures was done by importing the text files of the latest releases of SNOMED CT into a database. The basic relational structure that is reflected in the SNOMED CT text files were extended, so that for every content its number of superordinate, subordinate and coordinate concepts could be recorded, as well as the resulting information content.

Measures

Information content as a measure of the structure of terminological systems

Figure 1 shows the possible configurations of a terminological system consisting of 5 concepts. In this figure, all concepts are subordinate to exactly one superordinate concept, apart from the root concept, which has no superordinate concept.

From these straightforward examples, a number of measures can be determined. First, the total and average information content of the terminological system can be calculated. In this example, the total differs between 0 for configuration (a) and 8 for configuration (e). The average (excluding the root concept, which is 0 by default) differs likewise between 0 and 2. As shown in Figure 1, both of the configurations (a) and (e) have hardly any structure, from which it can be concluded that neither a large nor a small value for the total or average information content is preferred. In the examples, concepts with zero information content contribute significantly to the small total values. These concepts are subordinate concepts without co-ordinate concepts (i.e., they are the single child of their parent concept). As stated in [3] "the presence of such cases is reason to suspect the presence of error." In configuration (e), all concepts are co-ordinate. According to [3], when there are a large number of co-ordinate concepts, these concepts "may point to issues such as a lack of organization or incomplete descriptions."

These examples show that information content can provide a measure for the organization of the terminological system. A terminological system which is organized as a full binary tree (in which every node other than the leaves has two children) has an average information content of exactly 1, and can be regarded as a maximally organized system.

The configurations from Figure 1 are all mono-hierarchies, whereas terminological systems such as SNOMED CT are poly-hierarchies, in which concepts can be subordinate to more than one superordinate concept.

Examples thereof are shown in Figure 2. In these cases the information content is calculated from a likelihood which is the division of the total number of superordinate concepts by the total count of co-ordinate concepts, in which any concept that is a co-ordinate concept for multiple superordinate concept count multiple times.

In configuration (a) of Figure 2, one concept has 2 superordinate concepts, which have 1 and 2 subordinates respectively. So the information content is $-\log(2/3) = 0.58$. In configuration (b), the two "leaf" concepts both have two superordinate concepts, each of which has 2 subordinates. So for the leaf concepts the information content is $-\log(2/4) = 1$.

Using these measures, a terminological system can be characterized by the proportion of concepts with zero information content, and the average information content of the other concepts. These measures can also be calculated for parts of a terminological system, thereby providing insight in the structure of sub-hierarchies of the system.

Information content as a measure of the content of medical records

Information content can not only play a role in evaluating the structure of a terminological system, but also in estimating the information content of terminological-system-based data entered into a medical record. As terminological systems such as SNOMED CT should enable multiple use of patient information, data is preferably captured with maximal detail.

To determine the amount of detail a concept provides, rather than the individual information content of a concept, cumulative information content is used. A distinction is made between total and relative information content.

Total information content is the sum of the information content of superordinate concepts up to the root. In configuration (a) from Figure 2, the leaf nodes will have a total information content of 2 and 1.58 respectively.

Relative information content is the sum of information content of superordinate concepts up to a non-root superordinate concept. For example, if one records gender, the information content relative to gender (e.g., "Finding related to biological sex" in SNOMED CT) can be calculated.

Application to SNOMED CT

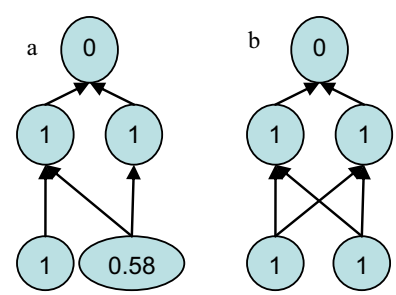

Figure 2- Example configuration of two rooted poly-hierarchical terminological systems with 5 concepts.

The above measures were calculated for the last three releases of SNOMED CT (July 2008, January 2009, and July 2009). To this end, all active non-limited concepts (i.e., those where concept status is 0) were taken into account, and all Is_A relationships between them. Table 1 shows the total number of concepts in each release, the proportion of concepts with zero information content, and the average information content of the concepts that have non-zero information content. Table 2 shows the measures for the 15 largest categories in the July 2009 release of SNOMED CT (based on the category mentioned in the fully specified name). The highest and lowest values for the proportion of concepts without information content and the average information content of the remaining concepts are shown in bold. These figures indicate that the subhierarchy of body structures overall contains relatively small numbers of subordinates per concept. This is indicated by the high proportion of concepts without information content (i.e., which are to only subsumer of a concept) on the one hand, and by the low average information content on the other hand. Conversely, the category "pharmaceutical/biological product" shows have relatively little organization, having many subordinates per concept. It turns out that the 4500 concepts with the highest information content in SNOMED CT are all products, with "Saliva stimulating tablet" having the highest information content of 11.33 (as it has 2580 co-ordinate concepts and 1 superordinate concept).

The "event" hierarchy combines a low proportion of concepts without information content with an adequate structure.

Application to data collected using SNOMED CT

At the department of Intensive Care of the AMC, SNOMED CT is used in a pilot to record reasons for admission to intensive care. This pilot started mid-December 2008. Figure 3 shows for the reasons for admission that were recorded at the Intensive Care of the AMC in the period January-June 2009 their average total information content and their total number of recorded concepts. This figure does not take into account a small number of concepts that were post-coordinated. Figure 3 suggests that the level of detail in which users are recording was stable for the first four months, and dropped thereafter. More data will be needed to see if this reduction is permanent, and further analysis of the data is needed to explain any loss of information content.

Table 1 – Measures for the latest releases of SNOMED CT

Release	# concepts	no content	avg content
July 2008	289028	5.14%	3.79
January 2009	292104	5.05%	3.94
July 2009	289897	5.11%	3.89

Table 2 – Measures for the 15 largest categories in SNOMED CT, July 2009 release

category	# concepts	no content	avg content
Disorder	63841	3.31%	3.79
Procedure	47880	3.86%	4.08
Clinical finding	32836	3.90%	3.43
Organism	31857	8.39%	4.18
Body Structure	26144	**10.27%**	**2.79**
Substance	23621	5.57%	4.61
Pharma/Biol. Product	16879	5.25%	**5.28**
Qualifier Value	8902	3.02%	3.96
Observable entity	7945	6.46%	2.85
Physical object	4420	5.45%	3.19
Morphologic abnormality	4307	3.34%	4.09
Occupation	3842	3.18%	2.88
Event	3579	**2.49%**	2.89
Situation	3090	6.83%	4.23
Regime/therapy	2875	5.36%	3.54

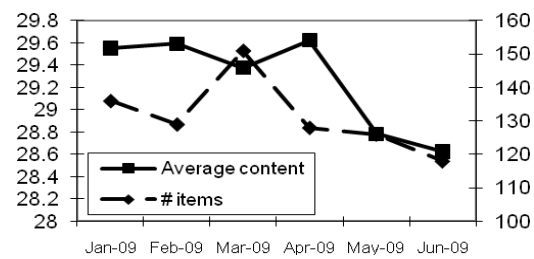

Figure 3 – Average of total information content (left axis) and number (right axis) of reasons for admission recorded at the intensive care unit of the AMC in the first six months of 2009.

Discussion

Information content as a measure of the structure of terminological systems

Two measures were introduced regarding the structure of terminological systems: the proportion of concepts with zero information content, and the average information content of concepts with non-zero information content. These measures provide insight into two complementing structural aspects of terminological systems: concepts without co-ordinate concepts and concepts with large numbers of co-ordinate concepts. These types of concepts are identified as possibly erroneous or ill-defined.

The benefit of these measures is that they can be applied to either a complete terminological system or any part thereof. A drawback of the measure of average information content may be that it is strongly influenced by concepts with large numbers of co-ordinate concepts. As all of the co-ordinate concepts have a large number of co-ordinate concepts, the higher information content is multiplied by the large number of concepts, and outweighs the concepts which have a small number of co-ordinate concepts and hence a lower information content. Further research is needed to determine whether this is actually a drawback, or whether this helps in pointing out areas that need review.

Information content as a measure of the content of medical records

Measuring total or relative information content is especially useful for record items that can be captured with a varying level of detail. This is the case for example when recording findings or procedures, which can be recorded with more or less detail. For example, with increasing level of detail, one can use SNOMED CT to record infective meningitis, bacterial meningitis, Gram-negative bacterial meningitis, Haemophilus meningitis, and thromboembolic meningoencephalitis. As not all detail will be available in any situation, the possibility of recording information with less detail must exist. However, it is useful to analyze whether users generally resort to generic concepts, or try to provide maximal detail. The information content can provide insight in this recording behavior, for example over time, or depending on the way in which information is recorded by users. In a previous study, an analysis was performed on the level of detail in which information was recorded and a comparison was made between free-text recording and terminology-based recording [7]. In that research it turned out that it was generally hard to determine whether one or the other provided more detail due to lack of an adequate measure for that. Figure 3 provides an example of how information content can be used for such purposes.

Further work

This paper applies the measures only to SNOMED CT, which shows that the three most recent releases are relatively constant regarding these measures. Applying the measures to other terminological systems will provide more insight into the results, enabling comparison between terminological systems rather than between versions or specific parts thereof.

Ideally, measures like these are not only calculated for evaluation purposes, but also for providing guidance or prioritization for future maintenance and improvement of these systems. It needs to be determined whether this is practically feasible.

Contemporary terminological systems such as SNOMED CT include other than Is_A relationships. Currently these relationships are not explicitly addressed in the measures presented, but only implicitly, as they are essential for the way in which the hierarchical structure in SNOMED CT is realized, namely by automated classification. However, as these attribute relationships are also important for supporting post-coordination, it would be important to address them. As post-coordination can play an important role when capturing information in a medical record, further research on the measure of information content of recorded data is necessary.

Conclusion

In this paper 2 measures are presented that are based on information content: the proportion of concepts with zero information content, and the average information content of a terminological system. Two other measures are described for the content of medical records that is captured using a terminological system: total and relative information content. Benefits of these measures are that they can be relatively easily calculated, and are grounded in information theory.

The measures are useful as an indicator of the overall structure of terminological systems or parts thereof. Information content is shown to provide a useful basis for assessing the structure of terminological systems and the content of medical records.

Quantifying the level of detail in which information is captured in a medical record is a first step towards assessing the quality of recorded data.

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Development of Structured ICD-10 and its Application to Computer-Assisted ICD Coding

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Abstract

This paper presents: (1) a framework of formal representation of ICD10, which functions as a bridge between ontological information and natural language expressions; and (2) a methodology to use formally described ICD10 for computer-assisted ICD coding. First, we analyzed and structurized the meanings of categories in 15 chapters of ICD10. Then we expanded the structured ICD10 (S-ICD10) by adding subordinate concepts and labels derived from Japanese Standard Disease Names. The information model to describe formal representation was refined repeatedly. The resultant model includes 74 types of semantic links. We also developed an ICD coding module based on S-ICD10 and a 'Coding Principle,' which achieved high accuracy (>70%) for four chapters. These results not only demonstrate the basic feasibility of our coding framework but might also inform the development of the information model for formal description framework in the ICD11 revision.

Keywords

ICD10, Ontology, Knowledge bases, Natural language processing, Computer-assisted coding

Introduction

The World Health Organization (WHO) officially launched the 11th revision of the International Classification of Disease (ICD) in April 2007 [1]. One important planned feature of ICD11 is structurizaton of the clinical meaning of each disease category to provide formal representations of ICD categories to describe the characteristics of each disease in various dimensions such as Etiology, Anatomic site, Manifestation attributes, and Pathophysiology. Figure 1 shows a possible formal representation of 'Venezuelan equine encephalitis (A92.2).' The meaning of the disease concept is represented as a tree-structure using two component concepts (*CC*) (e.g "Encephalitis") and semantic links of two types (e.g. "<hasCause>").

The structurization process might have several levels of granularity, but such a formal representation of ICD will be useful for advanced information retrieval systems. It is anticipated as a useful knowledge base for computer-assisted ICD coding.

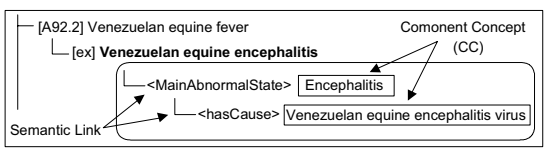

Figure 1 – Simple example of 'formal representation'.

Computer-assisted ICD coding (or Automated ICD coding) has attracted attention continuously since the 1990s. Although several studies have sought to represent ICD categories formally and to use it for ICD coding [2–8], their framework and information models for formal representations were insufficient to cover all ICD categories because they investigated only a few domains. For example, Héja et al. [6,7] developed an information model to describe ICD categories using six concept categories and semantic links of five types. However, they analyzed only two chapters. Moreover, it is not clear that such a small information model is applicable to all chapters. No comprehensive information model has included the complete list of semantic links to describe all ICD categories.

In addition, the ICD coding frameworks in those studies did not consider distinctions among concepts and their string expressions (labels). Fundamentally, the first step to perform ICD coding is to map input strings to *CCs*. However, that is not always possible because of an omission or an abbreviation. As might be apparent, no substring of the input disease name "*Venezuelan equine encephalitis*" can be mapped directly to the CC in Fig. 1 – "*Venezuelan equine encephalitis virus.*" A new methodology to address mapping between concepts and string expressions is needed to improve coding results.

This study has two major goals. The first is to develop a structured ICD10 ('*S-ICD10*'), which functions as a bridge between ontological information and natural language expressions, based on a robust and comprehensive information model that can cover all ICD categories. The second is to develop a methodology to use S-ICD10 for computer-assisted ICD coding.

Materials and Methods

Development of S-ICD10

Step 1): Structurizing the ICD10 Tabular List

First, 20 Japanese ICD coders manually analyzed the ICD-10 book (Volume 1: Tabular List, 2003 Japanese edition) and described formal representations for all ICD categories and example entries in 15 chapters (excluding Chps. 5, 15, 16, 18, 20, 21, and 22). It is noteworthy that Chps. 20, 21 and 22 are additional information, so the number of main chapters in ICD10 is 19. As Fig. 2 shows, each ICD category and an example entry has at least one formal concept representation (hereinafter '*FCR'*) represented as a tree structure, and each semantic link has cardinality information. The main tasks in this step were: (1) to identify CCs from the title of each category; and (2) to assign semantic links to CCs to form tree representations. Two Japanese medical and ontology experts reviewed all results. If at least one disagreed with the result, then the information model and the list of all semantic links were reconsidered; all descriptions were revised based on the new information model. We started this project in 2005. These iterative revisions were repeated three times.

Step 2): Expanding S-ICD10 and adding labels

Step 1 includes no distinction between CCs and their labels. Therefore, in this step, we separated those labels from CCs and assigned additional labels derived from Japanese Standard Disease Names (*JSDN*) [9] to S-ICD10. The 25,280 disease names in JSDN were manually parsed (every disease entry in JSDN has a proper ICD10 code); the 20 annotators (same as step 1) assigned each token—a morpheme or substring of each disease name—to the corresponding FCR as one of the following types: (1) *a direct label of CC(s)*; (2) *a label of subordinate concept of CC(s)*; and (3) *a label of an additional CC of the FCR.* For example, in Fig. 1, we assigned the label '*Venezuelan equine*', as a direct label of CC *[Venezuelan equine encephalitis Virus]*. It means that the string '*Venezuelan equine*' can indicate the CC under a certain context, even though the string itself is not a virus name. Regarding M254 in Fig. 4, a new concept *'[Knee Joint]'* together with its label '*Knee Joint*' was added to the CC *[Joint]*, as its subordinate concept; a new concept '*[Swelling]*' together with its label was also added to the FCR as an additional CC with cardinality '0..1'. These new concepts were derived from disease entries in JSDN that have the 'M254' ICD code.

This step was very important to perform ICD coding. ICD10 is a classification system and each ICD category is an aggregation of diseases. Therefore, component concepts of an input disease are sometimes more granular than CCs of ICD entries. Two experts (same as step1) reviewed the results obtained in this step. Furthermore, in cases where they did not agree, the annotation result was excluded. Results show that approximately 85% of all tokens in JSDN were included in the expanded layer of S-ICD10.

Automated ICD coding framework based on S-ICD10

Overview of our coding framework

Figure 2 depicts an overview of our coding framework. The coding module leverages a Japanese general tagger called YOMOGI, which we developed in 2007, for tokenizing an input disease name based on the label set in S-ICD10.

First, YOMOGI outputs *N*-best tokenization of an input disease name. Each token has corresponding CC(s) in S-ICD10. However, some tokens might correspond to various CCs in different ICD categories. For example, as shown in Fig. 2, an input disease name was tokenized into four tokens, and the token '*universal*' corresponds to a label of the CC in B007, D65, K650, L631, and so on. The system then considers all possible combinations of corresponding CCs and selects one which best covers a certain ICD code. As Fig. 2 shows, the system regarded "*universal*" as a label of CC in D65:ex3/ D65 and "*blood*" as a label of CC in D50–D89, because both D65 and D50–D89 are upper categories of D65:ex3.

Finally, the input disease is mapped to the ICD entry 'D65:ex3'; the system then outputs its ICD code (D65).

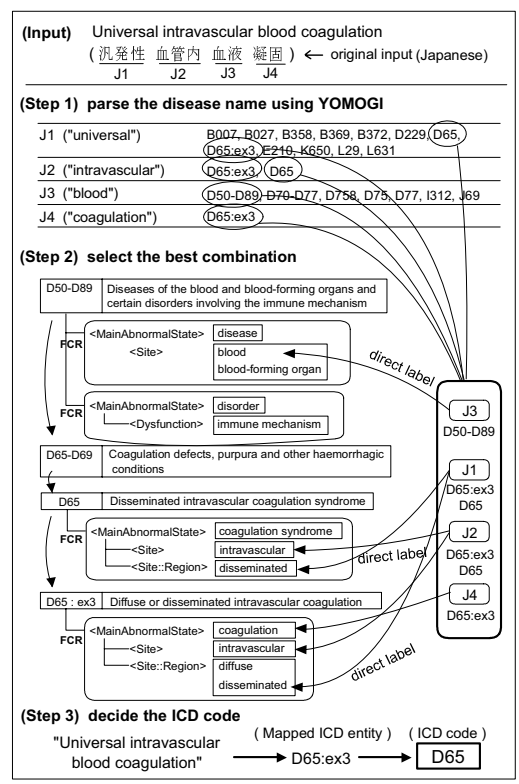

Figure 2 – Overview of our coding framework.

'Coding principle'

In the coding process, the system uses a '*Coding principle*' to decide ICD codes. From the ontological perspective, 'Concept B' is a child concept of 'Concept A' if: (1) every CC in 'Concept B' is the same as or the specialization of the corresponding CC in 'Concept A'; or (2) some additional CCs exist aside from the condition explained above, as shown in Figure 3.

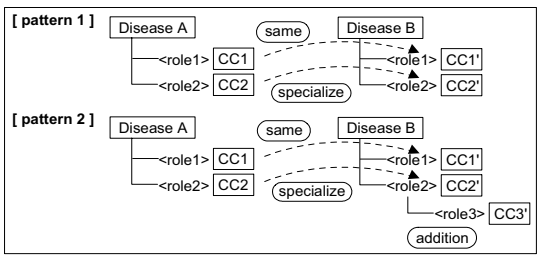

Figure 3 – Is-a relations between two concepts.

However, those rules are too strict for ICD coding purposes. In Fig. 4, the "*swelling*" label in the input string was mapped to the CC in M254; the "*knee joint*" label was mapped to the subordinate concept of the CC in M254. However, not all CCs in M254 were covered by the input string, although the input disease concept is fundamentally a child concept of M254. Therefore, we cannot apply the [pattern1] rule in Fig. 3 to this case. We used a *'Coding principle'* to solve this problem—"An input disease has the ICD code 'X' if every token in the input disease can be mapped to: (1) CC in X; (2) subordinate concept of CC in X; or (3) CC that can be inherited from ancestor categories of X". This '*Coding principle'* does not require that all CCs in X whose cardinality is one or more be covered by the input disease name. In that sense, it is a weakened condition of two patterns in Figure. 3 for coding purposes.

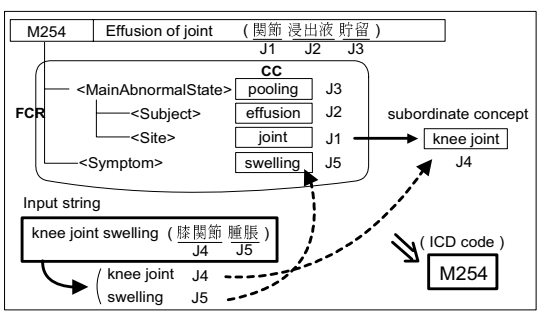

Figure 4 – Label mapped to a subordinate concept of CC. (where J1-J5 denote Japanese tokens)

If an input disease name cannot satisfy the Coding Principle, then the system outputs ICD code candidates according to the coverage ratio (# of tokens satisfying the Coding Principle / # of total tokens). The system outputs nothing in cases where the coverage ratio is low (< 50%).

Evaluation on the ability for ICD coding

To investigate the performance of the proposed coding framework, we evaluated the capability for ICD coding based on S-ICD10 and the '*Coding principle*'. We randomly chose 1,255 disease names collected from various hospitals in Japan and coded them manually. Entries present in Japanese Standard Disease Names (JSDN) were excluded beforehand because S-ICD10 had already included knowledge derived from JSDN.

Results

S-ICD10 and the information model to describe FCRs

Table 1 – Categorization of all semantic links

Category	Type of semantic link	# of ST	Freq.
Pathophysiology	Main Abnormal State	-	13,111
Site	Has Site	2	8,411
	Related Site	-	54
Cause	Cause	1	4,146
	Modifier of Cause Entity	2	4
	Cause-related	5	91
Function	Dysfunction	-	247
Temporal Relation	Features of Occurrence	-	298
	Progress/ Timing/ Age	-	1,110
Symptoms/ Findings	Symptoms/ Findings	1	1,428
	Modifier of Symptoms/ Findings	6	71
Specification of other items	State	11	545
	Treatment-related	2	2
	Type	3	152
	Route/ Mode of intake	2	10
	Certainty	3	3
	Others	7	35
Subject of others	Subject	2	565
Examination/ Diagnosis	Mode of confirmation	-	81
	Diagnostic method	-	1
Relation to other disorders	-	11	1,899
Other	-	9	66

15,221 ICD entries (categories and examples) in 15 chapters were structured. S-ICD10 has 15,463 FCRs, 55,453 CCs (20,320 unique CCs), and 81,478 labels (39,164 unique labels) in total. The information model to describe FCR includes 74 types of semantic links. Table 1 shows a categorization of all semantic links.

Each type of semantic link might have sub-types (the third column shows the number of sub-types). For example, the type 'State' includes 11 sub-types of semantic links, such as 'Shape', 'Benign/Malignant', 'Atypia', 'Severity', 'Quantity', and 'Grade of Progress'. The category 'Relations to other disorders' includes 11 sub-types, such as 'Complication', 'Underlying disease', 'Follow', and 'Sequela'. The fourth column shows the frequency of the semantic link. For example, the semantic link 'Diagnostic method' was used only once in the formal representation of 'I252:ex2' – "*Past myocardial infarction diagnosed by ECG or other special investigation, but currently presenting no symptoms.*"

Automated ICD Coding

Table 2 shows results of automated ICD coding. Overall, 61.7% (747/1211) disease names were coded correctly. The best result (76.4%) was Chapter 7 (Diseases of the eye and adnexa); the worst (46.2%) was Chapter 4 (Endocrine, nutritional and metabolic diseases). We excluded diseases of four chapters (5, 15, 16, and 18) because S-ICD10 does not cover them. However, diseases from those excluded chapters were only 44 (total = 1,255). Therefore, if those categories are included later, they will little affect the overall result.

Table 2 – Automated coding results

Ch	#C	#N	*R*(%)	Ch	#C	#N	*R*(%)
01	72	28	72.0	10	32	13	71.1
02	61	56	52.1	11	35	30	53.9
03	19	20	48.7	12	109	47	69.9
04	42	49	**46.2**	13	37	30	55.2
06	32	12	72.7	14	46	24	65.7
07	29	9	**76.3**	17	26	17	60.5
08	15	8	65.2	19	144	82	63.7
09	48	39	55.2	**Total**			**61.7**

Note: Ch, Chapter No.; **#C**, # of correctly coded diseases; **#N**, # of non-coded diseases; ***R*(%)**, the ratio of #C).

Discussion

Disease description framework

The S-ICD10 result description process showed that all ICD entries, at least in 15 chapters (of 19 main ones), can be represented formally using our information model to describe FCR. The information model based on the categorized list of the semantic link types shown in Table 1 is much more granular than in any previous study. Many newly found semantic link types were indispensable for formal representation of ICD categories, showing the importance of comprehensive analysis.

Some semantic links must be refined for further development toward more sophisticated ontological representation of ICD10. Also, a '*Subordinate'* relation should be separated into '*Is-a*' and '*Part-of*' relations from an ontological perspective. Consequently, we call it '*Structured*' ICD-10, not '*Ontology*'.

Nevertheless, the information model is useful for development toward ontological representation. It might inform the ICD11 revision project as a pilot study to create a comprehensive information model to describe ICD categories formally.

Computer-assisted ICD coding

As for the ability for ICD coding, although it is difficult to compare results among coding systems which use different test sets, the overall accuracy (61.7%) is similar to the best result among previous studies [13] and much better than other previous results. The system achieved high accuracy (>70%) for four chapters, but the accuracies of Chapter 3 and 4 diseases were low. The main reason is the lack of subordinate concepts, especially in anatomical entities. We added many subordinate concepts and labels derived from JSDN. However, JSDN had insufficient information to cover all disease names collected from various hospitals in Japan. A possible solution is the use of semantic relations between anatomical entities defined in other ontologies such as FMA and SNOMED-CT.

The system outputs other ICD codes along with the correct one in cases where candidates have equal scores (coverage ratios). We counted those cases as 'correctly coded' in the evaluation study because it is apparently easy for human coders to select the correct code from those candidates in later screening. The system can also output the reason for the coded result, showing the mapping result between tokens in the input disease names and CCs, which will be helpful for later screening.

The overall accuracy decreases to 34.8% if we do not use the 'Coding Principle' and perform ICD coding based on simple matching between an input and FCR. The 'Coding Principle' is important in terms of: (1) using information (CCs) inherited from the upper categories: and (2) allowing the case in which not all CCs of a certain FCR are covered. This important feature of our coding framework enables us to address the case in Fig. 4, which the previous knowledge representation-based approaches could not cover.

Related works

Substantial efforts have been made for automated or computer-assisted ICD coding to date. They are classifiable into two types: (A) using disease names or clinical notes, which already have correct ICD codes, to calculate similarities by statistic measure (***'example-based'***) [10–13]; and (B) using formal representation of ICD categories to describe coding rules (***'knowledge representation-based'***) [2–8].

Type-A methods can be implemented easily, but they have not shown high accuracy. The coding systems require numerous examples to achieve better results. However, it is difficult to collect them evenly. Some ICD codes have no coded example.

Moreover, it cannot provide explanation capability, which is useful for later screening by human coders.

On the other hand, Type-B methods present advantages to provide explanation capabilities. However, developers must describe vast amounts of knowledge. Therefore, previous studies only proposed designed framework or implemented the system in a small limited domain. Our framework is also 'knowledge representation-based'. However, it differs from other Type-B studies in the following respects: (1) our project achieved high coverage (15 of 19 main chapters), and our information model representing ICD10 categories is considered highly robust; (2) 'concepts' and their 'labels' are distinguished explicitly so that S-ICD10 can work as a bridge between ontological information and natural language expressions; (3) our coding framework uses the 'coding principle', which allows property inheritance and weakened conditions of concept subsumption.

Limitations and future directions

The S-ICD10 covers most chapters, but some, such as 'Mental and behavioral disorders (Chap. 5)' have not been addressed. The information model to represent disease concepts might not be sufficient to cover all disease concepts in ICD10. We plan to apply our methodology to the remaining four chapters and to produce a more comprehensive formal representation of ICD10. We also plan to map all concepts (CCs) and labels to the current existing terminologies and ontologies such as SNOMED-CT, GALAN, FMA, and Japanese Medical Ontology, and to create an English version of S-ICD10.

Conclusion

This paper presents: (1) a framework of formal representation of ICD-10, which functions as a bridge between ontological information and natural language expressions; and (2) a methodology to use S-ICD10 and the '*Coding Principle*' for computer-assisted coding. The results demonstrate the effectiveness of our framework. In fact, S-ICD10 has unprecedentedly high coverage of all ICD10 categories. The resultant information model to describe formal representation of ICD categories might inform ICD11 revision as a pilot study.

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Design and evaluation of a semantic approach for the homogeneous identification of events in eight patient databases: a contribution to the European EU-ADR project

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Abstract

The overall objective of the EU-ADR project is the design, development, and validation of a computerised system that exploits data from electronic health records and biomedical databases for the early detection of adverse drug reactions. Eight different databases, containing health records of more than 30 million European citizens, are involved in the project. Unique queries cannot be performed across different databases because of their heterogeneity: Medical record and Claims databases, four different terminologies for coding diagnoses, and two languages for the information described in free text. The aim of our study was to provide database owners with a common basis for the construction of their queries. Using the UMLS, we provided a list of medical concepts, with their corresponding terms and codes in the four terminologies, which should be considered to retrieve the relevant information for the events of interest from the databases.

Keywords:

Drug toxicity, Semantics, Medical records, Indexing, Information storage and retrieval, UMLS.

Introduction

The medical information gathered during clinical follow-up can be reused for a wide variety of related purposes from medico-economic and epidemiological applications to clinical alerts [1, 2]. This information, collected at every stage of the healthcare process, is often registered as free text and is increasingly coded by using one or several specific medical terminologies. Though time-consuming, choosing an appropriate code to describe medical information has the advantage of clarifying unambiguously the significance of the information. Information coding allows automated processing of the information and facilitates semantic interoperability between different information systems. Medical information with appropriate coding can be transmitted, interpreted and processed more easily by different systems and thus enables sharing and reuse of the data among information systems [2, 3].

In the area of drug safety, information sharing could enhance the current spontaneously reported information on adverse drug reactions (ADRs), as reporting rate is far from optimal. Underreporting is high, and it is estimated that only 4% of ADRs are reported through this channel [4]. Therefore, safety signals may be detected too late, as was recently highly debated after the rofecoxib (Vioxx®) withdrawal due to concerns regarding cardiovascular safety. It has been recognized that additional complementary systems are necessary [5, 6], which could profit from the wide availability of health care databases throughout Europe. The use of several medical databases for signal detection could overcome the underreporting problems existing with the current system and may detect signals faster and/or earlier.

From this rationale, the European EU-ADR project has been launched. The aim of this project is to design, develop and validate a computerised system to process data from eight electronic healthcare databases and biomedical knowledge databases for the early detection of safety signals [7]. Each of the eight healthcare databases contains information which is coded according to different terminologies, in different languages, and has its own specific characteristics, depending on its initial objective and local function (administrative, healthcare, medical records, etc.) [2]. Given the structural and semantic heterogeneity of the databases involved in the project, it is impossible to construct a single, completely reusable query system on the different databases, to undertake the same search for each event and drug.

Objective: The aim of this research was to provide a method for extracting relevant information contained in the various databases regarding the event under study and the drugs taken in the population. Our task also entailed a search for greater coherence to enhance our method of extracting information from the different databases. The method described was evaluated through a process using analogy as a logical tool.

Materials and Methods

Concept selection

Different terminologies are used to code the clinical events in the eight databases. Thus, a common basis was required in order to set up queries (adapted to target databases) built-on a shared semantic request. The aim was to provide researchers with a list of medical concepts and associated terms that they must use to identify the events being investigated in their respective databases. A unique query cannot be performed to extract information from the databases used since, intrinsically, different terminologies are used. We built a shared semantic foundation for the eight databases[8]. The constituents of this shared foundation are UMLS[9] concepts (grouping together terms from different terminologies with the same medical meaning) and not terms.

Medical terminologies are structured in the form of lists of concepts[1], generally set out in a hierarchical way. A concept can be defined in many ways since the terms[2] defining it come from different languages and, furthermore, because each language can use distinct synonymous terms to describe the same concept.

The eight databases involved in the EU-ADR project contained information stemming from the medical files of more than 30 million European citizens (Table 1). Four terminologies are used to describe the events: the «international statistical classification of diseases and related health problems» (ICD9-CM and ICD10), the «international classification of primary care» (ICPC) [10] and the READ CODE (RCD) classification[11]. Seven databases use the Anatomical Therapeutic Chemical (ATC) system[12] to code drugs. In the QRESEARCH database, drugs are initially coded using the British National Formulary (BNF) [13], but a mapping between the BNF codes and the ATC classification has been established by the QRESEARCH team. The Unified Medical Language System® (UMLS®) [14] is a biomedical terminology integration system handling more than 150 terminologies. The four terminologies used in the EU-ADR project are integrated in the UMLS. The Metathesaurus® consists of a central vocabulary comprising roughly 1.8 million concepts connected by more than 3.75 million relations. A UMLS concept is identified by a Concept Unique Identifier (CUI) and describes a single medical concept that can be expressed using different synonyms (terms).

To develop our method, we initially studied the event «upper gastrointestinal bleeding» (UGIB) which has a complex medical definition and thus raises difficulties when searching for it in a standardised way in databases. A similar approach is used for the other twenty-three events that have been identified to be of primary importance in the EU-ADR project [7].

Our method is based on the projection of UMLS concepts in the targeted terminologies. The whole method consists of the following: 1) literal definition of event, 2) identifying the UMLS concepts for the event; 3) discussion about concepts with database's administrators; 4) term identification for each concept in each terminology.

Regarding step 1, a «broad» definition approach was initially adopted. The definitions were drawn from clinical reference manuals and were validated by gastroenterology specialists.

Regarding step 2: for each literal expression matching the inclusion criteria listed in the definition of the event, we performed an automated search using Knowledge Source Server (UMLSKS, version 2008AA), in order to identify the UMLS concept and all the terms used to designate the concept in the four terminologies of the project. When this automated search failed to identify terms corresponding to a given concept in one of the terminologies studied, we undertook a manual search in the concerned terminology to identify the potential terms of interest.

In step 3, database's administrators were asked to follow their 'usual approach' to query their databases and compare the criterions they have used with the concepts and terms provided at the step 2 issue. The relevance of each concept, term and corresponding code were discussed via the EU-ADR consortium Internet forum, conference calls and plenary meetings. Thus a consensual list of items (codes, terms and free text expressions) was set up.

[1] A concept is a unit of thought [ISO 5963]

[2] A term is the designation of a given concept in a language in its linguistic formulation [ISO 1087]

Table 1- Description of the eight databases

Database	Terminology		Free text	Type of data*	Patients†
	Event	Drug			
Pedianet – Italia (ITA)	ICD9-CM	ATC	yes (ITA)	EHR	C
Health Search (ITA)	ICD9-CM	ATC	yes (ITA)	EHR	A/C
Lombardy Regional DB (ITA)	ICD9-CM	ATC	no	SDC, D	A/C
Tuscany Regional - ARS (ITA)	ICD9-CM	ATC	no	SDC, D, L, M	A/C
IPCI – Netherlands (NL)	ICPC	ATC	yes (NL)	EHR	A/C
PHARMO (NL)	ICD9-CM	ATC	no	SDC, P,L, M	A/C
QRESEARCH United Kingdom (UK)	RCD	BNF/ATC	no	EHR	A/C
Aarhus University Hospital DB (DK)	ICD10	ATC	no	SDC, D, L, M	A/C

*EHR (Electronic Health Record), SDC (Standardized Discharge Codes), D: Dispensation, L: Laboratory, M: Mortality, P : Prescription. † C: Child, A : Adult

In step 4, the list of items from different terminologies and languages were provided to the databases administrators. Every listed item had necessarily to be present in their query. The list of items that we provided was non-restrictive. Database administrators were free to add all additional criterions/terms that they would consider relevant in order to recover the UGIB event from their database, providing that these criterions offered a new way of describing the selected concepts. Hence, when a given code had "children" (i.e. a more accurate description), the query also had to include the "descendants" of this code that were considered relevant for the retrieval of the information.

Evaluation process

To evaluate this semantic-based method, we needed a knowledge source that could confirm that the events retrieved by the databases administrators correspond really to UGIB. Unfortunately, manual evaluation on a sample of events is a lenghty and expensive process that is not scheduled in the EU-ADR project. On the other hand, we found that sensitivity of the semantic-based method could be estimated in a fast, albeit indirect, way. By exploring the MEDLINE National Library of Medicine's (NLM) database. As in the patient medical records, the full-text versions of the articles indexed in MEDLINE include medical concepts. The MEDLINE notices created by the NLM indexers can thus be considered by analogy as discharge summaries where an effort of selecting an appropriate MeSH code to resume the full content is done. A subset of the MEDLINE database, identified through a classical Pubmed search, can then constitute a validation set. The sensitivity of the search methodology for the UGIB events could be evaluated by performing the search through the MEDLINE notice. The manual examination of the full-text versions of the articles included in the identified subset constitute the "gold standard" for the assessment of the presence of UGIB events in the indexed papers. In order to constitute the validation set using the Pubmed website, we entered the query "upper gastrointestinal bleeding" with the limits: "links to free full text" AND "Humans" AND ("English" or "French"). Using the "Humans" descriptor restricted the selection to notices with MeSH descriptors and then avoids the notices not yet indexed in MEDLINE. Restriction to English and French languages was due to the language expertise of the workgroup performing the manual examination. A random selection of 20% of the notices was done. We then examined the full-text versions of the selected papers to confirm that the notion of UGIB was present.

We compared three methods for retrieving the event UGIB within the notices validation set. The two first ones were initial methods written by the database owners of Lombardy (in ICD9-CM) and Aarhus (in ICD10) and the last one was our proposal.

Because the MEDLINE database is coded in MeSH terms, we first had to translate the ICD9-CM and ICD10 codes used by database owners into MeSH terms. Several steps were conducted: 1) we used the UMLS Metathesaurus to recover the UMLS CUIs associated with the ICD9-CM and the ICD10 codes; 2) we used the tool developed by Bodenreider[3] [15] to obtain only MeSH codes from the resulting CUIs. 3) we extracted the English preferred term for each MeSH code in the Metathesaurus (because there is no MeSH codes in MEDLINE, only the preferred terms); 4) Finally, we checked, for each of the three methods, the ratio of the notices retrieved (within the validation set, our gold standard) when using MeSH terms previously obtained. We then computed the retrieval sensitivity in our subset test of MEDLINE notices.

Results

Concept selection

For the event UGIB, a broad clinical definition was created including the following conditions: Upper gastrointestinal

[3] http://mor.nlm.nih.gov/download/rtm

haemorrage, Oesophagal haemorrage, Gastrointestinal haemorrhage, Bleeding from peptic ulcer, Haematemesis/blood vomiting and Melaena. We then devised a table listing all the UMLS concepts matching the inclusion criteria. Upon evaluation of the usual behaviour of the databases and the provided concepts, the concepts and terms were adapted. These included: *Upper gastrointestinal hemorrhage, Gastrointestinal Hemorrhage, Hematemesis, Melena, Esophageal bleeding, Acute {gastric|duodenal|peptic} ulcer with hemorrhage (and/or) perforation, Acute gastrojejunal ulcer with haemorrhage, without mention of obstruction, Acute gastrojejunal ulcer with hemorrhage and perforation, Acute gastrojejunal ulcer with hemorrhage, Atrophic gastritis, with haemorrhage, Other specified gastritis, with hemorrhage, Unspecified gastritis and gastroduodenitis, with hemorrhage, Acute gastric mucosal erosion.*

Subsequently all codes and terms were provided. As an example, the concept *"Haematemesis"* is coded "578.0" in ICD9-CM, "K92.0" in ICD10, "D14" in ICPC and "J680" in RCD. Some of the corresponding terms (useful for search in the clinical notes that are registered as free text) are as follows: "Ematemesi/vomito sanguinolento" in Italian, "Bloed; braken" in Dutch, "Haematemesis/vomiting blood" in English, etc.

Evaluation process

We performed a broad search on Pubmed, looking for possible citations of a wide set of gastroenterological disorders. From the resulting 1,044 MEDLINE citations, we extracted a random selection of 20% of them (n=208), only 199 of which were working with Pubmed LinkOut (the internet link to retrieve full-text articles). After full-text revision, we classified 151 articles as containing the UGIB notion. So 48 articles did not contain the UGIB notion but other medical notions (lower GIB for example). These 151 notices constitute the test set for our evaluation of the three extraction methods. The number of notices retrieved by each method is described in Table 2. Our proposal of a common semantic base method retrieved 107 notices out of a total of 151 notices with the event UGIB present in the full-text. The sensitivity is the percentage of retrieval in our subset test of MEDLINE (not in all MEDLINE).

Table 2 - Number of notices retrieved for each method

	Gold Standard: presence of UGIB in Full text article	**Sensitivity (%)**
Lombardy's initial method	100	*66.2*
AARHUS's initial method	108	*71.5*
Common Semantic based method	107	*70.9*
Total	**151**	

As a result, we can observe that the common semantic-based method is nearly as sensible as the better between the other two, that is, Aarhus accepting to delete some of its customary concepts on the ground of homogeneity with other databases did not lead to a dramatic fall in sensitivity, whereas Lombardy's sensitivity improved.

Discussion

The process we implemented allowed the homogeneous identification of events in various European databases. It is based on UMLS concepts. This foundation enabled us to propose a list of terms along with their codes and strings in order to standardise queries and, thus, extractions from the eight databases participating in the EU-ADR project. The discussion and harmonisation process led to additional concepts to be included in the list, the definite version included a total of 21 potentially usable concepts for the coding of the UGIB event in the databases. The databases were heterogeneous regarding the terminology used, the presence, or not, of free text data (used in two languages: Italian and Dutch), and the type of data they contain (medical record and claims databases). The UMLS may be helpful to map between these heterogeneous databases and to promote semantic interoperability among these databases. The sensitivity of the retrieval in our validation set is estimated by an analogy method to be around 70%, similar to those of initial queries from the participating databases.

Our process creates an homogeneous set of relevant terms/expressions useful for requesting heterogeneous databases, but does not exhaustively describe the event extraction. First, databases with free-text must perform a local algorithm, based on local information, that avoids ambiguities in the use of free-text. Second, databases with hospital discharge records must agree on whether looking for the UMLS concepts only in primary or also in secondary diagnosis fields. Third, all databases must specify in which health sources they are looking (e.g. only hospitalizations *or* both hospitalizations and deaths). Finally, some health sources contain information that is not corresponding to UMLS concepts: for example, the use of laboratory test results involves identifying a concept by its biological results and not by its name or its place in a nosologic description, and this identification might be crucial for some events (e.g. acute kidney failure). A more detailed terminology mapping instrument must be developed that further describes event extraction.

When common concepts are translated into database-specific codes, it is important to consider when analysing results that each database is confined to the granularity of its terminology. SNOMED CT for instance, can be coded by the user with a high level of granularity whereas ICD is much less granular. Hence, the level of information acquired is not always identical.

Concerning the evaluation process, the analogy between a medical doctor summarizing apathology in a clinical or claim database and a NLM indexer which selects the appropriate code to resume the full content of an article is new and needs confirmation. Secondly, the projection from ICD9-CM or ICD10 codes to MeSH terms could result in some classification bias, according to the numerous steps of the process. In order to compare the three methods, we used the same projec-

tion process. The different biases should then have affected equally the different methods. The EU-ADR workgroup selected 21 concepts for the search of UGIB. To create the selection of citations for the gold standard, we had to work on a small subset of MEDLINE focusing on gastroenterological disorders and to examine the full-text versions of the articles from this subset for the presence of UGIB. We decided to use only the concept "upper gastrointestinal bleeding" and to select only a sample of the relevant papers for the evaluation of the identification of the event UGIB. This does not constitute a major issue as our objective was not to determine the prevalence of the event UGIB in MEDLINE, but to constitute a validation set for our method. .Remark that the same technique cannot be used to estimate the specificity of the common semantic-based method because one can not have the confirmation of absence of the concept UGIB in the full text version of the articles indexed in MEDLINE and not identified by a classical Pubmed search for UGIB.

Conclusion

The projection of UMLS concepts in the terminologies and the additional manual adjustments have been exploited for the four terminologies used in our study. This enabled us to provide a shared semantic basis for the creation of queries adapted to the heterogeneous electronic health record databases we exploited. The list of concepts, accompanied by the list of associated codes, and strings in free text text (where applicable) have been used by the database administrators as a base to build queries designed to retrieve information from their database using the appropriate terminology. We provided evidence that the homogenization of concept selection does not worsen the sensitivity of each database. This method will be used for the other events selected for the EU-ADR project. The extraction of the same medical concepts from the eight databases will enable biostatisticians working on the project to use comparable data from different databases, with respect to the definition of the events sought despite of the high level of heterogeneity between the databases.

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The ObTiMA System – Ontology-based Managing of Clinical Trials

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Abstract

Clinical Trial Management Systems promise to help researchers in managing the large amounts of data occurring in clinical trials. In such systems Case Report Forms for capturing all patient data can usually be defined freely for a given trial. But if database definitions are automatically derived from such trial-specific definitions then the collected data cannot be easily compared to or integrated into other trials. We address this interoperability issue with an approach based on ontology and semantic data mediation. This resulted in the development of the ObTiMA system which is composed of a component for setting-up clinical trials and another for handling patient data during trials. Both components offer data reusability by relying on shared concepts defined in an ontology covering the whole cancer care and research spectrum.

Keywords:

Clinical trial management system, Application ontology, Semantic data mediation.

Introduction

Clinical Trial Management Systems (CTMS) promise to help researchers in hospitals and biotechnology/pharmaceutical companies to better manage the tremendous amounts of data involved when conducting clinical trials [1]. Their goal is to simplify and streamline the various aspects of clinical trials, such as planning, preparation, performance, and reporting, by providing functionalities, like automatic deadline tracking for legal or regulatory approval, progress report issuing, keeping participant information up-to-date, or import/export data from/into other clinical information systems. For example, it is still a common yet tedious and error-prone practice to collect data at each trial site on paper-based Case Report Forms (CRF) and then to enter them manually into the trial database at the trial center. CTMSs are supposed to avoid this by providing user interfaces that blend into clinical work settings and shield users from underlying data and system complexity.

But as standardized, commercial CTMSs are not yet widely deployed, trial databases and their entry interfaces are often developed in-house specifically for a given trial and therefore not readily reusable in other trials. This issue causes an additional reimplementation burden and makes it difficult to compare or integrate data between different trials. But even if CTMSs are used, the following issue remains unresolved: Those systems allow a user to freely define the CRF items and structures without the need of any informatics skills. But although this is very desirable, it can create the same interoperability problems. If a database is derived from the trial-specific CRF definitions, the database in turn is again also trial-specific and data reuse in further research stays problematic. Thus, our work focuses on solving this interoperability issue through an approach based on ontology and semantic (data) mediation.

This work has resulted in the development of the Ontology-based Trial Management Application, or *ObTiMA* for short. Its development started as part of the European Union project *ACGT* (Advancing Clinico-Genomic Trials on Cancer) aiming at creating an open, semantic and grid-based technology infrastructure to support clinicians and scientists in post-genomic clinical trials in cancer research [2]. Its development continues now in the European Union project ContraCancrum intended to develop a platform for simulating tumor development and response to therapeutic modalities to optimize the disease treatment procedure in a patient's individualized context [3].

An early ObTiMA prototype was presented in [4]. Here we describe the current state of its development. To this end, we first cover the ontology and semantic mediation as the basis of the data management in ObTiMA. Then we describe the two main components of the system: the Trial Builder for designing clinical trials and the Patient Data Management System for handling patient data within a trial. We conclude by referring to related research and how ObTiMA is now being evaluated.

Relevant ACGT Components

The advent of innovate technologies, like high-throughput screening or pharmacogenomics, has lead to the creation of new data on a previously unknown scale. However, tools to automatically analyze these data are still missing or not yet in an applicable stage. This is the core issue ACGT wants to

solve by developing a unified technology infrastructure to facilitate seamless, secure access to clinical and genomic data: High-performance knowledge discovery techniques are being created to support multi-centric, post-genomic clinical trials.

Among the various ACGT components, the two most relevant ones for ObTiMA are the *Master Ontology*, providing a unified set of (logically defined) domain concepts necessary to describe all aspects of clinical trials, and the *Semantic Mediator* providing ontology-based mediation between data sources.

Master Ontology

The task of this ontology is to comprehensively represent the domain of research on cancer and its clinical management and care, with special emphasis on mammary carcinoma (breast cancer), nephroblastoma (Wilms' tumor) and rhabdoid tumor. Due to the multiplicity of entities and processes present in this domain, the ontology contains elements ranging from genetics, the medical and administrative field, up to the legal domain. Therefore it forms a cross-section between all of these subdomains with each one being a vital part of the overall domain.

Basically, domain ontologies represent a given domain by formally and univocally defining the types and their connecting relations, as used within that domain. Hence, the Master Ontology could effectively be seen not as "proper" domain but rather as application ontology since it is tailored towards the functionality requirements of the application services of ACGT. For example, "proper" domain ontologies exhibit a clear-cut, distinguishable domain that can be found in basic scientific disciplines, like anatomy or cytology. But since our ontology incorporates many different aspects, it is not possible to clearly delineate such a single, specific domain. However, in using ontologies the differentiation between domain ontologies and application ontologies blur considerably, anyway.

An ontology is thus a representation of the referents, in the linguistic sense of the word, in some domain or for some specific application providing references for the terms used in describing the domain. All naming and labelling in the Master Ontology was checked against actual term usage in the domain to ensure end-user usability [5] (which also contains examples from the ontology missing here due to space restrictions).

For the ontology development, the principles for state-of-the-art ontology engineering, as proclaimed by the OBO Foundry [6] have been followed closely. Those "best praxis" criteria for ontology design support in producing an artifact which is both sensible from the point-of-view of content as well as coherent regarding its logical, internal structure. As an example, all concepts are defined by formal subsumption ("is-a" relation) and logical constraints based on the relations between concepts. Hence concepts are clearly delineated from each other and ambiguity of pure natural language definitions is avoided.

Semantic Mediator

The process of semantic (data) mediation involves the matching, combination, and retrieval of data stored at disparate data sources to offer a unified view over them. It is semantic since the relationships between all parts of the data are made explicit by using ontological concepts and relations. The Semantic Mediator has initially been designed to fulfil this task as a part of the ACGT platform. It accepts queries to and retrieves results from disparate data sources, like databases or flat files, based on Master Ontology concepts and relations. Hence, users who want to retrieve data via the mediator do not have to know any technical details of the underlying data sources but employ ontological concepts and relations and combine them into queries to access all data sources in a unified way [2].

A new data source is integrated into the semantic mediator by creating a set of rules for mapping this data source onto the Master Ontology. For databases, this task is simplified by a graphical tool that assists in mapping from database tables and columns onto appropriate ontological concepts and relations. Still this process remains a complex task that needs to be performed by users who are experts both in the domain, the database, and the ontology. They must be able to realize the subtle differences between similar ontological concepts and how this is mirrored in the data sources (and vice-versa) [7]. On the upside, this mapping needs to be created only once when a data source is first added but can be reused for other tasks, so a genomic data source can be directly reused in other trials.

ObTiMA System Components

Trial Builder

The Trial Builder represents one of ObTiMA's two main components (cf. Fig. 1) and enables the user to specify the various aspects of a clinical trial. The trial outline and metadata can be defined in a master protocol based on templates for describing the trial goals and its administrative data, like start or end date. Treatment plans can be graphically designed to guide clinicians through the treatment of individual patients and particular treatment events, such as chemotherapy or surgery, can be defined with all necessary information. The particular order of treatments for individual patients can be defined by placing them on a timeline. Also, treatment stratifications and randomizations to be applied for a patient can be described. For each stage on the treatment plan a CRF can be assigned to collect the data documenting the treatment.

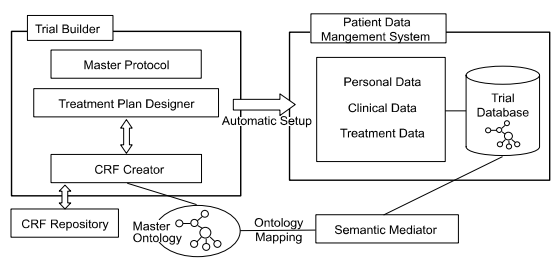

Figure 1 – ObTiMA System Components

Ontology-based CRF Creation

The creation of CRFs marks the core functionality of the Trial Builder. In a graphical user interface, the user can define the content, layout, and navigation of the CRFs which are used to

capture all patient data during a clinical trial, like the patient's history, medical findings, diagnostic data, or genomics data.

It is important that all information can be defined here which are necessary for the data integration, i.e., each CRF item is described based on ontology concepts together with metadata, like data type and measurement unit, to set-up the trial database. However, the internal CRF (data) representation is not the focus of clinicians but their "user interface" (layout) and their adaption and integration into the specific workflow of the planned trial: clinicians are not to be bothered with the underlying aspects of the trial database or the ontological metadata. Thus all these aspects are made transparent to the user through a graphical user interface which hides the actual complexity yet gathers all required information for automatically creating the trial database. This interface is derived also automatically from the content and structure of the Master Ontology but presents a simplified ontology view, adapted to the task of creating items (Figure 2). It comprises the following sections:

In the *Ontology View* (1), the user selects concepts from the ontology to create a CRF item. Here, the interface tries to overcome the gap between clinical practice and the actual logical representation of ontology concepts: Although the ontology provides natural language descriptions for its concepts/relationships (in addition to the logical definitions), those often do not fully mirror the needs of practical or clinical perception of reality. In order to meet this need, we do not present the full Master Ontology here but rather a simplified clinical view which contains a trial-independent basic classification of CRF contents from a clinician's point of view.

It is by intention that the clinical view is far less detailed as the actual Master Ontology and since this allows the possibility to provide a much easier entry point for the user. The interface of the clinical view is implemented as a tree always that starts at node of the concept "Patient" as focus of any clinical study (and hence CRF) and only presents those concepts that are directly reachable from this concept, like "Weight" or "Tumor" (indicating a patient's tumor). Only when a concept is selected then also the concepts directly reachable from this one are shown, such as "Laterality" in the case "Tumor" was initially chosen (indicating the laterality of the patient's tumor).

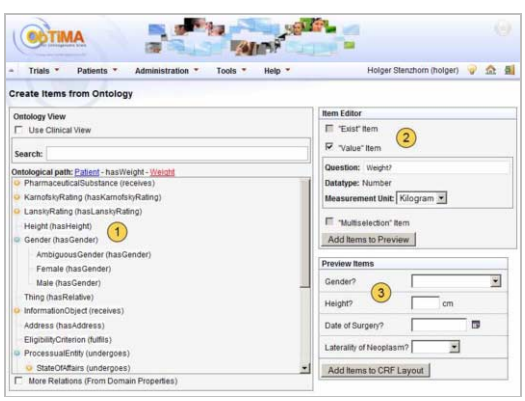

Figure 2 – Ontology Viewer while Creating CRF Items

When a concept is chosen in (1) then a corresponding item is automatically created and shown in the *Item Editor* (2) together with its attributes determined automatically based on the chosen concept, such as label, data type, or answer possibilities, and which can be manually adopted. For example, the concept "Weight" has a numerical data type and a list of suitable measurement units attached. So, when the CRF with this item is used in a clinical trial then the measurement units are offered as selection possibilities (in a drop down menu). The specified value (entered into a text field) is automatically tested to be of numerical type and also to be non-negative (since a weight cannot be negative). Finally, *Preview Items* (3) presents all created items in the order in which they are intended to appear on the CRF. Single items can be reordered by simple drag and drop and subsequently transferred to the interface where the overall layout of the CRF is then defined in turn.

CRF Repository

Revisiting the reuse and interoperability issue discussed in the introduction, in many trials similar or equal data are collected, yet stored differently because of different data(base) definitions. Applying the Master Ontology already improves this situation through using standardized concepts when creating CRFs. Going a step further, the situation would be further improved by partial or complete reuse of existing CRF in case similar data is collected. This idea realized by creating a unified CRF Repository as crucial part of ObTiMA. This repository allows the storage and retrieval of entire ontology-based CRFs and single CRF items or components for reuse and adaption in subsequent trials: When setting-up a clinical trial, fitting CRFs can either be directly reused or new ones quickly created by "plugging together" existing CRF items and components. This in turn fosters the standardization of CRFs even more, since CRFs can now be compared not only on the level of single items (through their basis on ontological concepts) but also on the level of larger components or in their entirety.

Patient Data Management System (PDMS)

The PDMS supports clinicians when conducting a clinical trial and is automatically set-up based on the master protocol and CRFs defined in the Trial Builder. The PDMS guides the clinicians through the actual treatment of patients according to their individual treatment plans and provides a graphical user interface to fill in the CRFs relevant to the patient's current treatment situation. The interface is adjusted to everyday clinical needs: As with the Trial Builder, the complexity of the underlying ontology is hidden from the user, yet its logic-based concept definitions are used to provide direct validity checking when CRF are filled in. The basic look of the data entry interface corresponds to section (3) on Fig 1 with each input element providing on-the-fly feedback about its current state based on the just mentioned checking, i.e., in case a negative value is specified for a weight then this error is immediately highlighted along with an explanation of the error.

Data Export

To integrate ObTiMA into real-world clinical settings, the system must be capable to interface with other existing CTMS

and be able to exchange data in a format they understand. To meet this requirement, ObTiMA allows to import and export trial metadata, CRF descriptions and patient data through an extended version of the CDISC Operational Data Model (ODM) format [8]. This platform-independent, quasi-standard for exchanging and archiving clinical trial data is supported by many current CTMSs. Observing CDISC's extension guidelines, we enriched this format by allowing the additional inclusion of (metadata) descriptions based on Master Ontology concepts. In the case other CTMSs want to import data generated by ObTiMA, they can chose to interpret the supplemental descriptions but if this is not feasible the resulting data is still "ODM complete" and can sensibly be used by those systems.

Administration, Security and Pseudonymization

To administer multicentric clinical trials, ObTiMA contains several advanced facilities for managing the multitude of institutions, researchers, and patients usually participating in such trials. An elaborated, fine-grained security architecture has been implemented to handle the rights and roles that can be attached to the system's users in order to guarantee that they can only perform the tasks which they are fully authorized for. It is also straightforward to dynamically react to changes within a running clinical trial, since new institutions and users can always be added or extra security roles and rights be defined.

It is also indispensable that ObTiMA, as a system holding real patient data, securely stores all of the data which could possibly identify some patient to non-authorized persons in pseudonymized and encrypted form. To foster security even more, such personal data is physically separated from the actual clinical research data through the use of two distinct database servers: One server holds the database for storing the personal data of the patients, such as their names and addresses (which must never be shared, e.g., via the Semantic Mediator). The protection of this database strictly follows all current legal regulations for data protection in clinical environments. The other server hosts the database that contains the actual research data collected in a clinical trial (through the use of the CRFs). It is possible within the Trial Builder to mark certain CRF items as personal which results in this data being stored in the database for personal data and not in the one for research data.

Advantages of Using Ontology and Semantic Mediator

Built-in Semantic Trial Interoperability

As pointed out before, when clinical trials are designed with the Trial Builder (and thus linked to the Master Ontology) then this means that all items defined on the CRFs are also attached to the corresponding ontological concepts. Therefore, when data is entered for some CRF item then this data is also directly linked to the ontology based on the item's attached concept. No manual and error-prone data annotation happening subsequently and using biomedical terminologies is necessary. The advantage can be easily seen when looking at recent studies highlighting that the accuracy of SNOMED annotations exceeds 50% only slightly for three different scenarios [9] and hence annotated data cannot be reliably compared at all.

The automatic link of the collected data to the ontology makes it further simple to "publish" collected data or "blend in" external data into a current clinical trial via the Semantic Mediator: As ObTiMA automatically generates the mapping rules needed by the mediator from the concept-based item definitions, its (research) database can be readily added as data source to the mediator. Other trials running on ObTiMA (and therefore also based on the Master Ontology) or other applications based on that ontology, can perform concept-based queries on the trial data using the Semantic Mediator. The opposite direction to integrate other, external data sources into the current clinical trial is also made possible: for biomedical or biomolecular data sources containing, e.g., genomic data or data collected in related clinical trials (but not using ObTiMA) a mapping based on the Master Ontology can be created for the mediator (see above). Then by using the same concepts (combined with using the same interface) to query external data and data collected in the current clinical trial, it becomes straightforward to perform cross-trial meta-analyses.

Increased Data Quality

Continuing the above, by basing the data collection on the shared Master Ontology which has been developed by clinical domain experts in cooperation with ontology experts, the data becomes consistent to the knowledge of the underlying domain and hence its quality increases. The Trial Builder in ObTiMA ensures, mostly transparently to the user, that during the creation of CRF items only concepts from the ontology are chosen and logical restrictions attached to the concepts, like domain and range restrictions, are satisfied. However, currently not all of the restrictions encoded in the ontology, such as number restrictions, can be guaranteed automatically. Therefore we are currently investigating novel algorithms to support the user in further improving the data quality and consistency [10]. As with the ontology integration, those algorithms will be applied "below the surface", in order to support the user and improve quality but without exposing their intrinsic complexity.

Conclusion

In this paper we have described ObTiMA, the Ontology-based Trial Management Application and presented the details of its two main components to design clinical trials and to manage the patient data within them, as well as the Master Ontology and Semantic Mediator as the foundation of the system.

Related Work

We are aware of other research initiatives aiming to achieve data integration by utilizing ontologies in the clinical trials. Ontology based data integration frameworks, such as the Epoch project [11], are a very active research field. The difference between the latter and ObTiMA lies in the fact that these frameworks focus on only integrating existing data sources (instead of creating CRFs to gather new shareable data). Other initiatives focus on applications for creating standardized CRFs by using ontologies, like TermTrial [12], which also allows automatic database creation based on those CRFs. ObTiMA combines the advantages of the two research strains enabling both a user-friendly ontology integration during the trial design and the automatic set-up of the PDMS as well as the seamless integration of external data and the "publication"

of its own database. It is also attractive that all ontology and semantic mediation integration is transparent to the user and so any additional complexity that might be introduced by those technologies/methodologies is hidden, but still their application provides a strong support and added value to the user.

Evaluation

ObTiMA is currently being evaluated within the SIOP 2001/GPOH study [13] at the Saarland University Hospital as that study's trial center. The evaluation is performed by two trial administration experts who, until now, have been using a Microsoft Access database created in-house along with self-defined templates to enter the data collected on paper-based CRFs. Both ObTiMA's trial design and execution facilities are evaluated, accompanied by a user study where users are asked to report their experiences and propose improvements. In the first step, the CRFs have been designed together with the Master Ontology developers. For this, the existing paper-based study CRFs were taken and "translated" into their electronic, ontology-based pendant. The Trial Builder's user interface was found to be mostly straightforward and quick to understand after a short tutorial. Yet some possible improvements, e.g. regarding performance and user guidance, were identified and are now being worked on. Also some minor concepts were initially missing from the ontology necessary to fully model all details of the original CRFs but which have been added since. In a second step, ObTiMA's PDMS is evaluated by entering a large collection of CRFs. Feedback is also very encouraging here since it was expressed that the given functionality and its interface suit the clinical audience and are easy and quick to use. Still, a scientifically valid evaluation on a larger user basis is needed and therefore an evaluation including several clinical centers (based on a Rhabdoid tumor study) is now on its way. (The feasibility of ontology-based data integration via the Semantic Mediator has been successfully proven in ACGT [7].)

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Querying the National Drug File Reference Terminology (NDFRT) to Assign Drugs to Decision Support Categories

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Abstract

Introduction: The accurate categorization of drugs is a prerequisite for decision support rules. The manual process of creating drug classes can be laborious and error-prone. Methods: All 142 drug classes currently used at Regenstrief Institute for drug interaction alerts were extracted. These drug classes were replicated as fully-defined concepts in our local instance of the NDFRT knowledge base. The performance of these two strategies (manual classification vs. NDFRT-based queries) was compared, and the sensitivity and specificity of each was calculated. Results: Compared to existing manual classifications, NDFRT-based queries made a greater number of correct class-drug assignments: 1528 vs. 1266. NDFRT queries have greater sensitivity (74.9% vs. 62.1%) to classify drugs. However, they have less specificity (85.6% vs. 99.8%). Conclusion: The NDFRT knowledge base shows promise for use in an automated strategy to improve the creation and update of drug classes. The chief disadvantage of our NDFRT-based approach was a greater number of false positive assignments due to the inclusion of non-systemic doseforms.

Keywords

National Drug File Reference Terminology, Drug classification, Knowledge bases, Computer-assisted drug therapy

Introduction

Clinical decision support for computerized provider order entry (CPOE) depends on the assignment of drugs to classes used to express generalized medical knowledge. For example, a CPOE system could detect a risk of interaction between Macrolides and Statins (for a patient who is given both). As a prerequisite, the computer must know which of the drugs on the patient's profile belong to these classes.

The Gopher CPOE system was developed by Regenstrief Institute over the past two decades, and has provided decision support to thousands of physicians caring for patients in central Indiana. Regenstrief informaticians have created drug classes (e.g., "HMG-CoA reductase inhibitors"), and have manually populated these with individual drugs (e.g., "Lovastatin" and "Simvastatin"). Such drug classes facilitate writing decision support rules to detect drug-drug interactions or to suggest laboratory monitoring.

As the years pass, old medications are retired, and new ones enter the market. We have found that the manually-created Gopher drug classes accumulate older medications, but lack newer ones. Therefore, we are searching for a solution – an automated strategy – to improve and update the Gopher drug classes.

The Food and Drug Administration (FDA) is driving the Structured Product Labeling (SPL) initiative. SPL is an HL7 version 3 standard for drug knowledge representation based on the HL7 Reference Information Model (RIM). The FDA has already published over 5000 drug labels in this format. As of June 2009, all drug manufacturers must use the SPL format to register all of their new products with the FDA. An "indexing initiative" is underway, which will annotate these products using the Veteran Administration's National Drug File Reference Terminology (NDFRT). [1]

Already today, the NDFRT contains knowledge annotations for a large number of drugs, and NDFRT drug concepts are linked to NDC, RxNorm and other terminologies in the Unified Medical Language System (UMLS). Can NDFRT knowledge improve the way that drugs are categorized for clinical decision support? Carter and Brown have delivered an initial analysis to answer whether the drug classes used in real systems might be encoded using the available NDFRT categories. [2] We have previously reported on the use of this knowledge to organize basic drug terminology, [3] improve detection of drug intolerances, [4] and to create links between drugs and a patient's problem list. [5] In this paper, we investigate if another area of decision support – the detection of drug interactions – can be supported by NDFRT knowledge content.

Principles

NDFRT is an ontology of medication-related concepts that uses a highly restricted description logic formalism to define drugs in the form:

$$D \sqsubseteq B_1 \sqcap \ldots \sqcap B_n \sqcap \exists\ R_1.\ C_1 \sqcap \ldots \sqcap \exists\ R_m.\ C_m,$$

i.e. a drug concept D is described as the conjunction of base classes (a D is a B_1 and a D is a B_n) and existentially quantified role restrictions.

Some of the important roles in the NDFRT include the following: (a) has ingredient, (b) has mechanism of action, (c) has physiologic effect, (d) may treat, (e) may prevent, or (f) is contraindicated with a disease. Using such roles, we can define Statins as "drugs that have some mechanism of action which is a hydroxylmethylglutaryl-CoA reductase inhibitor"; or Tricyclic antidepressants as "drugs that have some ingredient which is a tricyclic ring structure derivative, and which may treat depression".

The NDFRT does not include fully-defined concepts to represent drug classes. (A fully-defined concept is one defined so that the constraints of the definition are sufficient criteria to declare a concept subsumed.) Instead, the NDFRT distribution file marks all concepts as primitive, where the criteria are descriptive (and necessarily true) for all subsumed concepts, but are not sufficient. In this paper, we attempt to show how we can describe conventional drug classes as fully-defined concepts in the NDFRT ontology.

Methods

NDFRT Knowledge Adapted to a Relational Database

The NDFRT knowledge base is made available for public use in a proprietary description logic XML format. [6] We downloaded the 2008.11.11 version of this file, and applied an XSLT transform to load it into our relational database.

As a matter of routine, we reason with such proprietary file formats in a relational database schema, which we have repeatedly described elsewhere. [3,4,7] In this schema, all NDFRT concept relationships are represented in one table with a relationship type, source concept id, and target concept id (see Figure 1). If the relationship type is transitive and reflexive (like the "is_a" relationship), then we compute the materialized transitive and reflexive closure and distance metric:

- reflexive: distance = 0
- direct: distance = 1
- transitive distance = 2,3,4…

We have found that this approach is fast even for large terminologies and instance databases.

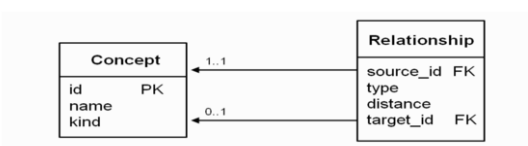

Figure 1 – NDFRT simple relational schema

Our relational database contained 136,054 NDFRT concepts. Of these, there were 120,877 drug concepts: NDC-level packages; drug products (with strength); and abstract "drug preparations" (without strength). There were also 8433 chemicals (derived from the MeSH chemical classification), 1815 physiologic effects (PE), 438 mechanisms of action (MoA), and 4258 diseases. Our relational database contained NDFRT-derived relationships as well: 158,717 is_a relationships, 4720 has_ingredient, 3167 has_PE, 2150 has_MoA, 5670 may_treat, and 793 may_prevent relationships.

Regenstrief Gopher Drug Classes

The Regenstrief Terminology Dictionary stores drug classes relevant to clinicians. Each drug class has a numerical identifier, a name, and a brief description. Physicians can create prescriptions for some of these drugs – in this paper, we will call these "Leaf-Level Drug Classes" (LLDC). Lisinopril is an example. There are also other drug classes, not at the leaf level, and not orderable by physicians. ACE Inhibitor is an example.

The Regenstrief Gopher CPOE system uses 808 non-leaf-level drug classes for various decision support purposes. Each such drug class has been assigned – manually – a set of LLDC identifiers representing orderable drugs. In order to focus our analysis on patient safety, we extracted only those 142 drug classes used by Gopher decision support to identify drug interactions. These drug interactions have been compiled over many years by Regenstrief pharmacists. Although there are several drug knowledge bases in the United States which list drug interactions, there is no single source recognized as a standard.

Defining Drug Classes as NDFRT Queries

The 142 Regenstrief drug classes were encoded using a few description logic templates (see Figure 2) and implemented as relational database queries (written in SQL). The authors, both physician-informaticians, captured the definition of each of the 142 drug classes taking into consideration: (a) the name of the class, (b) the LLDC members of the class, and if in doubt (c) the purpose of the class as it is used in the interaction rules. For example, "Macrolides" and "HMG-CoA reductase inhibitors" are understood from the name. For "Antipsychotics", the name was not sufficient, and the LLDC members of the class had to be examined to see that "Neuroleptics" are meant – excluding Antidepressants. For "Non-sedating antihistamines", the use of the interaction rule had to be examined to see that only those Antihistamines with the risk of QT interval prolongation (e.g., Terfenadine) were intended.

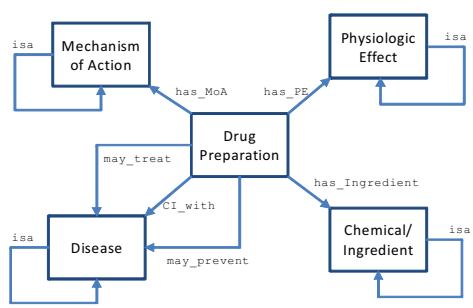

Figure 2 – Some of the Concepts and Relations in the NDFRT. The ones shown were used in this study to define drug classes.

Most (137 of 142) class definitions could be written as one of the following two schemata:

1. For 133 cases: $D \sqsubseteq \exists\ R.\ C$

Role R indicated these relationships: has_ingredient (94 times), has_MoA (21 times), has_PE (7 times), may_treat (7 times), may_prevent (3 times), and contraindicated with (1 time). Oxidizing meds were defined as those contraindicated with glucose-6-phosphate dehydrogenase insufficiency.

2. For 4 cases: $D \sqsubseteq \exists R_1.\, C_1 \sqcap \exists R_2.\, C_2$

In two of these cases, the roles R_1 and R_2 indicated the "has_ingredient" relationship (Cotrimoxazole and Advicor had been defined as sets, and each represents two ingredients). In the two other cases, one of the roles indicated "has_ingredient" and the other role indicated "may_treat" (e.g., Azole antifungals and Tricyclic antidepressants)

These NDFRT-based class definitions can be implemented as SQL queries. For the definition $D \sqsubseteq \exists R.\, C$, the role R is implemented as a database table linked to two other tables: the source concept of the role, and the target concept of the role. We join the source concept via a transitive and reflexive "is_a" relationship to the drug concept D. We join the target concept via another transitive and reflexive "is_a" relationship to the concept C. For the definition $D \sqsubseteq \exists R_1.\, C_1 \sqcap \exists R_2.\, C_2$, the conjunction is implemented as an SQL intersection.

Finally, 5 of the 142 drug classes could not be defined based on the knowledge in the NDFRT ("CYP3A4 inhibitors", "Class Ia antiarrhythmics", "Class III antiarrhythmics", "Non-sedating antihistamines", and "Kayexelates"). The minor effect (e.g., increased repolarization time for "class III antiarrhythmics") was not annotated in the NDFRT knowledge base. In order not to introduce a bias into the comparison of the manual approach with the NDFRT-based approach, these classes were not excluded from analysis, but were left to count against the NDFRT method.

Mapping NDFRT Drug Preparations to Regenstrief LLDC

In order to compare the NDFRT-based drug classes with the manually-created Regenstrief drug classes, we needed an element common to both. NDFRT-based drug classes consist of NDFRT Drug Preparations. Regenstrief drug classes consist of Regenstrief LLDC. We needed to link the two terminologies together. (See Figure 3 for a summary of the links required.)

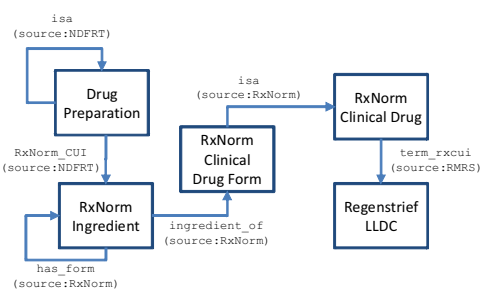

Figure 3 – Relations linking NDFRT Drug Preparations to Regenstrief LLDC

Comparing NDFRT Classes with Regenstrief Drug Classes

The analysis of the comparison is based on a full outer join table that connects NDFRT class members with Regenstrief class members, if either exists. The unit for comparison was the Regenstrief LLDC. In other words, the definition of Regenstrief classes as sets of Regenstrief LLDCs was not disturbed. However, the definition of NDFRT classes was expressed as a set of Regenstrief LLDCs, relying on the mapping linkages described above.

For each of the 142 drug classes: we examined the Regenstrief LLDCs assigned to that class during the manual creation of the class; and we examined the Regenstrief LLDCs assigned to that class by the automated NDFRT-based queries. If a LLDC was assigned to the class by both strategies (manual and NDFRT-based), it was declared to be correctly assigned. If a LLDC was assigned by only one strategy, and not the other, then it required review. A reason for the discrepancy was determined. This review established a consensus set against which both methods were measured.

Results

Over the years, Regenstrief knowledge engineers had manually populated the 142 classes with a combined total of 1271 LLDCs. Our NDFRT-based definitions subsume a combined total of 1905 LLDCs. The two strategies overlap for 754 LLDCs. (See Figure 4.)

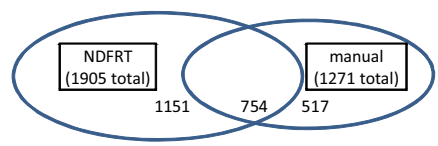

Figure 4 – Overlap of LLDCs collected by the two strategies

The combined totals are disproportionately affected by classes with many LLDCs; therefore, we broke down the counts by class. NDFRT definitions subsume more drug LLDCs in 64 cases; Regenstrief classes subsume more in 54 cases; and the two strategies collect equal numbers in 24 cases.

In order to study performance metrics, we needed to assign some "gold standard" of true class membership. We declared that the 754 LLDCs returned by both the NDFRT-based queries and the Regenstrief classes were true members of their classes. We reviewed the 517 LLDCs in the Regenstrief classes (which had not been included in NDFRT queries), and could only find 5 cases of inappropriate class membership. For example, Digoxin Fab antibody fragments do not share the proarrhythmic effects of the other cardiac glycosides, and thus were considered inappropriately placed in that class. Finally, we reviewed the 1151 in the NDFRT queries (which had not been manually included in the Regenstrief classes). We designated 774 as truly members of the class – in accordance with the original Gopher definition of the drug class. As discussed below, making this designation was a matter of judgment. In sum, we found 2040 class-member assignments (754 + 512 + 774 = 2040) which we considered true.

Having made this designation of true class membership, we calculated sensitivity and specificity. (See Figure 5.) Note that the 2616 LLDCs lacking true class membership are calculated as the sum of the 5 LLDCs inappropriately placed in Gopher classes, the 377 LLDCs inappropriately placed in the NDFRT-based classes, and the 2234 remaining Regenstrief Dictionary Drug LLDCs which do not participate in either strategy.

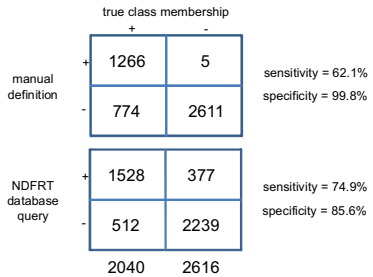

Figure 5 – Performance metrics of the two strategies for defining classes: manual (top) and NDFRT-based (bottom)

The low specificity calculated for the NDFRT strategy derives from 377 false positives. We discovered that 44 of these were due to a medication of incorrect formulation for a drug class where the formulation was explicitly stated. For example, topical Erythromycin gel had been assigned to the class of "Macrolides Systemic". An additional 192 were due to incorrect formulation, where the formulation was implied. For example, Atropine ophthalmic drops had been assigned to the class of "Antiarrhythmics". The systemic route is implied, though not explicitly stated.

The sensitivity calculated for the NDFRT strategy depends on the number of NDFRT Preparations successfully mapped to a Regenstrief LLDC. But 387 of the LLDCs in the manually defined classes are not mapped to RxNorm clinical drugs, and thus cannot be linked to NDFRT Preparations. The greater part of these unmapped LLDCs are outdated medications which are no longer marketed (e.g., Oxytriphylline). These unmapped LLDCs contribute to the count for the manual strategy, but cannot contribute to the count for the NDFRT strategy. Simply excluding the unmapped LLDCs would improve sensitivity of the NDF-RT approach to (1528/1653 =) 92.4%.

The sensitivity of the manually-defined classes is greatly affected by the failure to include combination products. For example, among the medications detected by NDFRT queries, but not included in manually-defined classes, were 229 combinations of ingredients. For example, Fiorinal had been correctly included in the Gopher Barbiturates class; but it had not been included in the Gopher Aspirins class.

Discussion

In this study, knowledge derived from the NDFRT was used to categorize medications and enable a specific type of decision support: checking for drug interactions. However, the accurate categorization of drugs has broader applicability, and can enhance other types of decision support, such as treatment guidelines (e.g., Beta blockers for myocardial infarct).

We demonstrated that classes defined in the NDFRT ontology subsume a greater number of medications than the manually defined classes currently used by our institution. The manual classes are incomplete, and lack many medications which could rightly be assigned to them. This fact is not surprising. We know how difficult it is for a limited number of knowledge engineers to monitor the unrelenting arrival of new drugs on the market, and to manually update drug classes and other features of a complex decision support system. This is especially problematic for combinations of ingredients (e.g., Amlodipine/atorvastatin should be assigned to two classes: Statins and Calcium channel blockers). If we could harness an automatic process of class assignment based on NDFRT definitions, we could improve the completeness of our Gopher classes.

We measured a modest improvement (from 62% to 75%) in sensitivity with the use of NDFRT. But these numbers understate the potential benefit of the NDFRT strategy. Our analyses used Regenstrief LLDCs as the unit of measure. This had no negative impact on the Gopher classes. However, this put the NDFRT queries at a disadvantage. Not all of the NDFRT Preparations in the queries were successfully mapped to Regenstrief LLDCs. Despite the handicap of incomplete mapping, the NDFRT strategy outperformed the manual strategy.

Nevertheless, it would be premature to use NDFRT definitions "as is". This strategy could introduce a lack of specificity. This problem is especially important in the domain of drug interaction decision support. Physician users consider most drug interaction reminders unhelpful; in one study, they overrode 89.4% of such alerts. [8]

We determined that the majority of false positives were due to the wrong formulation of the right ingredient. Thus medications intended for non-systemic (e.g., topical or ophthalmic) use were placed with medications intended for systemic use. As noted by Carter et al, a reference hierarchy of formulated routes would greatly improve the NDFRT. [2] Another promising approach is the definition of drug classes based on the SPL model, which includes dose forms and routes, and will include NDFRT annotations. Such an approach would routinely take form and route into consideration. [3]

An important lesson learned is that to correctly assign drugs to a class, one must understand the purpose of the drug class. A drug class assembled for the purpose of allergy detection may include more members (be more sensitive at a cost of specificity). For example, Penicillamine might be included in a set of warnings for Penicillin allergy. A drug class assembled for treatment guidelines should have less members (be more specific at a cost of sensitivity). For example, not all Quinolones should be suggested for treatment of pneumonia. A drug class to monitor interactions might include only those formulations known to produce sufficient systemic concentrations. Unfortunately, at our institution, a drug class, once it is defined, is often reused for several different purposes – and may not suit them all.

The expressiveness of NDFRT has already been investigated: Rosenbloom et al determined that the Physiological Effect hierarchy is adequate for representing the effects of commonly prescribed medications. [9] Nevertheless, not all of the possible physiological effects of a medication have been instantiated as relationships. We found that the primary treatment effects were well represented; but not all the possible side effects were. For example, the class of anticholinergic medications collected by the NDFRT query did not include some medications (e.g., Diphenhydramine) which geriatricians at our institution have flagged for anticholinergic side effects.

One limitation of our study is the use of Regenstrief LLDCs as the unit of measure: other institutions do not use Regenstrief terminology. However, it must be noted that Regenstrief LLDCs have survived real-world testing over several decades. Furthermore, many Regenstrief LLDCs have a direct correspondence to RxNorm identifiers. Finally, we needed to use Regenstrief LLDCs to put the NDFRT strategy to a real-world challenge. The fact that the NDFRT strategy still outperformed in sensitivity adds credibility to our belief that this strategy should replace the manual maintenance of drug classes.

Another limitation is that these performance metrics depend on our own designation of which drug LLDCs are correctly assigned to a class. In many cases, the authors reached consensus promptly. However, in some cases, careful judgment was required. For example, an NDFRT relation states that Warfarin "may treat" Atrial Fibrillation. But Atrial Fibrillation is an Arrhythmia. Thus the "may treat" relation places Warfarin in the class of Antiarrhythmics. In our judgment, this was a false positive.

Categorization of medications is an important feature of commercial drug knowledge bases. Our experience with some of these products has been favorable. The advantage of the NDFRT is that it has been made freely available in the public domain and that it is part of the SPL system of drug product descriptions published by the pharmaceutical industry through the FDA. We believe there is future potential for decision support that uses a knowledge base maintained by these authoritative sources. An additional advantage of using our method to manipulate a medication terminology is the high degree of expressiveness allowing us to adjust the definition (especially the granularity) of a drug class provided the drugs are annotated with the NDFRT concepts at sufficient detail.

Conclusion

The manual process of creating and updating drug classifications could be automated by a strategy based on the NDFRT, with some human oversight. The level of detail and consistency of assignment of the NDFRT relationships should be improved to allow even more precise definition of classes. Knowledge engineers who write decision support rules could then be more specific about the drug classes they require for the purpose at hand.

An important improvement that our automated method still requires is the recognition of form and route. We believe that the most promising strategy to implement this may derive from the SPL indexing initiative, which will link detailed product descriptions with NDFRT role relationships.

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Visualization of disease distribution with SNOMED CT and ICD-10

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Abstract

Methods for presentation of disease and health problem distribution in a health care environment rely among other things on the inherent structure of the controlled terminology used for coding. In the present study, this aspect is explored with a focus on ICD-10 and SNOMED CT. The distribution of 2,5 million diagnostic codes from primary health care in the Stockholm region is presented and analyzed through the "lenses" of ICD-10 and SNOMED CT. The patient encounters, originally coded with a reduced set of ICD-10 codes used in primary health care in Sweden, were mapped to SNOMED CT concepts through a mapping table. The method used for utilizing the richer structure of SNOMED CT as compared to ICD-10 is presented, together with examples of produced disease distributions. Implications of the proposed method for enriching a traditional classification such as ICD-10 through mappings to SNOMED CT are discussed.

Keywords:

Visualization, Disease distribution, Health problems, ICD-10, SNOMED CT, Terminology models

Introduction

Methods for visualization of disease distribution in a health care environment rely on the structure of the controlled terminology used for coding. In this study this is explored with a focus on the use of ICD-10 and SNOMED CT.

ICD-10 [1] is primarily intended for statistical reporting and administrative tasks such as disease monitoring and quality assurance. Although neither based on nor intended as a model of health problems, the ICD classifications are by far the most used terminology systems in electronic health records [2]. The grouping of diseases in the ICD classifications, and still reflected in ICD-10, is done based on categorization of health problems into epidemic diseases, constitutional or general diseases, local diseases arranged by site, developmental diseases and injuries [3].

While ICD-10 is mono-hierarchical, SNOMED CT is poly-hierarchical, allowing one concept to have multiple parents [4]. SNOMED CT is also more fine-granular as compared to ICD-10. The SNOMED CT hierarchy *Clinical findings* contain approximately 110,000 concepts as compared to 12,000 disease categories in ICD-10. SNOMED CT is a clinical terminology intended for clinical documentation and reporting [4], and could be used as the basis for coding and aggregation in Electronic Health Records (EHRs). However, there is still a need to explore the potential of SNOMED CT in EHRs and other clinical information systems.

Use of Electronic Health Records (EHRs) by general practitioners is almost universal in Sweden [5]. EHRs also support diagnostic coding, which is mandatory, and has made it possible to systematically collect information on health problems [6]. In Swedish primary health care practice there is a widespread tradition of using a primary care version of ICD-10 [7] with the Swedish abbreviation KSH97-P. Sweden, being a member of the IHTSDO-organization [8], is in the process of introducing SNOMED CT as a terminological resource in the health care sector.

The primary objective of this study was to explore the use of SNOMED CT as a mean to enrich visualization of disease distribution through mapping from KSH97-P to SNOMED CT. A second objective was to analyze the distribution of health problems from a large primary health care database and to describe and compare the results from using the KSH97-P/ICD-10 versus the SNOMED CT structure.

Materials and Methods

Diagnostic data

The diagnostic data used in this study were coded by primary care physicians and collected from Electronic Health Records (EHRs) in Stockholm County during 2006, in all approximately 2,5 million encounters. Diagnostic codes were reported in an average of 78% of the encounters. Up to 15 diagnostic codes were allowed for each care contact. 82% of all care contacts had one (1) code, 13% of all care contacts had two (2) codes, and 2% of the contacts had three or more diagnostic codes.

Coding systems

The Swedish National Board of Health and Welfare has worked out a primary health care version of ICD-10 with the Swedish abbreviation KSH97-P [7]. KSH97-P contains 972 categories which relate to diseases and health related problems

that are common in primary health care. KSH97-P has the same chapter division as ICD-10. The exceptions are that chapter XX, External causes of morbidity and mortality is left out from KSH97-P and chapter XXII, Codes for special purposes, is left out in both the Swedish version of ICD-10 and KSH97-P.

SNOMED CT is intended both for clinical documentation and reporting [4]. SNOMED CT consists of concepts, descriptions and relationships. Relationships link concepts to each other and relationships are of different relationship types. The generic relationship type "Is a" relates from subtypes to supertypes and is always defining relationships. All concepts, except for the root concept, have at least one "Is a" relation to a supertype concept. The other relationship types that are defining relationships are the defining attribute relationships. The defining relationships logically represent a concept by establishing relationships between the concepts.

Mapping between KSH97-P and SNOMED CT

We used a category mapping from KSH97-P to SNOMED CT that was based on a previous mapping reliability study [9]. Of the 972 categories in KSH97-P, 14 (1%) did not have a matched concept in SNOMED CT and 67 (7%) were mapped to more than one concept. We applied an additional mapping on an ICD-10 chapter level, described in another study [10]. Two ICD-10 chapters (Symptoms, signs, abnormal clinical and laboratory findings, not elsewhere classified (XVIII) and Factors influencing health status and contact with health services (XXI)) had no direct mapping match to SNOMED CT concepts.

Computational methods

We used the mapping results of categories and chapters to aggregate the diagnostic data through SNOMED CT "Is a" relationships to describe the data and make comparisons between ICD-10 and SNOMED CT on the chapter level. For each chapter we extracted the mapped chapter concept(s) together with the mapped concepts' "Is a" descendants. All diagnoses belonging to a category that were mapped to any of the extracted concepts were assumed to belong to the specific chapter. This implies that a specific category could belong to zero, one or more chapters.

To explore complementary ways of aggregating diagnoses, we used the category mapping. We carried out aggregations through the defining "Is a" relationships and defining attribute relationships. For each category the mapped concepts were extracted together with their ancestors (all supertypes) to a mapped set. All defining attribute relationships from concepts in the mapped set were then followed, and the target concepts were included in a specific attribute value set for each relationship type. In each attribute value set the concepts that were ancestors of another concept in the same attribute value set were removed. The remaining concepts in each attribute value set were assumed to be attribute values of the respective attribute types in the category.

The computational methods are performed in a relational database management system (PostgreSQL).

Results

A chapter level comparison of the diagnostic data between KSH97-P/ICD-10 and SNOMED CT is presented in Figure 1. The frequency distribution differs somewhat between ICD-10 and SNOMED CT due to the poly-hierarchical structure of SNOMED CT, allowing one ICD-10 category to be mapped to more than one SNOMED CT concept. This means that each category may belong to zero, one or more new chapter(s), which is shown in Table 1.

The use of "Is a" relationships in SNOMED CT aggregated the diagnostic data to 2861 concepts, showing a new, multidimensional view of different medical aspects, where every view can be further explored. A subset of such concept views is shown in Table 2, with a diagnosis percentage share cut-off at 10 %. Examples of new concept views below the 10 % cut-off are "Neurological finding" (8.0%), "Acute disease" (9.5%), "Pain/sensation finding" (6.6%), and Acute inflammatory disease (5.8 %). Aggregations into high-level concepts such as Clinical finding or Disorder by body site are not presented.

The attribute relationships in SNOMED CT can also be used for creating new views of the diagnostic data. Unlike the "Is a" relationship showing disorders concepts in Table 2, Table 3 could be used for further analysis of specific perspectives of e.g. causative agents, finding sites or associated morphologies for disorders and clinical findings.

Discussion

The results of this article show hidden information about health problems and diagnoses, coded with KSH97-P/ICD-10. The multiple views that are explored in this study illustrate the advantage of a poly-hierarchy. The multiple views of diagnostic data offer new possibilities for follow-up of specific aspects of the disease panorama. Clinically relevant views could also be used for navigation in order to support classification, thereby possibly improving coding validity and reliability.

The results presented rely on the soundness of the chapter and category mapping between KSH97-P and SNOMED CT which have been developed by the research group [9, 10]. Although rigorously developed, these mapping tables need to be further validated in an international research context. Another limitation is that the impact of possible quality errors in the diagnostic coding process that have been shown in previous studies is unknown [5, 6, 11, 12].

The results are also dependent on the soundness of the SNOMED CT concept model. Analysis and further refinement of the SNOMED CT model are beyond the scope of this study, but is obviously a topic for further research.

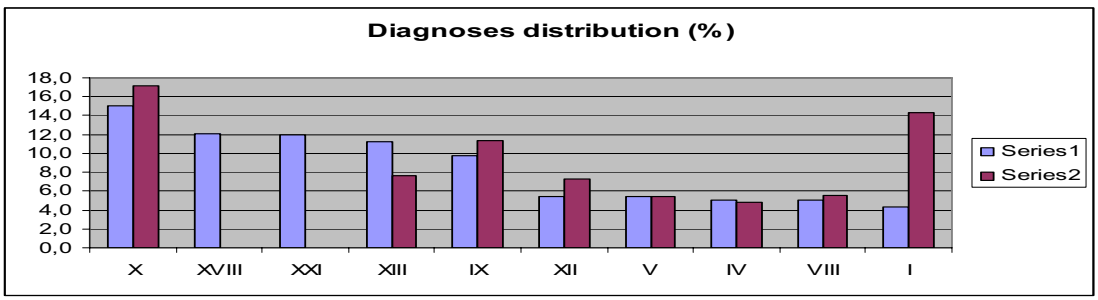

Figure 1- Distribution of diagnoses in top-ten ICD-10 chapters (left bars) and corresponding SNOMED CT concepts (right bars). (The table is truncated at a cut-off level of 5 %).

Table 1- Multiple chapter division of ICD-10/KSH97-P chapters. (The table is truncated due to space limitation – only chapters I-XIII are presented).

		Original chapter													
		I	II	III	IV	V	VI	VII	VIII	IX	X	XI	XII	XIII	All
Multiple chapter division chapter	I	98 528									184 971	19	31 953	69	316 391
	II		29 184										5 641		34 878
	III		262	12 480			78			176	49 908		2 332		67 378
	IV		135		101 187			76						4 108	105 988
	V					115 424	1 535						18		118 342
	VI	380	502		212	25 862	16 509	590	111	7 622				2 157	55 061
	VII	375	6					38 628						591	40 818
	VIII		92						120 150						120 980
	IX	3				498	7 096	85		240 451		42	138	1 064	251 984
	X	56	723							2 536	371 927				377 837
	XI	10 614	1 578		49 889					6 507	76 197	47 470	531	591	194 904
	XII	24 013	2 630					3 027					116 700		160 319
	XIII	17	72				348		35		280	2 494	189	130 869	168 815

Table 2- Aggregation of diagnostic data in new groups through the SNOMED CT "Is a" relationship.

Snomed CT concept	Percentage share (%)
Finding of head and neck region	21.9
Finding of trunk structure	18.9
Inflammatory disorder	17.9
Inflammation of specific body structures	17.7
Inflammation of specific body systems	17.5
Respiratory finding	17.3
Inflammation of specific body organs	15.6
Ear, nose and throat finding	15.6
Disorder of body cavity	15.6
Ear, nose and throat disorder	15.4
Disorder of respiratory system	15.1
Disorder of trunk	14.9
Head finding	14.3
Disorder of head	13.5
Infectious disease	12.6
Viscus structure finding	11.0
Upper respiratory tract finding	10.6
Cardiovascular finding	10.6
Disorder of upper respiratory system	10.6
General finding of abdomen	10.3

Table 3- Number of disease categories with specific attributes.

Attribute	Number
Finding site	722
Associated morphology	457
Causative agent	126
Interprets	61
Has definitional manifestation	59
Occurrence	54
Clinical course	31
Has interpretation	20
Due to	16
Associated with	14
Method	14
After	10
Finding method	10
Subject relationship context	6
Temporal context	6
Finding context	5
Has focus	4
Finding informer	3
Pathological process	2
Procedure site	2

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Ontology Based Modeling and Execution of Nursing Care Plans and Practice Guidelines

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Abstract

Nursing Care Plans (NCP) and Nursing Clinical Practice Guidelines (NCPG) promote evidence-based patient care, but in their paper form they are difficult to be applied at the point-of-care. We present our approach to generate patient-specific nursing care plans by modeling and computerizing these nursing knowledge resources. We present a Nursing CarePlan Ontology (NCO) that models the NCP and NCPG to realize an integrated knowledge base for designing and executing patient-specific nursing CarePlans. We adapted the METHONTOLOGY methodology for ontology engineering to develop our OWL-based NCO, and instantiated a set of NCP and NCPG. We have developed an execution engine that provides recommendations to nurses based on the patient's data. NCO was successfully evaluated for representational accuracy and completeness using a set of test NCP and NCPG.

Keywords:

Nursing care plan, Nursing clinical guidelines, Ontology, Care planning, Clinical decision support systems.

Introduction

Nurses represent the largest group of health care professionals that are directly involved in patient care in hospitals. The quality of care to hospital patients is strongly linked to the performance of nursing staff [1]. Hence, nurses need to be informed about evidence-based methods as well as being skillful in applying these methods, in a timely manner, to achieve the desired patient care outcomes [2].

Nurses organize the care process in terms of a Nursing Care Plan (NCP) that are concise, structured written 'plans of action' targeted at providing patient-specific care. A patient-specific NCP is designed guided by the disease diagnosis (performed by a physician) and a critical assessment of the patient care needs in terms of his/her condition—the resulting NCP comprises a summarized plan of action and tools to monitor the care activities undertaken by nurses and to record the patient's progress [3]. To execute the care activities stipulated in the NCP, nurses need to have knowledge of numerous medical procedures and how to interpret patient's physiological parameters. Nursing Clinical Practice Guidelines (NCPG) provide evidence-based instructions/recommendations about how to handle specific patient care issues related to nursing.

For quality patient care, we argue that a patient specific CarePlan [4] needs to be both customized to the patient's care needs and standardized in terms of best evidence. This means that to design a patient-specific CarePlan the following activities are needed: (a) the available NCP need to be customized as per the patient care requirements; and (b) the care activities within the customized CarePlan need to be supplemented with corresponding NCPG to ensure quality and standardization. Given the work pressures on nurses, the reality is that (i) the manual design, modification and maintenance of the patient's NCP is quite difficult, especially in response to the changing dynamics of the patient; (ii) the manual referencing of NCPG, which are not readily available, is not practical; and (iii) the execution of a paper-based care plan, in a timely and coordinated manner, is challenging. In this regard, we argue that to improve the quality and standardization of patient care there is a need to provide nurses with computerized nursing care planning and management systems to support their care roles.

In this paper, we present our research covering the computerization of NCP and NCPG in order to design and execute patient-specific nursing CarePlans. We take a semantic web approach, whereby we model the NCP and NCPG in terms of an OWL-based ontology. We modeled both the form and function of NCP and NCPG in terms of domain and workflow concepts, establishing semantic interrelationships between the concepts, and instantiating select NCP and NCPG using our Nursing CarePlan Ontology (NCO).

Nursing Care Planning: Concept & Solution

Individualized care has been described as ".. the management of care of the patient on the basis of his unique needs, the objective being maximum independence from the necessity of such care" [5]. This demands that the nursing care plan is customized to the specific needs of a patient and is able to dynamically adapt as the patient needs change. Although, nursing care is guided by the medical diagnoses, nurses work on the basis of a subsequent nursing diagnosis that deals with the nursing interventions required to treat the patient. At a conceptual level, the nursing care plans are categorized on the basis of the medical diagnosis and illustrate a set of care activities pertinent to the patient care for that specific disease (as shown in Figure 1). At the operational level, the patient-specific CarePlan is based on nursing diagnosis that determines a selection of care processes relevant to the patient—a single medical diagnosis can lead to multiple nursing diagnoses. Therefore, a patient' CarePlan transcends across multiple nursing care plans and is a composite of individual patient-specific tasks originating from multiple disease-specific nursing care plans.

Here, two patients with the same medical diagnosis can have different nursing care plans (shown in Figure 2).

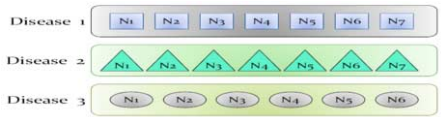

Figure 1–Nursing care plans for different medical diagnosis

Figure 2–Patient-specific CarePlan comprising tasks, in a particular order, selected from the disease-specific NCP based on the nursing diagnosis to handle co-morbidities.

To model NCP for the generation of CarePlans, we argue that it is important to work with modeling formalisms that allow the decomposition of larger concepts into constituent components, and then inter-relate the relevant components to realize a customized solution. Semantic web ontologies provide such a knowledge modeling formalism, whereas Task Network Models (TNM) organize knowledge components to realize a composite executable process workflow [6]. A number of existing formalisms to model clinical practice guidelines, such Asbru, EON, GLIF, PRO*forma,* and SAGE use ontologies and some form of TNM. Therefore, since NCP and NCPG outline complex actions, we plan to model them as ontological TNM as it will allow us semantic descriptions of concepts and reusability of the components to generate a range of CarePlans.

Modeling Nursing Care Process

In line with our modeling decisions of using ontologies and TNM, as the first step we developed a hierarchal representation scheme that takes into account the hierarchical knowledge and workflow classifications observed in NCP and NCPG. We examined NCP and NCPG to determine the different levels of care process classifications. We observed that the terms 'Procedure' and 'Activity' consistently appeared in NCP and NCPG. We used UMLS to disambiguate their meaning and functional purpose in the care process, and determined a three-level care process classification as follows: *Procedures* → *Activities* → *Tasks*. Each process can have *n* number of procedures (P_n), while a procedure itself can have *n* number of activities (A_n) and finally an activity can have *n* number of tasks (T_n) as shown in Figure 3. It may be noted that processes in the NCP/NCPG are typically recommendation/intervention. Thus, in our nursing care model, NCPG based Recommendations and NCP based Interventions are represented as procedures, activities, and tasks. A CarePlan is a composite of recommendations/interventions employing individually modeled procedures, activities and tasks in a patient-specific workflow.

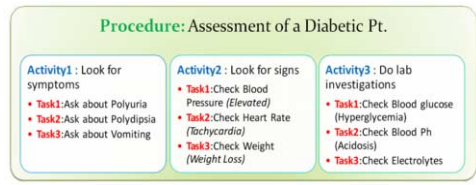

Figure 3 – Hierarchical decomposition of NCP and NCPG

Nursing CarePlan Ontology Engineering

To develop NCO we designed a three-stage methodology, an adaptation of METHONTOLOGY [7], as discussed below:

Stage 1 - Ontology Specification and Knowledge Identification: The first stage involved the specification of ontology parameters such as domain, purpose, scope, and identification of knowledge sources. A large set of NCP and NCPG were collected and used to design the NCO.

Stage 2 - Ontology Modeling: The second stage involved ontology conceptualization in which we abstracted concepts from a sample of NCP and NCPG, described concept hierarchies, defined relationships, and finally axioms. We then constructed our primitive Ontological model using Protégé-OWL. We used a cyclic inductive approach for concept abstraction, where in each cycle we refined our model based on concepts from the sample NCP and NCPG. Model refinement was concluded when we achieved a concept saturation point whereby no further modifications were required to the NCO to model additional concepts abstracted from new NCP/NCPG.

Stage 3 - Ontology Evaluation: The final stage involved evaluating our ontology in three steps. First, we evaluated our model for representational accuracy by encoding five randomly selected NCP and NCPG. Secondly, we evaluated our model with the guideline modeling dimensions described by Peleg [8]. Finally, we evaluated our ontology against the standard ontological design principles [9, 10]. The resultant NCO was found to be consistent and complete.

Ontological Representation of NCP and NCPG

To describe our NCO, class names are given small caps e.g. DISEASE, properties using italics e.g. *isFollowedBy*, while Individuals are written within quotes e.g. "Tuberculosis".

NCO depicts NCP (NURSINGCAREPLAN) and NCPGs (NURSINGCLINICALPRACTICEGUIDELINE) as a set of Interventions (NURSINGINTERVENTION) and Recommendations (NURSINGGUIDELINERECOMMENDATION) respectively, and in order to activate them, a predefined INCLUSIONCRITERIA has to be satisfied. The inclusion criteria can be a particular AGEGROUP, GENDER, SYMPTOM, SIGN, or a particular DIAGNOSIS. An EXCLUSIONCRITERIA can also be defined which excludes a NCP or NCPG from activation. The top-level recommendation/intervention is modeled as NURSINGGUIDELINERECOMMENDATION, and it has sub-classes PROCEDURE, ACTIVITY and TASK, where each has PRECONDITIONS and EXPECTEDOUTCOMES. This is modeled as NURSINGGUIDELINERECOMMENDATION *hasPrecondition*

PRECONDITION and *hasExpectedOutcome* EXPECTEDOUTCOME. To model sequences among procedures, activities and tasks we defined properties *isFollowedBy* and *isPreceededBy*. To describe the status of tasks we modeled four discrete Task States by defining a class STATE with individuals "Inactive", "Active", "Completed", and "Failure" (also shown in Figure 4). Next, we describe how we use NCO to model the workflow of NCPG.

Modeling Workflow of a NCPG

Outcomes play an important role in our model, as they not only define the result of a task but also link different tasks together. We modeled the interconnection between tasks by relating the EXPECTEDOUTCOMES of one or more tasks as PRECONDTIONS for other tasks (see Figure 4). In this regard, our model operates as a workflow, where states have binary outcomes such as 'Yes' or 'No' depending on their a priori desired outcomes. Depending upon the outcome of a task the workflow takes a specific path. The advantage of this approach is that it is intuitive to model using an ontology as this does not demand complex rules. Furthermore, the interlinking of tasks in this manner allows us to control the workflow for tasks that entail multiple choices and need the satisfaction of multiple constraints before proceeding to the next task.

Modeling NCPG Execution Criterion

The first step in executing the CarePlan is the satisfaction of the INCLUSIONCRITERIA of the NCP/NCPG—the said NCP/NCPG is considered active and our execution engine searches for the satisfied PRECONDITIONS of their component tasks. The component tasks are by default in an "Inactive" State even after the activation of the NCP or NCPG. Once the PRECONDITIONS for any task are satisfied the STATE of that task changes to "Active". In Figure 4, the lower left task is "Active" since its PRECONDITION has been satisfied (depicted by the yellow color). Activation of any task causes the execution engine to display that task to the user who then acts upon it. After executing the task, the user is presented with a list of EXPECTEDOUTCOMES for that particular task and can choose the one that reflects what actually happened. This user feedback is modeled as the ACTUALOUTCOME of that task. When the ACTUALOUTCOME entered by the user is one of the predefined EXPECTEDOUTCOMES, the state of the task changes to "Completed" (depicted by a blue color, First task in Figure 4). In Figure 4, for the first task there are only two EXPECTEDOUTCOMES defined, the number "1" or "2", the ACTUALOUTCOME in this case turned out to be the number "1" and this outcome had already been defined as a PRECONDITION of the next task and thus the following task is activated. The newly activated task then goes through the same steps as described for the preceding one to reach completion. In cases where the ACTUALOUTCOME is not any one of the predefined EXPECTEDOUTCOMES, the state of the task changes to "Failure" (depicted by a red color). Here we imply that the task did undergo completion but was deemed a "Failure" since the ACTUALOUTCOME was simply not what was intended and such an outcome is modeled as an UNEXPECTEDOUTCOME. An unexpected outcome could be because of an adverse event or reaction. We intend to use unexpected outcomes to gain insight into that particular clinical scenario. They are saved for variance analysis and provide feedback to the authors of the original NCP and NCPG.

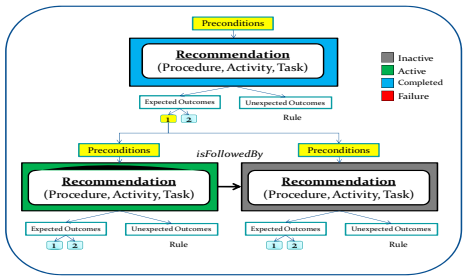

Figure 4 - The interrelationships between tasks and their states are shown using the color code

Modeling NCPG Execution Control Rules

To model the execution of a NCP we designed a set of ontology-based rules that work in tandem with the NCO. The rules are written using the Semantic Web Rule Language (SWRL). Below we give some rules in natural language.

Rules governing Preconditions

- A Recommendation/Intervention may or may not have PRECONDITIONS but their 'Expected Outcomes' should be defined whenever possible.
- IF two or more PRECONDITIONS are defined, THEN a 'Satisfaction Criteria' (All, Any One, Any Two, Major, Minor) has to be declared for activation.

Rules governing State Change

- Interventions are all initially in an 'Inactive' STATE.
- After activation, all TASKS will terminate with an outcome. This will be provided by the user by selecting from a list of predefined EXPECTEDOUTCOMES or manual input and will be declared as that Task's ACTUALOUTCOME.
- The "Inactive" state changes to "Active" only if Preconditions & satisfaction criteria are satisfied i.e. PRECONDITION (Expected Outcome of a Task) = ACTUALOUTCOME of any 'Completed' TASK and/or PRECONDITION = 'User Input'.
- IF the ACTUALOUTCOME of a TASK is equal to any of its EXPECTEDOUTCOMES THEN set STATE to "Completed".
- IF the ACTUALOUTCOME of a TASK is not equal to any of the predefined EXPECTEDOUTCOMES THEN set STATE of that TASK to "Failure". "Failure" implies that the task has completed but failed to achieve the expected outcome.
- IF EXPECTEDOUTCOMES have not been defined for a task THEN set the STATE to be "Completed".

Rules for competing Recommendations/Interventions

In situations where multiple interventions are available and only one intervention has to be selected but the selection criteria is not clearly defined, then interventions will be prioritized based on the number or type of satisfied preconditions—i.e.

by employing major and minor criteria. For example if three interventions are competing then the one with the most pre-conditions satisfied will be activated.

Rules governing 'Task Reuse'

- IF two different ACTIVITIES want to reuse the same task THEN the PRECONDITIONS and Sequence cannot be directly related to one TASK. The TASK should then have a PRECONDITION defined that belongs to the class SCENARIO.
- Individuals belonging to the subclasses of SCENARIO will serve to define uniquely the PRECONDITIONS and Sequence for that TASK for a particular scenario.

From NCO to Patient-Specific CarePlans

The modeling of NCP as a set of atomic procedures, activities and tasks, allows these constituent elements to be systematically selected and organized, as a task network, to design a patient-specific CarePlan. A CarePlan comprises a linked graph of procedures/activities/tasks from different NCP (as shown in Figure 5), where the individual properties of its components and its execution workflow (i.e. pre-conditions and outcomes) is determined based on the patient parameters.

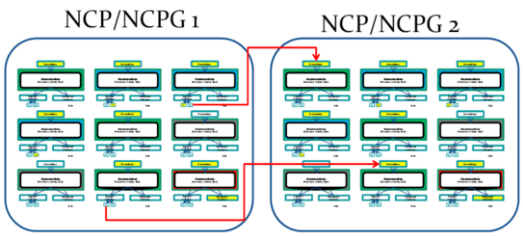

Figure 5 – A CarePlan comprising connected atomic components spanning multiple NCP/NCPG

NCO-Driven Execution Engine

The execution engine assists nurses in coordinating the care process as follows: (a) Recommending the sequence of care steps that need to be performed as per the NCPG; (b) Showing all the currently active steps; (c) allowing nurses to record the patient's parameters—note that a patient's condition determines the next steps; (d) allowing nurses to record the completion of a step by specifying its outcome or by specifying their decision; (e) the completion of previous steps and/or the availability of the observed outcomes triggers the recommendation of the next appropriate step. In this manner, the execution engine enacts the NCPG to guide nurses through the care process. At any stage, the execution engine can inform nurses the completed steps, past outcomes, the current active steps and their expected outcomes and the prospective next care steps.

Our execution engine executes NCP/NCPG, modeled using NCO, based on patient data and nurse input. The domain and execution concepts modeled in the NCO (described earlier) were extended as per the execution logic to achieve the desired outcomes, for instance the NCO describes four possible states of a task, however to control the execution as per the intended semantics of the NCP/NCPG we added three additional states. We use JENA reasoning API to access and manipulate RDF statements defined in the instantiated NCO.

Our execution strategy is to consider each NCPG step (Procedure, Activity or Task) as a Deterministic Finite State Machine (DFSM). The entire NCPG is therefore a directed graph of DFSMs. A DFSM is a quintuple (Σ,S,s_0,δ,F). Σ is the input (finite and non-empty), S is set of possible states, s_0 is the start state, δ is the state transition function: $\delta:S\times\Sigma\rightarrow S$ and F is the set of final states. Below is a brief description of the transitions needed for executing NCPG (shown in Figure 6a).

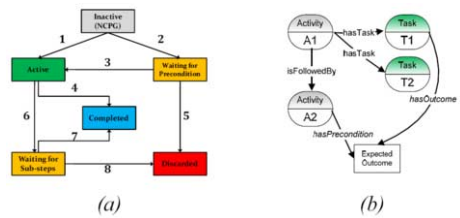

Figure 6 – (a) The DFSM assigned to each step, its states and possible state transitions (b) A small instantiated ontology

- **1** and **2:** An active step can activate its sub-steps and a completed step can activate the steps following it**.** For example when a *procedure* is executed, its first *activity* (or *task*) is added to the active list. If the step that is going to be added to active list is waiting for a precondition to be satisfied, it will go the "Waiting_for_Preconditions" state instead of "Active" state.
- **3:** If the precondition of a step is satisfied (either because of the outcome of other steps or user input) the task's state changes to "Active" state.
- **4:** If the step is a leaf in the hierarchy (it has no further sub-steps) and it is selected for execution, then subsequently it will be moved to "Completed" state.
- **5:** If all the steps that produce outcomes necessary for satisfaction of the preconditions of a task undergo completion and the precondition remains unsatisfied, the waiting step moves to "Discarded" state.
- **6:** If a non-task step (a procedure/activity) gets selected for execution, it will move to "Waiting_for_Sub-steps" state.
- **7** and **8:** If a step is waiting for completion of its sub-steps, then as they are completed it will be regarded a completed task. If any of its sub-steps were discarded instead of being completed, it will move to "Discarded" state as well.

To execute a NCPG we first build its RDF graph, where nodes are instances of classes and edges are the properties of the NCPG. This RDF graph captures the information flow between DFSMs as per the NCPG workflow. During execution, the Σ for each DFSM (step) is the state and the expected outcome of other incoming steps. For instance, in Fig 6b the Σ for A2 is the state of A1 and expected outcome of T1 and Σ for

A1 is the states of T1 and T2. In figure 6b, we show a segment of a NCPG with multiple steps and explain an execution scenario through DFSM. Suppose that the states of the steps are A1 (Waiting_for_sub-steps), A2 (Inactive), T1 (Completed) and T2 (Active). Now, when the engine executes T2, its DFSM will move to "Completed" state. This state transition will cause A1 to change its state from "Waiting_for_sub-steps" to "Complete". State change of A1 will trigger DFSM of A2 to change its state from "Inactive" to "Active". In this manner, execution proceeds till all DFSMs reach their stable state and no further state transition is possible. Our execution engine is able to handle multiple active steps, whereby we have implemented a timesharing breadth first search strategy that allows all active tasks to progress in parallel.

Evaluation Results

We evaluated our ontological model in three phases. We first tested our model for representational accuracy by encoding a sample of test guidelines and care plans and documenting any instantiation problems. Secondly, we tested our model against the guideline modeling dimensions described by Peleg et al [8]. Finally, we tested our ontology against the standard ontological design principles [9, 10].In terms of representational accuracy, NCO was found to miss knowledge about various drug doses and titrations. We plan to link NCO with a drug ontology to address this issue. Otherwise, NCO successfully represented the concepts found within the test NCP and NCPG. We evaluated NCO using the 8 CPG representational dimensions, proposed by Peleg et al [8], that cover structural and linkage aspects of a CPG model. We instantiated the original test guidelines used by Peleg et al using our NCO, and observed that NCO was able to aptly represent these guidelines. Finally to assess compliance with the design principles mentioned by Gomez-Perez [9] we manually went through the class hierarchy, properties and individuals in NCO. Additionally, we checked NCO to be compliant with the ontological principles described by Bodenreider for the medical domain [10]. Hence, NCO was deemed to be fully compliant with these principles.

Conclusion

We have encoded 6 NCPG using the NCO and they are now available for execution through our execution engine.

The computerization of NCP and NCPG is the first step towards their incorporation in the care process and their availability at the point of care. We presented an ontology-based modeling and execution framework for the computerization of NCP and NCPG, leading to the generation of patient-specific CarePlans. The key feature of our approach is that we were able to decompose large monolithic NCPG and NCP into small-scale, independent atomic components that can subsequently be used (and re-used) to design patient-specific CarePlans that cover clinical workflow, nursing knowledge and care coordination. The linkages between the care processes given within NCP with corresponding evidence within NCPG provides an integrated care environment where knowledge is impacting the care process—such linkages are desired by nurses but are neither practical in a paper-based setting nor implemented in current nursing systems. At the execution level, we have demonstrated the execution of complex NCP/NCPG through a rather simple graph traversal approach that is supported by lightweight SWRL rule based reasoning. At the next stage, we will be building data transfer interfaces to both collect and store data from the patient's EMR. Here we are planning a semantic web services based architecture built using HL-7 standards—the use of a OWL-S service ontology will allow for improved data interoperability between different care services. Although, our execution engine is capable of handling concurrently active care processes (i.e. execute processes in parallel), we lack the ability to reason with time and duration. Our future plan is to incorporate the OWL-Time ontology, developed by W3C, to handle the temporal aspects of NCP/NCPG execution.

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Mapping ICNP Version 1 Concepts to SNOMED CT

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Abstract

The purpose of this study is to evaluate the ability of SNOMED CT to represent concepts of the ICNP Version 1 – the 7-Axis model. We selected the 1568 concepts of the ICNP 7-Axis model. From January 2007 through June 2007, the first author mapped the ICNP Version 1 concepts to the SNOMED CT using CLUE browser 5.0. The second author from the SNOMED Terminology Solutions and the third author from the ICN validated mapping result. In total, SNOMED CT covered 1381 concepts of 1658 (83%) ICNP 7-Axis model concepts ranging from 65% coverage rate of the Actions Axis concepts to 94% coverage rate of the Judgment Axis concepts. SNOMED CT can represent most (83%) of the ICNP Version 1 concepts. Improvements in ICNP Version 1 in terms of concept naming and definition, and adding missing concepts to the SNOMED CT would lead to greater coverage of the ICNP Version 1 concepts.

Keywords:

Clinical terminology, ICNP, SNOMED, Coverage

Introduction

Standardization in the field of health information becomes important as computer-based information system and electronic health record are being introduced rapidly in health care facilities around the world. A variety of standard development activities are happening in the International Standard Development Organizations such as ISO, HL 7 and CEN. Standardized health care terminologies and classifications are the most important standard for data quality, data sharing and exchanging and decision support [1].

Unfortunately, most of application packages and institution-based systems have its own terminologies, resulting in overlooked synonymy and semantic collisions among concepts, which in turn producing non-interoperable data. Furthermore, most of countries have designated more than one health care terminology and classification standards for institution-based and interoperable medical records instead of recommending one single terminology and classification. For example, the United States, United Kingdom, Canada and Australia recognize more than one health care terminology and classification [2]. Thus, critical challenges are to link terminologies and classification used in the existing clinical information systems to standardized terminologies and classifications for data sharing and exchange. One solution for this problem is to map different terminologies to a broader health care terminology such as SNOMED CT (Systematized Nomenclature of Medicine – Clinical Terms) before storing data in database.

SNOMED CT is the most widely used health care terminology in EHR because it is richer, more granular expression, more familiar to clinicians, hierarchical, and group-able and susceptible to concatenation, which are ideal qualities for decision support analysis and population-based clinical and public health intervention [3]. ICNP (International Classification for Nursing Practice) is the most widely used nursing terminology in electronic nursing record because it allows communicating and comparing nursing data across settings, countries and languages [4].

The SNOMED CT is a systematically organized computer processable collection of health care terminology covering diseases, clinical findings, and procedures. It is designed to capture granular detail and provides common language for clinical data to be indexed, stored, retrieved, and aggregated across specialties and sites of care. Clinical expressiveness of SNOMED CT supports clinical care and drives decision support technology. It is designed for use in electronic medical records, reducing the variability in the way data is captured, encoded and used for clinical care of patients and research.

The SNOMED-CT is a reference terminology that provides a means of integrating healthcare classification and terminologies from different healthcare disciplines. Many healthcare classifications have been mapped into SNOMED-CT such as ICD -9-CM Epidemiological/Statistical Mapping, ICD-O3, ICD-10 (UK edition), OPCS-4 (UK edition), NIC, NOC, NANDA, PNDS, Clinical Care Classification, and The Omaha System.

The ICNP® is a unified nursing language system. It is a compositional terminology for nursing practice that facilitates the development of and the cross-mapping among local terms and existing terminologies. The ICNP Version 1 is comprised of 7 different axes, Focus, Judgment, Means, Action, Time, Location and Client [5].

The ICNP Version 1 is used to represent nursing diagnoses (client status, problems, needs, and strengths), nursing interventions (or nursing actions), and nursing outcomes. The 7-Axis model is intended to facilitate the composition of nursing diagnoses, interventions and outcomes statements. These statements can be organized into meaningful sets for nursing practice, which is called ICNP catalogues [6].

In order to support interoperability of nursing concept with other health care concepts, it is important to have a collaborative effort to come up with principles, processes and strategies to integrate, map and/or model nursing concepts within wider healthcare related concepts. As a part of this described collaborative effort, we would like to propose draft principles, processes and strategies that would be necessary to integrate, map and/or model ICNP Version 1 concepts within SNOMED CT, a copyrighted work of the International Health Terminology Standards Development Organization (IHTSDO). For the purpose of this project, concepts from the ICNP 7-Axis model, will be examined in the context of their potential for addition to a broad healthcare based terminology, SNOMED CT. This process hopes to contribute valuable feedback to the ICN (International Council of Nurses) regarding refining the definitions and hierarchies of ICNP Version 1 concepts. The study also hopes to inform the IHTSDO about the benefits of providing ICNP content to the participating member organizations.

Materials and Methods

We selected the 1658 concepts from the ICNP 7-Axis Model. The first author mapped the ICNP Version 1 concepts with the concepts of the SNOMED CT using Apelon's TermWorks and CLUE browser 5.0.

The first phase of matching is the linguistic matching of concepts based on concept label. Label matching involves putting the label into a canonical form by stemming and tokenization; comparing equality of labels; and matching sub-strings [7]. Concept names with suffix such as verb variation (ex, assessing vs assessment vs assesses) and singular versus plural (medication vs medications), use of preposition (ex, monitoring vs monitoring for,), American English versus British English (ex, diarrhea vs diarrhoea), compound word with or without space (well being vs wellbeing), and compound word with or without hyphen (ex, self toileting vs self-toileting) were treated as linguistically identical. Apelon's TermWorks was used for this phase.

If a concept in ICNP Version 1 matches linguistically with a concept in SNOMED, The next phase is the structural matching of concepts based on the similarities of their context or vicinities in the hierarchy of concepts. In structural matching, parents, sibling and children concepts were examined. If a concept in ICNP Version 1 matches with a concept in SNOMED linguistically and structurally, then it is classified as mapped. CLUE browser 5.0 with SNOMED CT 2007 July release was used for this phase.

If a concept in ICNP Version 1 does not match linguistically or structurally with a concept in SNOMED, next phase is the semantic matching of concepts. Semantic matching is an approach where semantic relations are examined between concepts (not between labels) based on textual definition or usage in nursing practice and hierarchical relationship of the concept with other concepts [8, 9]. For semantic matching, we traced back to the original source of the ICNP Version 1 concepts, examined the display name of the concept in the source language and then tried to map the display name to SNOMED CT concept. Possible semantic relations are equivalence, more general, less general, mismatch, and overlapping. Again CLUE browser with SNOMED CT 2007 July release was used for this phase.

For our study, mapping results were classified as following. If an ICNP Version 1 concept is matched linguistically and structurally to a SNOMED CT concept, it is classified as lexically mapped. If an ICNP Version 1 concept matched semantically to a SNOMED CT concept, it is classified as semantically mapped. If an ICNP Version 1 concept matched to a more general SNOMED CT concept, it is classified as mapped to broader concept. If an ICNP Version 1 concept matched to a less general SNOMED CT concept, it is classified as mapped to narrower concept. If a concept is a compound concept or has text definition describing more than one concept we mapped to more than one concept of SNOMED CT (ex, 'Craving' mapped to 'Craving for food or drink' and 'Craving for drugs'). In this case, we classified as one-to-many mapped. However, we tried not to map to either a broader or a narrower concept as much as possible. Otherwise, it is classified as not mapped.

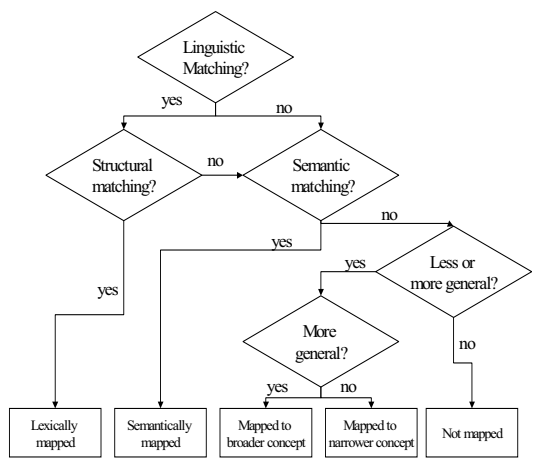

Figure 1- Mapping process of ICNP Version 1 concepts to SNOMED CT concepts

The mapping was validated by a team of SNOMED and ICNP experts including the second and third authors by more than fifteen 1-2 hour web conferencing such as GoToMeetings and four two day face-to-face meetings. If there was any disagreement during validation process, we convened another meeting to reach a consensus.

During mapping, we used the text definition of ICNP concept as our first mapping criteria. If an ICNP concept does not have a working definition, we tried to find where the term came from and how it is being used in nursing practice. If we could not find how it is being used in nursing practice, we did not attempt to map the concept. If possible, we tried not to map to either a broader or a narrower concept.

Results

Concepts in the Focus, Mean, Time, and Location Axis were mapped to more than one SNOMED CT hierarchies. Concepts in the Focus Axis were mapped to Clinical findings, Observable entity, Body structure, Environment, Event, substance, Organism, Physical force, Specimen, and Qualifier value hierarchies. Concepts in the Mean Axis were mapped to Physical object, Procedures including Regime/Therapy, Social context - occupation, Substance, Product, Staging and scales including Assessment Scales, and Qualifier value hierarchies. Concepts in the Time Axis were mapped to concepts in the Qualifier value and Event hierarchies of the SNOMED CT. Concepts in the Location Axis were mapped to concepts in the Body structure including Morphological abnormality, Environment, Qualifier value, Findings, and Physical object hierarchies of the SNOMED CT. Concepts in the Judgment, Action and Client Axis were mapped to one hierarchy of the SNOMED CT, the Judgment Axis to Qualifier Value hierarchy, the Action Axis to the Procedure hierarchy, and Client Axis to the Social context hierarchy of the SNOMED CT.

Table 1 shows the mapping result. In total, 1381 out of 1658 concepts were mapped. (83%). Mapping rates range from Axis to Axis. While most of concepts in the Judgment and Location Axis were mapped to concepts of the SNOMED CT (94%), the Action Axis has the lowest mapping rate (66%).

Table 1-Mapping results of ICNP concepts to SNOMED CT concepts

Mapping Result		Focus	Action	Means	Time	Judg-ment	Loca-tion	Client
Mapped	LM	345	20	122	22	15	153	18
	SM	304	111	115	21	17	68	1
	BT	20	2	5				
	NT	10	7					
	1:n Map	2	1				3	
Not Mapped	add new con-cept	122	3	18	18	1	8	8
	No usage	13	70	9		1	6	
Total		816	214	269	60	34	238	27

In detail, Focus concepts describing disease, disorders, signs and symptoms were mapped concepts in the Finding hierarchy of SNOMED CT. 'Community leadership', 'management', 'participation', 'law', 'committee, and policy' were mapped to Community Resource findings of the Finding hierarchy.

Focus concepts with neutral connotation such as Process, Function, Status and Pattern related concepts were mapped to concepts in the Observable entity hierarchy of SNOMED CT. 'Process' concepts of the ICNP Version 1 were mapped to Function concepts of the Observable entity hierarchy of SNOMED CT, because they are describing body function (ex, cardiac process). 'Status' concepts of the ICNP Version 1 were mapped to concepts in the Observable entity of SNOMED CT (ex, respiratory status). 'Pattern' concepts of the ICNP Version 1 were mapped to concepts in the Observable entity hierarchy (ex, eating pattern).

System concepts of the Focus Axis were mapped to concepts in the Body structure hierarchy of SNOMED CT (ex, cardiovascular system). Morphological abnormalities without any judgment or body sites were mapped to concepts in the Morphologic abnormality of SNOMED CT, which is part of Body structure (ex, ulcer).

Focus concepts describing pressure, radiation, light, and weather were mapped to concepts in the Physical force hierarchy of SNOMED CT. Focus concepts describing abuse, suicide, and environmental events such as flood, earthquake, and wind were mapped to concepts in the Event hierarchy of SNOMED CT. Focus concepts describing agricultural development, industrial development, residential development, recreational development, infrastructure, food supply, and foul odor were mapped to concept in the Environment hierarchy of SNOMED CT.

Focus concepts describing Body secretion, gastric contents, body fluid, and body material were mapped to concepts in the Substance hierarchy of SNOMED CT. Concepts describing animal, microorganism, and plant were mapped to concepts of the Organism hierarchy of SNOMED CT. Specimen concept was mapped to hierarchy of the Specimen of SNOMED CT. Social status concepts of the Focus Axis were mapped to Social context hierarchy of SNOMED CT. Focus concepts describing Services (ex, funeral service), rate and ratio were mapped to concepts in the Qualifier value hierarchy of SNOMED CT.

All of concepts in the Judgment Axis except 'Positive or negative judgment' and 'Potential for enhancement' were mapped to concepts in the Qualifier value hierarchy of the SNOMED CT. 'Positive or negative judgment' is a compound concept used as a grouper in the Judgment Axis. We did not map this concept to SNOMED CT. 'Potential for enhancement' can be modeled as a child concept of 'Finding context value' of the Qualifier value hierarchy of SNOMED CT.

Means Axis of the ICNP consisted of artifact, care provider, health service, material, technique and therapy. Artifact concepts were mapped to Physical object and Qualifier value hierarchies, care provider concepts to Social context hierarchy, health service concepts to Qualifier value hierarchy, material concepts to Substance and Product hierarchies, and technique and therapy concepts to Procedure hierarchy of the SNOMED

CT. We did not map compound concept in the Mean Axis used as a grouper to organize concepts. Examples of compound concepts are 'Absorbing or Collecting Device.' 'Meal' concept was not mapped to SNOMED CT because it has IS-A relationship problem with its parent concept, 'Nutrient.' There are synonymous concepts in the Means Axis. For example, 'Hemostasis technique' and 'Hemostasis technique for patient' are synonymous.

The Action Axis has the lowest mapping rate because concepts in the Action Axis are mainly gerund form of verbs used to as a building block to populate nursing intervention catalogue concepts rather than actual nursing intervention or nursing activity (ex, facilitating, promoting, and collaborating). These verb concepts are very ambiguous and can be used only when they are combined with concepts from other axis. There are over 200 verbs in the Action Axis. Some of these verbs are very difficult to distinguish from one another. One example is 'Teaching', 'Educating', and 'Instructing'. Another example is 'Describing', 'Documenting', and 'Recording'. On the contrary, there are very specific concepts in the Action Axis which has more detailed granularity than the other verbs. Examples are 'Alcohol life style prevention', 'Contamination prevention', 'Fall prevention', 'Safety measure', and 'Anticipatory guidance.' These concepts can be moved to the ICNP nursing intervention catalogues. There are compound verb concepts with unnecessary word 'act' attached (ex, 'Setting up act', and 'Giving act'). For these concepts removing the word 'act' would not change the meaning of the concepts.

Concepts in the Time Axis were mapped to concepts of the Qualifier value and Event hierarchies of SNOMED CT. 'Birth', 'Death', 'Fall', and 'Rite of passage' were mapped to concepts of the Event hierarchy of SNOMED CT. Most of the Time Axis concepts were mapped to the Qualifier value hierarchy. However, for the Time concepts not mapped to SNOMED CT such as 'Always', 'Never', 'Future', 'Today', 'Tomorrow', 'Yesterday', 'Toddler period', 'Pre school childhood', 'School childhood', 'Duration of operation', 'Examination', 'Delivery' and 'Menarche' can be added to the Qualifier value hierarchy of the SNOMED CT. There are synonymous concepts in the Time Axis. For example, 'Neonatal period' and 'New born period' of ICNP are synonymous and mapped to 'Neonatal (qualifier)' of SNOMED CT.

Concepts in the Location Axis were consisted of construction, position and structure related concepts. Construction related concepts were mapped to the Environment hierarchy of SNOMED CT. Position related concepts were mapped to the Qualifier Value and the Findings hierarchies of SNOMED CT. Structure related concepts were mapped to the Body structure including Morphological abnormality, the Qualifier value and the Physical object hierarchy of SNOMED CT. Concepts not mapped to SNOMED CT includes grouper such as 'Body opening', 'Structure', 'Social structure', and 'Diagnostic department'. Also, there is a problem of hierarchical relationship among 'Parenteral route', 'Intravenous, Intramuscular', and 'Subcutaneous route' of ICNP Version 1. These four concepts were treated as siblings even though 'Parenteral route' and three other routes should have a IS-A relationship.

Concepts in the Client Axis consisted of fetus, group and individual. All the concepts except 'Fetus', 'Couple', 'Nuclear family', 'Extended family', 'Single parent family', 'Female headed single parent family', 'Adolescent community', 'Family caregiver' were mapped to concepts of the Social context hierarchy of SNOMED CT.

Discussion

Mapping ICNP Version 1 concept to SNOMED CT was a very challenging task because two terminologies covers different domains and areas of focus, and have different structures. SNOMED CT is a very broader healthcare terminology covering nursing as well, however ICNP is a nursing terminology. ICNP is consisted of 7-Axis (Focus, Judgment, Means, Action, Location, Time and Client) to represent nursing diagnoses, nursing interventions and nursing outcomes and SNOMED CT is consisted of 19 hierarchies to represent diagnosis, procedures, anatomy, chief complaints, vital signs, physical findings, plans, problem list, history, allergies, immunization and medication management.

Also, the two terminologies have different areas of focus. ICNP covers not only critical care nursing but also community health nursing; however SNOMED CT focuses more on critical care. Also, a concept with same label has different meaning in the two different terminologies. For example, 'depression' in medical domain means 'depressive disorder', however 'depression' in nursing means 'sadness'.

Mapping was also very challenging because it was hard to understand different hierarchies of SNOMED CT. Same concept label was found in different hierarchies. Especially it was hard to distinguish the Finding hierarchy from the Observable entity hierarchy when mapping concepts of ICNP Focus Axis and the Procedure hierarchy from the Qualifier value hierarchy when mapping Service related concepts.

The ICNP concepts were mapped to SNOMED CT concepts based on the definition and/or location of the concept in the hierarchy. Descriptive definitions of ICNP concept was very helpful when mapping to SNOMED CT, however, there are quite a few concepts without text definition (ex, environmental process), with ambiguous definition (ex, obstruction) or more than one definitions (ex, informal settlement). The definitions need to be clarified or new definitions needs to be added.

There was hierarchy problem between parent and child concepts. For example, Integrity was a concept describing a trait of person; however a child concept of Integrity, Skin integrity is a concept describing physical aspect of skin. There are concepts misplaced in wrong Axis. For example, pregnancy prevention, and pregnancy promotion are in the Focus Axis. These concepts should be in the nursing intervention catalogue. Also, there are catalogue concepts in the 7-Axis model. Examples are Alcohol life style prevention, Contamination prevention, and Fall prevention in the Action Axis. They should be in the nursing intervention catalogues.

During the mapping process, we found that SNOMED CT lacks concept describing community health such as health ser-

vices, health policy, community resources, population statistics (e.g., mortality rate, incidence rate, immunization rate, infant death rate, unemployment rate); industrial health, value belief and psychological finding. This can be explained by the history and scope of the two terminologies. ICNP was developed to describe not only acute care setting, but also the community health; however focus of the SNOMED CT has been the acute care setting.

We also found that ICNP concept can be mapped to more than one SNOMED CT concept from different hierarchies. For example, 'specimen' can be mapped to concept in the Substance hierarchy and the Specimen hierarchy. 'Social Status' concept with home ownership, income and social isolation as children concepts can be mapped to concepts of the Observable entity hierarchy and the Social context hierarchy. Concepts describing Services can be mapped to the Regime/Therapy hierarchy and the Qualifier value hierarchy of the SNOMED CT. This is due to the fact that ICNP Version 1 – the 7-Axis model is a building block that can be used to generate nursing diagnosis, nursing interventions and nursing outcomes statements. Thus, a concept can be very ambiguous and not be used before it combines with concepts from other axis.

There are many synonyms in the ICNP Version 1 concepts (ex, 'rash' and 'exanthema'; 'autonomic dysreflexia' and 'dysreflexia'; 'care plan' and 'critical pathway', 'guideline' and 'protocol'). There are concepts hard to distinguish even though their concepts labels are different (ex, 'Tissue perfusion' vs 'Tissue perfusion status', 'teaching' vs 'educating' vs 'instructing'; 'dressing' vs 'getting dressed or undressed' vs 'putting on clothes vs taking off clothes)

There are compound concept which used as a grouper, these concept need to be renamed or divide into two different concepts. Examples are Positive or Negative Judgment from the Judgment Axis, Self dressing or undressing from the Focus Axis, Absorbing or collecting device from the Means Axis, and Heating cooling device from the Means Axis.

When mapping ICNP to SNOMED CT, sometimes parent and child concepts were mapped to different hierarchies of SNOMED CT. For example, 'weight' of the Focus Axis was mapped to Weight in the Observable entity hierarchy; however 'overweight' which is a child concept of 'weight' was mapped to 'overweight' in the Finding hierarchy.

When a concept is not mapped to SNOMED CT concepts and is being used in nursing practice, we either can model the concept in the SNOMED CT or post-coordinated the concept by combining existing SNOMED CT concepts. Examples are pain related concepts such as arthritis pain, cancer pain, and ischemic pain. They can be added under 'Pain (finding)' or they can be post-coordinated by combining 'Pain' in the Finding hierarchy and other concept from other hierarchy. SNOMED CT has atomic concept as well as pre-coordinated concept. Thus, it is hard to decide to add a new concept or post-coordinated a concept by combining two concepts. However, for the concepts from ICNP Version 1 concepts, we have decided to model the concept in the SNOMED CT rather than post-coordinate the concept. We recommended unambiguous fully specified name of the concept and location within the hierarchy to model the concept.

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Chapter 16.

Data, Databases and Information

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Facilitating Secondary Use of Medical Data by Using *open*EHR Archetypes

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Abstract

Clinical trials are of high importance for medical progress. But even though more and more clinical data is available in electronic patient records (EPRs) and more and more electronic data capture (EDC) systems are used in trials, there is still a gap which makes EPR / EDC interoperability difficult and hampers secondary use of medical routine data. The openEHR architecture for Electronic Health Records is based on a two level modeling approach which makes use of 'archetypes'. We want to analyze whether archetypes can help to bridge this gap by building an integrated EPR / EDC system based on openEHR archetypes. We used the 'openEHR Reference Framework and Application' (Opereffa) and existing archetypes for medical data. Furthermore, we developed dedicated archetypes to document study meta data. We developed a first prototype implementation of an archetype based integrated EPR / EDC system. Next steps will be the evaluation of an extended prototype in a real clinical trial scenario. Opereffa was a good starting point for our work. OpenEHR archetypes proved useful for secondary use of health data.

Keywords:

Computerized medical record systems, Clinical trials, Interoperability, Multiple use of data, Single source, *open*EHR archetypes.

Introduction

Clinical trials are the major element in clinical research and of high importance for medical progress. By now, more and more clinical data is available in electronic patient records (EPRs). Similarly, there is a trend to collect data in clinical trials by using electronic data capture (EDC) systems. Numerous efforts in research and industry have led to improvements of EPR and EDC systems in the past years. However, there is still a gap which hampers a straightforward data exchange between EPR and EDC systems and which makes it difficult to use routinely collected medical data in clinical research [1-3] – especially in multicenter studies [4].

The lacking interoperability between EPR and EDC systems not only hampers translational biomedical research but also results in the necessity to manually enter data for a clinical trial in an EDC system which is already available electronically in an EPR: A time-consuming task which beyond that may also cause transcription errors [5].

Another obstacle for EPR / EDC interoperability is that standards for electronic data exchange in clinical care (for instance Health Level 7 version 2) and in clinical research (for example standards of the Clinical Data Interchange Standards Consortium – CDISC) are still quite different [2-4].

Facilitating EPR / EDC system interoperability would not only help clinical research by saving time and money and avoiding transcription errors but also support translational research by reusing clinical care data for medical research and vice versa. Therefore, different efforts have been made in the last years to bridge this gap and there are some examples of successful approaches (for instance [5]). These approaches often integrate a particular EPR system with a particular EDC system (for example [6]). Even though this is a good starting point, many times multicenter trials involve trial centers which have different EPR systems in place.

Bridging the gap with *open*EHR

The *open*EHR architecture for Electronic Health Records (EHRs) is based on a two level modeling approach which makes use of 'archetypes' [7, 8]. Archetypes "... are reusable, structured models of clinical information concepts that appear in EHR, such as 'test result', 'physical examination' and 'medication order'..." [9]. We think that archetypes could not only facilitate the documentation of medical data and interoperability between different EPR and EDC systems but also support data recording in clinical trials and help to integrate study data management systems [10].

The overall aim of our study is to explore how a system for recording data in clinical trials can be built based on the *open*EHR approach so that it is able to reuse the data of an EPR system. We further want to investigate whether such an archetype-based approach enables smooth integration of existing medical data at different sites.

Therefore, we built the **open S**tudy **D**ata **M**anagement **S**ystem (openSDMS). OpenSDMS is a prototypical system based on

*open*EHR concepts which allows not only recording of medical routine data but also electronic data capture for clinical trials. OpenSDMS facilitates both entering medical data for clinical trials manually and also (in a 'single source approach') reusing medical routine data which were previously stored in the EPR module. Furthermore, the system shall be able to integrate data of different (also non-*open*EHR) EPR systems for one trial. This paper describes our concept and first experiences with implementing the openSDMS.

Materials and Methods

Opereffa

As a basis for openSDMS we use the '***open*EHR REF**erence **F**ramework and **A**pplication' (Opereffa – http://opereffa.chime.ucl.ac.uk) which is developed at the University College London. Opereffa is a web based application which uses Java Server Faces as web layer technology. In addition, the Dojo Toolkit is used to provide Asynchronous JavaScript and XML (AJaX) and extended user interface capabilities. To physically store data Opereffa uses Hibernate with an underlying PostgreSQL database as persistence layer. In an entity-attribute-value (EAV) model approach all archetype nodes are saved as attribute/value pairs in a single generic table [11]. That means the system uses only one table to store all medical data. Every row of this table contains one data element recorded for a certain patient at a certain time. Expressed in simplified terms, one dataset respectively one row consists of the following elements: Patient id (identifying a certain patient), session id (identifying a certain documentation context), archetype name, archetype path (together with archetype name unambiguously identifying one data element) and the actual value of the data element.

Opereffa itself makes use of the *open*EHR Java Reference Implementation [12].

Archetypes for clinical trials

As we wanted to document not only medical data which has been recorded for a clinical trial but also the structure and a description of the trial itself, we started to assemble meta data which describe typical concepts of clinical trials. We identified these data elements in a systematic review of the feature categories which are recorded in the German Clinical Trials Register (German CTR – http://www.germanctr.de) respectively in the International Clinical Trials Registry Platform of the WHO (ICTRP – http://www.who.int/ictrp/en/). Additionally we evaluated feature categories which are used in the Coordination Center for Clinical Trials Heidelberg (http://www.kks-hd.de) to register information about the trials conducted or supported by the coordination center. This list of feature categories was developed in an iterative process involving its end users.

In a next step, we defined archetypes for the study meta data in addition to existing archetypes for medical data. For this, we designed a model of concepts based on the previously assembled meta data which are necessary to describe the structure and nature of a clinical trial. The model is described in detail in the results section (Figure 1).

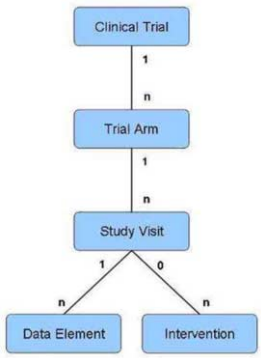

Figure 1 - Generic trial structure

Even though, these concepts are not directly related to clinical data but to clinical trials at a meta level, we used the *open*EHR Clinical Knowledge Manager (http://www.openehr.org/knowledge/) to check whether corresponding archetypes were already available or not. We used 'clinical trial', 'clinical study', 'trial', and 'study' as search terms. As suitable archetypes were not available, we started to define new archetypes using the 'Ocean Archetype Editor'. We created one archetype per concept of our model. Each of these archetypes defines the data elements which are necessary to describe an instance of the underlying concept.

openSDMS

In a next step, we built the openSDMS by extending Opereffa according to our requirements. For this, we added a 'trial view' to the user interface of Opereffa and implemented the underlying program logic. There, we took advantage of existing Opereffa code and used our newly defined archetypes.

Results

Archetypes for clinical trials

Based on our model of concepts for describing the structure and nature of clinical trials (Figure 1) we defined the archetypes 'clinical trial', 'trial arm', and 'study visit' which allow describing clinical trials by recording the particular meta data. For instance, the archetype 'clinical trial' defines 47 data elements like 'trial name' or 'phase' (Figure 2).

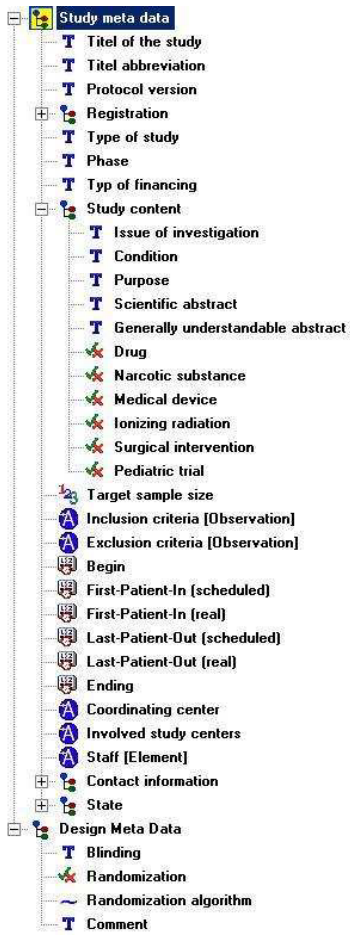

Figure 2 - Definition of the archetype 'clinical trial'

The concept 'clinical trial' is the root element of our model. One trial consists of at least one 'trial arm'. One trial arm consists of at least one 'study visit'. Within one visit at least one data item is captured or one intervention (medication, surgery...) is undertaken and recorded. While an observational study typically consists of one arm maybe with only one visit, a controlled trial consists of at least two arms.

Using the archetypes which reflect our model enables easy storage of data which describe a clinical trial in a system based on archetypes. It thus becomes possible to collect and store medical data and to assign these data to a certain trial arm, for example.

openSDMS

Our overall aim was to build a prototypical system based on *open*EHR concepts which allows electronic data capture for clinical trials not only by entering the data manually but also by reusing data which were previously stored in an EPR module in a single source approach. With openSDMS we now have a prototype for such a system. OpenSDMS is completely based on archetypes which means, that almost all data processing and storage within the system is based on archetypes.

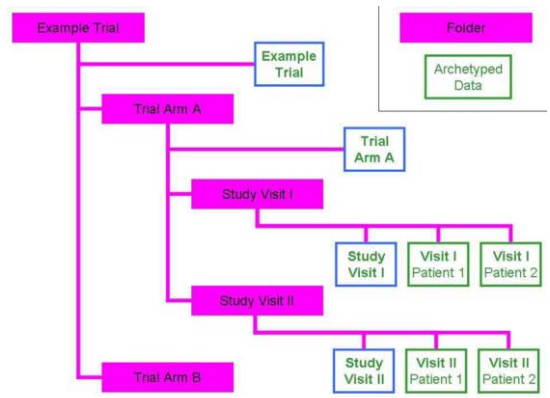

Figure 3 - Folder structure to model clinical trials

To facilitate a smooth presentation of all data items which logically belong together (for instance all data items which were captured for a certain study visit in a certain trial), we used the *open*EHR concept of 'folders' [13]. *Open*EHR folders enable logically grouping of recorded data and thus presenting the same data compositions in different folders. We used a similar mechanism in openSDMS to pool medical data not only of one patient but also of a certain clinical trial. For this, we use a virtual folder structure (Figure 3) according to our previously introduced generic trial structure (Figure 1). As a result, every folder contains – beside the medical data –some kind of meta data which describes the particular element and which is based on our newly defined archetypes. The concrete mapping of our generic trial structure to the folders is described in the following.

The 1:n relation between clinical trial and trial arm is modelled by having one folder per clinical trial which contains one dataset describing the trial itself (based on the clinical trial archetype) and a number of subfolders where each subfolder represents one trial arm. The 1:n relation between trial arm and study visit is represented analogously. The folder of each visit contains a visit description (based on the study visit archetype) and all medical datasets of different patients which have been recorded in the context of that particular visit. The single medical datasets will be visible in respective folders of the single patients together with further medical data. This means that medical data – independent of its use in a medical record or a clinical trial record – is physically stored only once in a generic way in openSDMS which complies with a 'single source approach'.

That way, it is possible to bring together all data of one study visit (of a particular trial arm in a particular trial) in one folder. The respective medical data of all patients at whom that visit took place is mapped to the respective directory. Supplemented by a description of the trial structure and other study

meta data, that results in a complete data set of one clinical trial.

Discussion

Archetypes for clinical trials

Per definition, *open*EHR archetypes are geared to comprehensively describe and structure a clinical concept in any context (cf. [14], pp. 10). Therefore, we believe that archetypes used to record medical data in EPR systems are also suitable to record medical data in the context of clinical trials. Furthermore, if an archetype was not found to be sufficient for the requirements of a clinical trial, it can be extended. It seems to be of advantage especially for clinical research that data stored in an *open*EHR based system have a 'built in' degree of validity as they have to conform to both a generic and stable information model and the models of clinical data as defined by the used archetypes.

We developed a dedicated set of archetypes to enable documentation of study meta data and to describe concepts associated with clinical trials like 'trial arm' or 'study visit' in the openSDMS. It would have been also possible to store these data just by creating additional tables in the database used by openSDMS. However, we decided to make use of archetypes because of two reasons:

1. Archetypes originally allow to systematically structure and describe the data which characterize the underlying concepts and by that, built a helpful discussion basis for the description of these concepts.
2. The archetype based representation enabled us using the same (already existing) program code which is used to process, store and transmit medical data, also for the processing of study meta data.

The archetypes we have developed for clinical trials are still draft versions. To enable their reusability in clinical trials nationally and internationally, we will bring these archetypes into a critical, public review process.

openSDMS

With our system we are able to explore technical issues associated with secondary use of medical data in EPR systems for clinical trials and to evaluate possible solutions. However, our system is still a prototype in the sense that just core functionality has been implemented. In contrast to a real study data management system further functionality is missing. For instance no plausibility checks or query management functionality have been implemented, yet.

Furthermore, Opereffa proved as a good starting point for the development of openSDMS. However, Opereffa itself is still under development and has to be improved step by step to fully implement the openEHR specifications. Therefore, we tried to implement openSDMS based on Opereffa but by observing information hiding principles as good as possible to allow for an update of Opereffa without having to adjust internal parts of the openSDMS implementation.

One relevant aspect of reusing data in EPR systems for clinical trials is data privacy protection. The underlying database of openSDMS consists of mainly one entity-attribute-value model based data table which only contains a patient id for relating the single entries to the particular patients. This seems to be an advantage, as it facilitates a separation of identifying data (like patient name) and medical data. According to the respective view and user (for instance medical record/physician or trial record/data manager) the system could display the patient name respectively only a pseudonymized patient id. We will explore whether this idea can be supported by integrating a pseudonymization software which has been developed by the German ‚Telematikplattform – Verbund zur Förderung vernetzter Medizinischer Forschung' (TMF – http://www.tmf-ev.de) specifically for scenarios like this one. The TMF crosslinks medical research in Germany as umbrella organization.

Perspective

In a next step, openSDMS will be extended by an export function for the study data based on the Operational Data Model (ODM – [15]) which has been developed by the Clinical Data Interchange Standards Consortium (CDISC). This shall enable openSDMS to export the captured trial data to other study data management systems.

However, the system shall not only facilitate storing data in an integrated EPR module and using that data for clinical trials but also to integrate data of different EPR systems for one trial. Therefore, in a further step, interoperability with other EPR systems will be established to enable importing of existing medical data into openSDMS. It is planned to make use of integration archetypes for that task.

Having openSDMS acting as a bridge between EPR and EDC systems, in a third step, the strengths and weaknesses of openSDMS will be evaluated. We plan, to evaluate the openSDMS in a real but manageable clinical trial setting.

Our approach and aims have similarities with other existing approaches – for instance the STARBRITE Proof-of-Concept Study [5] which uses the CDISC Operational Data Model and HL7 Clinical Document Architecture to integrate clinical routine and trial data in a single source approach. In contrast to these approaches we use openEHR archetypes for integrating clinical routine and trial data. Archetypes as structured models of clinical information concepts pledge to be a good basis for the future integration of different data sources which typically occur in multicenter trials. Furthermore, in contrast to other approaches, systems based on *open*EHR archetypes promise high sustainability as they strictly separate the modeling of clinical concepts (archetypes) and the technical implementation. If a concept has to be adapted to new requirements this can be done easily and not only by technicians but also by domain experts – for instance physicians.

Conclusion

Archetypes for clinical trials

*Open*EHR archetypes which have been defined to document medical data in EPR systems seem to be also suitable to document medical data in the context of clinical trials and to support single source approaches. Furthermore, the archetypes we developed make it possible to document trial metadata in an *open*EHR based system in the same way as medical data.

openSDMS

The core functionality of openSDMS has been developed. However, some fine tuning is required – for instance with regard to the graphical user interface – until the system can be evaluated in a real clinical trial scenario. This will be a further step of our research. We assume that one necessary key factor for the success of openSDMS in addition to its flexibility will be its ease of use. Especially the generation of case report forms has to be supported by easy-to-use tools.

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The Impact of a Growing Minority Population on Identification of Duplicate Records in an Enterprise Data Warehouse

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Abstract

Patient medical records are often fragmented across disparate healthcare databases, potentially resulting in duplicate records that may be detrimental to health care services. These duplicate records can be found through a process called record linkage. This paper describes a set of duplicate records in a medical data warehouse found by linking to an external resource containing family history and vital records. Our objective was to investigate the impact database characteristics and linkage methods have on identifying duplicate records using an external resource. Frequency counts were made for demographic field values and compared between the set of duplicate records, the data warehouse, and the external resource. Considerations for understanding the relationship that records labeled as duplicates have with dataset characteristics and linkage methods were identified. Several noticeable patterns were identified where frequency counts between sets deviated from what was expected including how the growth of a minority population affected which records were identified as duplicates. Record linkage is a complex process where results can be affected by subtleties in data characteristics, changes in data trends, and reliance on external data sources. These changes should be taken into account to ensure any anomalies in results describe real effects and are not artifacts caused by datasets or linkage methods. This paper describes how frequency count analysis can be an effective way to detect and resolve anomalies in linkage results and how external resources that provide additional contextual information can prove useful in discovering duplicate records.

Keywords:
Record linkage, Subpopulations, Minority population

Introduction

It is common in large healthcare databases for information to be collected at different times in different places by different people. The disparate and sometimes inconsistent manner in which information is collected can lead to fragmented pieces of a person's medical information being persisted. Multiple records belonging to the same person, but mistakenly thought to belong to different people are called duplicate records. Having a single person's medical information spread across multiple records increases the time it takes to retrieve information, increases the risk of providing an incomplete patient history, and ultimately can impact patient care [1]. It therefore is important to find and eliminate duplicate records. Duplicate records are found by comparing pairs of records in a process called record linkage. The dominant method for linkage is the probabilistic approach formalized by Fellegi and Sunter [2]. This method is used in the non-trivial case where record identifiers do not match perfectly, but are close enough that they may be identified as duplicates.

Duplicate records are often found by comparing pairs of records within a single database. This paper describes an alternative situation where a second, external database exists which can be used to help identify duplicates. The enterprise data warehouse (EDW) of the University of Utah Health Sciences Center is an aggregate of medical records generated from inpatient and outpatient settings. It is routinely examined internally for duplicate records and is also linked to the Utah Population Database (UPDB), an external resource containing family history and vital records. In this second comparison, when two or more records in the EDW link to the same UPDB record, they are marked as potential duplicates. The EDW staff is notified of potential duplicates, verifies and resolves them if needed. All records, even known duplicates, are linked to the UPDB as an additional check to EDW internal deduplication processes.

In this study, we compared the frequency of name values in records in the duplicate subset with records in the full EDW and UPDB and describe instances where records in the duplicate subset are not typical of the database at large. We provide considerations for others looking at duplicate records in healthcare databases that help detect and resolve anomalies in

linkage results with population characteristics and linkage methods that are applied.

Materials and Methods

Data Sources

The University of Utah Health Sciences Center maintains an EDW that contains records for more than 1.8 million people resulting from all inpatient and outpatient visits to its hospitals and clinics since 1993. The demographic data in the EDW comes from both patient administration systems and physician billing systems. The EDW maintains a demographic record for each patient that contains fields describing a person's names, date of birth, sex, Social Security Number, addresses, phone numbers, and information about spouse and next of kin.

The UPDB is a research resource administered by the Utah Resource for Genetic and Epidemiologic Research. It was created in the mid-1970's using family histories from the Utah Genealogical Society containing the genealogy of the descendents of the Utah Pioneers [3]. The UPDB has since added records of Utah births, marriages, divorces, and deaths along with diagnosed cancers and driver license records. Each of these data sources gives extra information that can aid in the matching process. Records for each individual are grouped together into a person record - the composite of the best information available about a single person from one or more UPDB records. The more than 7 million person records in the UPDB contain demographic and family history information about individuals. Because of the scale and diversity of sources used to create the UPDB, most families living in Utah are represented in it. Birth and marriage certificates are used to expand the genealogy records and some families span as many as eleven generations. These data can only be used for biomedical and health-related research; the privacy of individuals represented in these records and confidentiality of the data is strictly protected [4]. The ability to correlate genealogy, medical, and demographic information makes the UPDB a valuable resource that has been used in many research studies [5]. For example, the UPDB was instrumental in discovering genes related to breast cancer [6,7], melanoma [8], colon cancer [9], and several other diseases.

Linkage Methods

In the interest of investigating the heritability of disease, the medical records available in the EDW are regularly linked with UPDB person records. The staff that manages the UPDB complete this activity using software that implements probabilistic record linkage.

First, middle, and last names of a patient are compared directly to the first, middle, and last name fields in a UPDB person record. Names for spouse and next of kin are compared to records linked through genealogy with the respective relationship to a particular person record. Because the EDW contains the patient's mother's maiden name, it is compared with the record linked through genealogy that is the mother of a particular person record. Both addresses in the EDW are compared with the address histories in the UPDB. Although the UPDB does not contain a history of phone numbers, the home and work phone numbers in the EDW are included since phone numbers are common identifiers used in linking at other institutions. Both the EDW and the UPDB contain more than Male and Female values for sex, including Unknown and a few other medical classifications.

Statistical Analysis

The top 2,500 most common last name values in the EDW were empirically categorized as *Founder* for Northern and Western European names; as *Traditionally Hispanic* for names typical of Latin and South America; or as *Other Ethnicities* as a collective group of Asian, Middle Eastern, and Native American names. Categorization of ethnicity based on last name was determined based using lists of names common in countries and by searching the origin of the name.

We compare frequency counts of demographic field values in the set of records identified as duplicates with the EDW generally. If duplicates occur at random within the EDW we would expect that values in these two sets would have the same relative frequencies. Comparisons that reveal notable deviations from this expectation may indicate possible areas where the matching process can be improved. Regression lines were calculated for each category comparing frequencies in the duplicate set with the EDW and the EDW with the UPDB.

Results

Of the 1,850,683 demographic records in the EDW, 1,375,704 were linked to UPDB person records. Of those, 209,852 EDW records linked to UPDB records that were simultaneously linked to by other EDW records; these were marked as potential duplicates and were used in this analysis.

Figure 1 shows the frequency of the 2,500 most common last name values in the EDW and duplicate set.

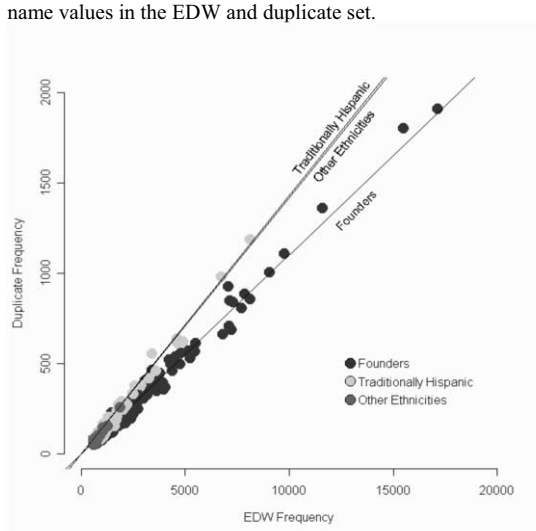

Figure 1 - Comparative frequency of ethnicity in the EDW and duplicate set

The name values are separated by assigned ethnicity with linear regression trend lines for each showing that Traditionally Hispanic names and names of Other Ethnicities are overrepresented in the duplicate set.

Figure 2 shows the frequency of the same 2,500 most common last name values in the EDW and UPDB.

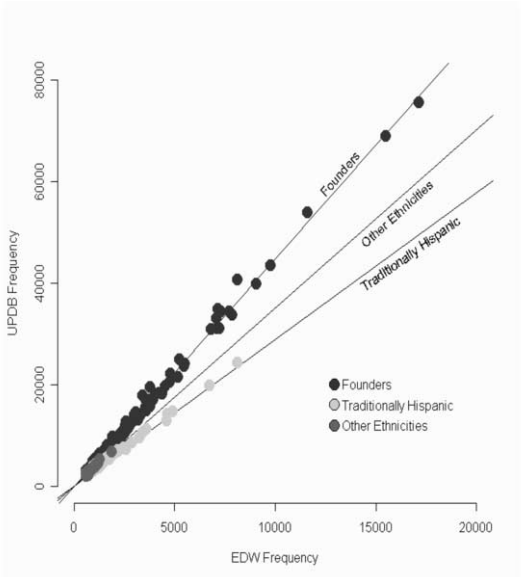

Figure 2 - Comparative frequency of ethnicity in the EDW and UPDB

The separation between Traditionally Hispanic names and those common among Founders in this comparison is even greater.

Discussion

An interesting artifact revealed in the linkage process was a division between names common among Utah founders and those common in the state today. First identified with the value Maria, a first name common in the overall population that is even more common among Hispanics, it became apparent that many of the names overrepresented in the duplicate set were traditionally Hispanic. Although less pronounced because much less frequent in the population, common Vietnamese, Korean, Chinese, Navajo, and Arabic names exhibited the same overrepresentation in the duplicate set. It was important to understand whether the higher proportion of Hispanic names existed in the duplicate record as an artifact of the linkage process or a real effect of the changing population.

The UPDB historically contains information that reflects the mostly North and West European background of the initial settlers of Utah [10,11]. The cultural face of Utah is changing, however, including a recent increase in the Hispanic population of Utah. In 1970, 95% of the Utah population was white and non-Hispanic compared to 85% in 2000 [10]. During the decade between 1990 and 2000, the Hispanic Population in Utah increased by 138% while the overall population increased by only 30% [12,13] This trend has continued since 2000 as the Hispanic population in Utah has increased at least three times faster annually than the overall population of Utah [13]. In addition to the recent increase, more than half of the Hispanic population lives in Salt Lake County, the area serviced by the University of Utah and thus represented in the EDW [14]. The recent demographic changes may not be adequately reflected in the UPDB. Temporary migrants who receive care at a hospital or clinic, but do not remain in Utah long enough to have a life event recorded in the UPDB will not have a person record created.

It is possible that by performing a single linkage with records of persons from all ethnicities, that a record linking process may not appropriately weight name frequencies. For instance, Martinez is the most common Hispanic last name in the duplicates, but only the 5th most common last name overall in the EDW and only the 19th most common name in the UPDB; Torres is the 10th most common Hispanic name in the duplicates, 59th in the EDW, and 203rd in the UPDB; and so on. As many of the common names in the EDW are found much less frequently in the UPDB, the likelihood of records being classified as duplicates when values match may artificially be inflated. Performing linkage on individual subpopulations may produce a more accurate result set, though it may be difficult to correctly decide how to classify records, particularly in cosmopolitan populations with diverse and inter-marrying ethnic populations. Other work suggests that it is not the ethnicity of an individual that causes linkage issues but the characteristics of names of certain origins that follow different naming conventions and phonetic rules than linkage tools are designed to consider [15]. Our work suggests that the uneven distribution of names between the datasets also affects linkage. Linkage artifacts caused by such a discrepancy may be less of an issue when values in both datasets are more balanced.

On the other hand, it is possible that a group may be legitimately overrepresented in the duplicate set. It is likely that names unfamiliar to registration clerks and other hospital staff would have an increased occurrence of misspellings. This could happen either during transcription, when a clerk enters information into a computer record from a paper sheet the patient filled out, or dictation, when a clerk writes or types information that a patient speaks. It may be the case for persons who do not speak English as their first language that information presented at different times and places may contain inconsistencies because of confusion, miscommunication, different traditions and feelings about record keeping, or the possible use of translation services.

Additionally, many database designs, including the EDW and the UPDB, hold that a person's name consists of a first name, a middle name, and a last name. In many cultures, this is not the case. Hispanic names often include more than one first or middle name, and it may be appropriate to use different last names in different situations. Asian names often have the last or family name presented before the first or given name. While these format variations may fool a hospital system in initially creating duplicate records, many commercial linkage systems

contain algorithms to recognize and correct these name differences. The ability of the EDW-UPDB linkage to classify these types of records as duplicates may account for their overrepresentation.

The overrepresented Hispanic names do not necessarily mean that the entire Hispanic population is overrepresented, but could be restricted to further subpopulations. The undocumented Hispanic population of Utah was estimated at between 55,000 and 85,000 in 2005 [16]. It may be less common that this group discloses complete and consistent demographic detail during medical visits [17]. Undocumented workers are more likely to be uninsured than either Hispanic or non-Hispanic legal residents and may receive care at the University of Utah which, as a state funded hospital, may have more flexibility to fund care for individuals who do not qualify for either federal or private reimbursement [18]. Care at the University of Utah indicates inclusion of records in the EDW and inconsistent information increases the likelihood of creating duplicate records. Recent immigrants are another subpopulation that may be less settled or more mobile. This may result in records being created at a number of different clinics that are later resolved as duplicates.

We found that the use of an external resource for discovering duplicate records in a healthcare database did affect which records were identified. We present the strengths and limitations of such a process along with considerations for those attempting such a linkage.

Strengths

Duplicate records are usually found by comparing sets of records within a single database and both the EDW and the UPDB undergo internal de-duplication as new records are added. Additionally, a linkage is made where the EDW is used as a database of interest and the UPDB as an external reference standard. Mistakes are made in de-duplication when dissimilar records are not matched, but are actually duplicates and when similar records are matched when they are not really duplicates. Using an external resource representing the population in the target dataset can provide the extra information and context needed to distinguish pairs that are truly duplicates and those that are not. The UPDB is such a resource that contains the majority of the population that receives healthcare from the University of Utah.

The additional information provided in links to family members and demographic field histories found in the UPDB allows duplicate records to be identified in the EDW that may not be found by other methods. For example, twins often have similar names, share a birth date, have the same parents, and may have the same address. Despite how similar these records are, the UPDB would show multiple births on each person's birth certificate and the two records could match properly to siblings instead of each other. As a further example, a woman who has recently married may have different last names and addresses on two records. Despite the records being dissimilar, UPDB person records would list her maiden name, her new last name and her husband's identity – obtained from a marriage license – a history of her known addresses, and a history of addresses for her husband. The two records could then be matched to the same person.

Limitations

Using an external reference for de-duplication may not eliminate the need for other methods of de-duplication. Duplicate records in the EDW cannot be found for individuals who do not have a record in the UPDB or where duplicates exist in the UDPB itself. Although the UPDB represents the population served by the University of Utah, it is not a true super-set. As a large academic research hospital, individuals may be referred from other states for specialized care. Others may receive care while visiting, but not living in the state. In addition, even for persons living in Utah to be included in the UPDB, they must have a life event that triggers the creation of a record.

Conclusion

The EDW and UPDB have different record characteristics and forces acting on them. Information is collected independently and for different purposes. When two different datasets are used for linkage, especially when they are collected at different times and for different purposes, a portion of the results may be explained by dataset differences. It is important to know when anomalies occur and if they describe real effects or artifacts caused by the datasets.

The changing face of the population represented in these datasets shows how subpopulations and changes in demographic trends may affect linkage. It is possible that segmenting data into homogenous demographic groups may lessen the impact that minority populations have on linkage results.

Understanding the impact of dataset characteristics and record linkage methods is a first step in improving duplicate record detection. We suggest the use of frequency count analyses as an effective way to detect anomalies in linkage results and as a tool for validating records identified as duplicates.

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Record Linkage System in a Complex Relational Database - MINPHIS Example

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Abstract

In the health sector, record linkage is of paramount importance as clinical data can be distributed across different data repositories leading to duplication. Record Linkage is the process of tracking duplicate records that actually refers to the same entity. This paper proposes a fast and efficient method for duplicates detection within the healthcare domain. The first step is to standardize the data in the database using SQL. The second is to match similar pair records, and third step is to organize records into match and non-match status. The system was developed in Unified Modeling Language and Java. In the batch analysis of 31, 177 "supposedly" distinct identities, our method isolates 25, 117 true unique records and 6, 060 suspected duplicates using a healthcare system called MINPHIS (Made in Nigeria Primary Healthcare Information System) as the test bed.

Keywords:

Record linkage, Data mining, Duplicates, Databases, MINPHIS

Introduction

Many private and public organizations in the health sector capture, store, process and analyze fast-growing amounts of data with millions of records. The records are made up of patient's bio-data and health records. Linking and aggregating records that relate to the same person from several databases is becoming increasingly important as information from multiple sources needs to be integrated, combined or linked in order to allow detailed data analysis or mining or warehousing. The aim of such linkages is to match all records relating to the same entity for better informed decisions at various levels.

The basic methods compares name and address information across pairs of files to determine those pair of records that are associated with the same entity. The most sophisticated methods use information from multiple lists [7]; create new functional relationships between variables in two files that can be associated with new metrics for identifying corresponding entities [8] or use graph theoretic ideas for representing linkage relationships as conditional random fields that can be partitioned into clusters representing individual entities [4].

The main challenge in this task is designing a function that can resolve when a pair of records refers to the same entity in spite of various data inconsistencies. Data quality has many dimensions or qualities, one of which is accuracy. Accuracy is usually compromised by errors accidentally or intentionally introduced in a database system. These errors result in inconsistent, incomplete or erroneous data elements. In order to improve the accuracy of the data stored in a database system, we need to compare them either with their real world counterparts or with other data stored in the same or a different system.

Materials and Methods

This section describes the material and method that were used in achieving the desired or set goal.

MINPHIS is an acronym that stands for Made in Nigeria Primary Healthcare Information Systems; a software system that was collaboratively developed by the Health Information Systems Research and Development Unit of the Obafemi Awolowo University Ile-Ife, Nigeria and the Health Information Systems Research and Development Unit of the University of Kuopio Finland in 1989. Currently, MINPHIS has been deployed to over eleven (11) teaching and specialist hospitals in Nigeria. Over 30, 000 records were pulled out of MINPHIS database deployed at the Obafemi Awolowo University Teaching Hospitals Complex for testing the system developed.

Given databases A and B, record linkage finds or detects the common entity between them, (figure 1). Each record from A potentially has to be compared with all the records from B. The total number of potential record pair comparisons thus equal to the product of the size of the two databases.

Sur-name	Other Names	Sex	DOB	UID
Peg	R. Smith	M	24-09-1964	01-001
Joe	Smith	M	26-10-1983	01-008
John	Thereza	F	26-06-1984	01-007

Database A

Matches

Sur-name	Other Names	Sex	DOB	UID
Robert	P. Smith	M	24-09-1964	01-016
Joe	Smithy	M	26-10-1983	01-008
Jon	Theresa	F	26-06-1984	01-007

Database B

Figure 1- Record Linkage Example

To reduce the large amount of potential record pair comparisons, our system employs a technique called 'blocking'; a single record attribute or a combination of attributes called blocking key or variable was used to split the database into blocks. Therefore, we sorted the records in our database alphabetically using surname, sex and date of birth, so that only records that falls within the same block are compared with their counterparts.

All records having the same value in the blocking key were inserted into one block and candidate record pairs are generated only from records within the same block. While the aim of blocking is to reduce the number of record pair comparisons made as much as possible by eliminating pairs of records that obviously are not matches, it is also important that no true matches are removed by the blocking process. That was why; we had to block records alphabetically to allow scalability or robustness of the blocking process and also to ensure that no true match is missed.

Two main issues are considered when blocking key is defined:

1. The error characteristics of the attributes used in blocking keys will influence the quality of the generated candidate record pairs. Therefore, attributes containing the fewest errors or missing values should be chosen as any error in an attribute value in a blocking key will potentially result in a record being inserted into the wrong block, thus missing true matches.
2. The frequency distribution of the values in the attributes used as blocking key will affect the size of block generated. So, if *m* records are in a block from database A and *n* records in the same block from database B, then *m* x *n* record pairs will be generated from this block. The largest block will dominate the execution time of the comparison step as they will contribute very large numbers of record pairs.

In order to address the problems enumerated above, we developed a string matching function that is embedded in the record linkage system algorithm to cater for strings with typographical errors as a result of keystroke mistakes or fatigue during the data entry process. This will enhance the blocking process because true matches will not fall into wrong block. The string matching function compares two strings say **JULIUS Babatunde** and **JULIUUS Babatunde; or Achimugu Philip** and **Chimugu Philip,** and calculates the number of common character and transposition. So if the total number of common characters between the two strings is more than three quarters of the length of the shorter string, then the function suspects and reports a likelihood of typographical error in the two strings, before other attributes such as Date of Birth, Sex and address information are finally compared to determine the status quo of such entities.

In this experiment, the blocking technique used for our health database allows the size of blocks to be controlled directly through parameters. All the candidate record pairs generated by the blocking process are compared by the comparison function applied to one or more (or a combination of) record attributes.

Each comparison returns a numerical similarity value called 'matching weight' (1 if the strings are similar or agreeing and 0 if the strings are not similar or disagreeing). A vector is formed for each compared record pair containing all the values calculated by the comparison function. These vectors are then used to calculate record pairs into match, non-match and possible match based on the decision model developed. Therefore, record pairs that were removed by the blocking process are classified as non-match or unique records without being compared explicitly. Figure 2 depicts the record linkage process.

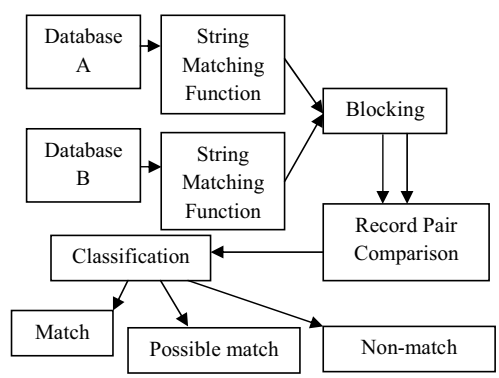

Figure 2- The Record Linkage Process

Experimental Results

To evaluate the performance of this algorithm, normalized measures such as precision and recall were used to determine the efficiency of the algorithm. The experiments performed consisted of finding matches between two data sets.

Test Data

The test used a simplified dataset containing all bio-data of patients from the MINPHIS database. The datasets contain a range of identifying information such as names, address, diagnosis, referrals, ward allotment etc for 31, 177 supposedly distinct patients.

For the purpose of this research however, the attributes that were extracted from the MINPHIS database for experimental evaluation are Hospital Number, Surname, firstNames, Sex, Date of Birth and Address information. Records representing the same entity based on the static decision rules were given the same value of 1 while those that are not were given the value 0. That was the criteria for duplicate detection.

We therefore, conclude that two records are match if they correspond in names (Surname, FirstNames), date of birth, sex and address.

Evaluation of the System

The evaluation of the algorithm encompasses two main issues: (1) the accuracy and (2) the behaviour of the similarity threshold k. First, the distances between all possible pairs of records (r_i, r_j) are computed and stored in a matrix. Then, for each value of k, the total number of true positives (TP), false positives (FP), false negatives (FN) and true negatives (TN) matches are computed using the formula below:

$$\text{Recall} = \frac{TP}{TP + FN} \quad \textbf{(1)}$$

$$\text{Precision} = \frac{TP}{TP + FP} \quad \textbf{(2)}$$

Reference Tables

We used eight blocks for the experiment. The first reference table is the combination of unique given names and surnames from the dataset giving a reference table size of 3415 unique names. The second reference table is every second name from the first reference table, starting with the first name, while the first reference table is every second name starting with the second name. The fourth reference table contains unrelated data, the unique surnames and given names from the MINPHIS database.

Table 1- Result of the System

Block	Correct Matches	Correctly Unlinked	Incorrect Matches	Precision	Recall
1	3415	302	400	0.92	0.90
2	3308	292	295	0.92	0.91
3	3936	200	225	0.95	0.94
4	3501	109	305	0.96	0.91
5	3566	190	300	0.95	0.92
6	3486	217	320	0.94	0.91
7	3299	130	178	0.96	0.95
8	3175	17	11	1.0	1.0

Analysis of the Result

As expected there is a trade-off between Precision and Recall when the threshold k is varied. Its optimum value is considered to be in the intersection of the two curves (Figure 3). The system employs a method called **blocking** in order to reduce large comparisons between potential duplicate records, so only records that falls within the same block or neighbourhood are compared and tracked for duplicate detection hence, decrease in computational time. From table 1 therefore, it is deduced that the system produced a high level of quality duplicates detection as evidenced in the values for precision and recall. In Block one, it is observed that only 400 incorrect matches was found after retrieving 3415 records, that is, matches that could not be tracked by the static decision rules embedded in the algorithm and the final match status is determined by the human expert. It goes on through all the rest of the blocks until the information retrieval process is completed. Although, the system is automated but the final decision for records that falls under the possible match category is determined by the human expert. This is important because patients in health organizations are seen as owners of their medical records; therefore, adequate care must be taken to ensure that data are not altered in any way throughout the record linkage process.

Furthermore, Figure 3 depicts the graphical representation between precision and recall. It shows a significant increase in precision as regards the quality of duplicates detected by the enhanced system. For example, it is approximately 0.18, corresponding to 0.95 of precision and recall (Figure 3). In comparison with exact record matching, which is equivalent to the case k = 0, the approximate record matching (with higher values for k) provided a good gain in Recall, without significant loss in Precision. But, when the dataset from MINPHIS database was tested on the algorithm which has embedded a string matching function that caters for typographical errors in candidate's names, exact record matching obtained a Recall of only 40% (Figure 4).

There are also large regions (0.14 < k < 0.19, for the

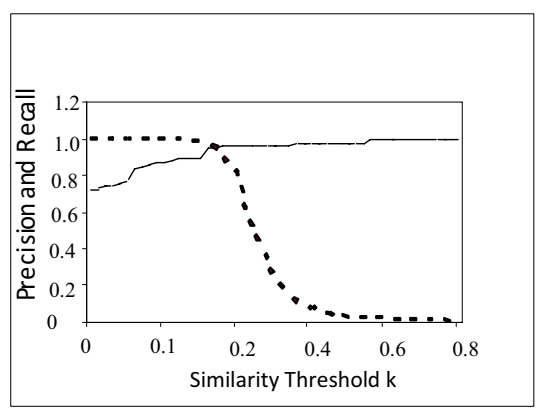

Figure 3- Tradeoff between Precision and Recall

algorithm; and $0.09 < k < 0.19$, for the tradeoff between precision and recall), where both precision and recall are high (greater than 0.9). For a while, this allows some freedom and safety in the choice of k.

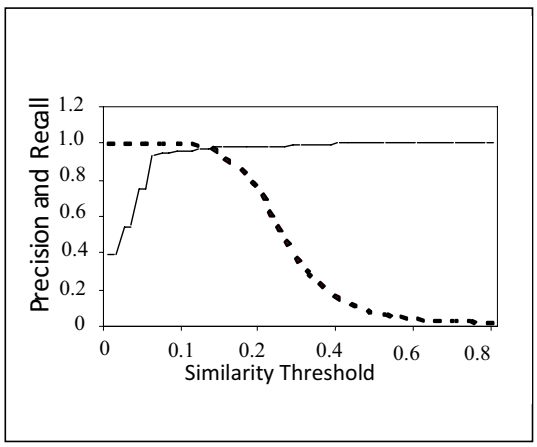

Figure 4- MINPHIS Dataset Bahaviour in the Record Linkage Algorithm

Discussion

The initial idea for record linkage was conceived by Halbert Dunn in 1946 who was the then chief of U.S. National Office of Vital Statistics. He used the term to refer to linking vital records, such as birth and death certificates, pertaining to a single individual [2]. Computerized record linkage was proposed a decade later when Howard Newcombe and colleagues used computers to link vital records in an effort to track hereditary diseases. The theory of record linkage was further expanded by Ivan Fellegi and Alan Sunter who demonstrated that probabilistic decision rules were optimal when the comparison attributes are conditionally independent [6]. Our method gives those specialists responsible for merging similar records a representative view to show them how close records in some homogenous or heterogeneous sets are. Additionally, the algorithm and underlying database support real-time detection of duplicate records. This can help to avoid the creation of duplicate records by alerting the user that several neighbour records already exist. This real-time use could also be used in multi criteria searches for identities and a simple as well as easy to use front end algorithm was employed in the implementation of the record linkage system so that short response times are achieved. Response time is closely related to optimization of the algorithm and especially the blocking part. Its improvement allows the reduction in the number of potential duplicates to be tested by the main algorithm.

Conclusion

In this paper, a record linkage system for health information systems was developed and applied to health informatics in developing countries (particularly Nigeria). The methodology implored for achieving our goal is discussed herein and we believe that the result would be useful and the system more efficient than existing ones.

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Towards an implicit treatment of periodically-repeated medical data

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Abstract

Temporal information plays a crucial role in medicine, so that in Medical Informatics there is an increasing awareness that suitable database approaches are needed to store and support it. Specifically, a great amount of clinical data (e.g., therapeutic data) are periodically repeated. Although an explicit treatment is possible in most cases, it causes severe storage and disk I/O problems. In this paper, we propose an innovative approach to cope with periodic medical data in an implicit way. We propose a new data model, representing periodic data in a compact (implicit) way, which is a consistent extension of TSQL2 consensus approach. Then, we identify some important types of temporal queries, and present query answering algorithms to answer them. We also sketch a temporal relational algebra for our approach. Finally, we show experimentally that our approach outperforms current explicit approaches.

Keywords:

Databases, Temporal information, Periodic data

Introduction

Most clinical data (e.g., patients' clinical records) are naturally temporal. In order to be meaningfully interpreted, patients' symptoms, laboratory test results, and, in general, all clinical data, must be paired with the time in which they hold (called *valid time* henceforth). In many cases, medical data concerns events that have to be repeated at periodic time. Such events include, e.g., routine activities that nurses have to perform daily on hospitalized patients, as well as intrinsically repeated activities such chemotherapy cycles, or dialysis (which is usually an *open-ended* activity, since it has to be performed for all the life of certain diabetic patients). An explicit representation of all the repetitions to be performed might be important, e.g., for scheduling purposes and resource allocation. Nevertheless, it is very costly, both in terms of storage allocation, and of disk I/O when data have to be retrieved.

Periodic data in databases

Unfortunately, the research about temporal data has widely demonstrated that the simple addition of some timestamped attributes (e.g., the START and END times for the valid time of a tuple) is not enough, since many complex problems need to be tackled. For instance, Das and Musen have identified several types of mismatches between the temporal support of standard databases and the richness of clinical data [1]; analogously, James and Goble [2] have pointed out the requirements that medical records impose on a temporal model. Designing, querying and modifying time-varying tables requires a different set of techniques. Such techniques have been studied in more than 20 years of research by the temporal database (TDB henceforth) community (consider, e.g., the overview [3]). Although TDB is still an open area of research, many researcher have already consolidated a "basic core" of results, by defining the TSQL2 consensus approach [4].

In the medical area, several temporal database approaches have been devised. For instance, Chronus [5] and Chronus II [6] have provided an implementation of a subset of TSQL2 [4], with specific focus on valid time. On the other hand, although actions repeated at periodic time are quite frequent in the medical context, no approach has been developed in order to cope with such data in an efficient way. For instance, since periodic actions are an intrinsic constituent of clinical guidelines, several approaches in the area have devised expressive languages to represent complex periodic patterns (such as, e.g., those in chemotherapy treatments). Among the others, Asbru's [7] and GLARE's [8] temporal languages have been devised to model complex cases of periodically repeated actions. However, while in Asbru's and GLARE's languages repetition patterns in the guidelines can be represented, to the best of our knowledge no medical database approach has been devised to store in a (relational) database the actual data modelling the effective execution of repeated actions (e.g., dialysis) on each specific patients on which it has to be physically executed.

Explicit vs. implicit approaches

The trivial way to store a repeated action in a database is to explicitly store all the repetitions of that action. E.g., consider the following therapy for multiple mieloma (such a therapy has been used as one of the example of application of GLARE's temporal representation language [8]).

(Ex.1) The therapy for multiple mieloma is made by six cycles of 5-day treatment, each one followed by a delay of 23 days

(for a total time of 24 weeks). Within each cycle of 5 days, 2 inner cycles can be distinguished: the melphalan treatment, to be provided twice a day, for each of the 5 days, and the prednisone treatment, to be provided once a day, for each of the 5 days. These two treatments must be performed in parallel.

While GLARE's representation language provides an high-level language to represent such a periodic pattern, a separate problem is to provide a proper support to store the time of execution the actions on specific patients affected by multiple mieloma. An *explicit* storage of all the actions (and the time when they have to be executed), although possible, is quite storage expensive. For instance, in a standard relational database approach it would consist, for each patient, of at least 90 tuples, modelling 60 melphalan applications, and 30 prednisone applications. While it is important that all such actions are recorded in some way (e.g., for scheduling purposes, and resource allocation), it is worth noticing that the main drawback of such an explicit approach is not just the waste of memory, but the increase of time devoted to physical disk I/O whenever such data need to be accessed. Additionally, from the logical point of view, an explicit storage of all the actions is not even possible in the case of open-ended repetitions, in which the end of repetitions is unknown (consider, e.g., the dialysis example). For such reasons, in the area of temporal databases, some initial approach has been devised to provide an implicit representation of periodically repeated data (consider, e.g., [9,10]). In such approaches, periodically repeated data are not explicitly elicited: on the other hand, the pattern of repetition is directly stored in the database, so that a compact representation is achieved.

However, to the best of our knowledge, no "implicit" approach to periodic data in the literature has explicitly focused on issues related to the efficient representation and management of periodical data. In this paper, we describe an approach overcoming such a limitation, with specific focus on medical data.

Methods

In this paper, we propose an "implicit" approach to cope with periodical data, which is based on the "consensus" definition of granularity taken from the TDB glossary [11], and on its extensions to cover periodical data [12]. The generality of our approach is also granted by the fact that our representation model is a "consistent extension" of TSQL2 [4], the most famous "consensus" approach to temporal relational databases. Our approach articulates as follows:

(i) We identify a (relational) data model to store periodic data in an implicit way;
(ii) we consider a "prototypical" class of queries (i.e., temporal range queries), and we address the problem of identifying a suitable query answering approach (with specific attention to the query answering algorithm);
(iii) we extend the approach (at the algebraic level) to cope with other kinds of queries
(iii) finally, we have developed an extensive experimentation of our model and methodology, showing that our "implicit" approach overcomes the performance of traditional "explicit" approaches both in terms of space and disk I/O's, and in terms of answer response time.

Temporal data model

In our approach, a periodic activities are *implicitly* represented through a new type of relation (that we term *periodical* relation), plus an additional relation, PERIODICITY, that we use to define periodicities.

Definition 1 (periodical relation): Given any schema $R=(A_1,...,A_n)$ (where $A_1,...,A_n$ are standard non-temporal attributes), a periodical relation r is a relation defined over the schema RP = $(A_1,...,A_n \mid VT_S, VT_E, Per, Per_{id})$ where VT_S, VT_E, are timestamps representing the starting and the ending point of the interval of time containing all the repetitions (called "frame time" henceforth), *Per* is an interval, representing the duration of the repetition pattern, and Per_{id} is an identifier, denoting a periodical pattern in the PERIODICITY relation.

Definition 2 (PERIODICITY relation): The PERIODICITY relation is a relation over the schema $(Per_{id}$ *Start, End),* in which Per_{id} is a periodicity identifier, and *Start* and *End* are temporal attributes (timestamps) denoting the starting and the ending points of the periods in the periodical pattern.

Example (Ex.2): As a simple example, let us suppose that an activity A1 has to be executed on a patient P1 each Monday, Wednesday and Friday for 10 weeks, starting from day 100, which is a Monday (for the sake of simplicity, here we use natural numbers instead of dates, and we assume that the base temporal granularity of the database is 'day'). Such an information is implicitly represented in our approach as shown in Tables 1 and 2 in the following.

Table 1- A periodical relation.

ACTIONS

Action	**Patient**	**VT_S**	**VT_E**	**Per**	**Per_{id}**
A1	P1	100	169	7	Id1

Table 2- PERIODICITY relation, concerning the periodicity in the example only.

PERIODICITY

Per_{id}	Start	End
Id1	100	100
Id1	102	102
Id1	104	104

In the ACTIONS relation, VT_S and VT_E states that the *frame time* is 70 days, from day 100 to day 169. The repetition period is 7 days (attribute *Per*). Per_{id} provides a link to the table PERIODICITY, in which the repetition pattern for the first week is stored. Notice that, although not explicitly stated, all the days in which action A1 has to be executed (on patient P1) can be inferred from the above implicit representation, looking at the pattern in the relation PERIODICITY as a pattern to be repeated each 7 days (*Per* attribute of the relation ACTIVITY), stopping repetitions after day 169 (see the explicit representation in Table 3) <end example>

It is important to notice that the temporal attributes of our periodical relations, in conjunction with the PERIODICITY relation, allows us to capture the implicit definitions of periodical granularities, as defined in the temporal database literature:

Property 1 (expressiveness): Our extended data model can represent periodical granularities, as defined in [12].

Moreover, it is worth noticing that non-periodical temporal data could be easily represented as a degenerate case of the periodical one, using tuples in which VT_S and VT_E model the start and the end of the valid time, and the *Per* and Per_{id} attributes are set to NULL[1]. Therefore, our approach can be seen as an extension of the "consense" TSQL2 approach [4], to cope also with periodic data.

Property 2 (consistent extension): Our data model is a "consistent extension" of TSQL2 data model.

Query answering: range queries

Here we take into account *range* queries since, according to the temporal database literature, they are particularly relevant. Specifically, the type of query we deal with is the following: given a set of periodical data (e.g., activities in the ACTIVITY table) and an interval denoting the span of time one is interested in the query (e.g., from day 120 to day 124), one wants to know which data holds during such a time period. In particular, in the context of periodical data, we identify two different types or range queries, depending on whether:

(i) one is interested in the non-temporal part of the tuples only (e.g., What activities have to be performed from 120 to 124?)
(ii) one is interested in the tuples and in their explicit time (e.g., what activities have to be performed from 120 to 124? For each of them, list all the times when they have to be performed, between 120 and 124).

For the sake of brevity, however, we will focus only on the type (i) of queries in the rest of the paper.

Given our (implicit) temporal data mode1, the process of answering such basic types of queries is quite complex, since we only have an implicit representation of data. Given a periodical relation *r* (e.g., ACTIVITY) and a query interval I_Q (e.g., [120,124]), in the following we sketch the algorithm we propose for efficiently answering queries of type (i):

(1) For each tuple $t \in r$
(2) Let P_t be the intersection between I_Q and the frame time of t
(3) IF the duration of P_t is greater or equal than the period of t (attribute Per of t) THEN return t
(4) ELSE
(4.1) get in PERIODICITY the intervals constituting the repetition pattern of t
(4.2) Using the 'module' function, "project" I_Q and the intervals retrieved at step (4.1) onto the same span of time, and check intersection
(4.3) IF there is intersection, then return t

Notice that step (3) above is simply an optimization: in case the interval of interest (i.e., $P_t \cap I_Q$) is longer than the period of t, than for sure some of the intervals in the repetition must intersect the interval $P_t \cap I_Q$, so that the tuple can be directly provided in output, avoiding other checks. In (4.2), the module function is used to check intersection between the pattern and the interval of interest in an efficient way, avoiding an explicit generation of all the intervals of repetitions.

Query answering: temporal algebra

Besides temporal range queries, all kinds of relational queries must be possible on our new data model. Codd designated as complete any query language that is as expressive as his set of five relational algebraic operators: relational union ($\cup$), relational difference (-), selection (σ), projection (π), and Cartesian product ($\times$) [13]. We propose an extension of Codd's algebraic operators to query our data model.

Several temporal extensions have been provided to Codd's operators in the temporal database literature [4,14]. In many cases, the extended temporal operators behave as standard non-temporal operators on the non-temporal attributes, and involve the application of set operators on the temporal parts. This approach ensures that the temporal algebrae are a consistent extensions of Codd's operators and are reducible to them when the temporal dimension is removed. For instance, in BCDM [4], which provides a uniform semantics underlying several temporal database approaches, including TSQL2, temporal Cartesian product involves pairwise concatenation of the values for non-temporal attributes of tuples and pairwise intersection of their temporal values. Analogously, in BCDM [4], relational union, projection and difference behave in a standard way on non-temporal attributes, and perform union (for relational union and projection) and difference on the temporal part of value-equivalent tuples. We ground our approach on such a "consensus" background, extending it to cope with periodic data. For the sake of brevity, we sketch only our definition of temporal Cartesian product. The other operators are defined in a similar way, according to the above-mentioned discussion. In the definition below, we denote by $t[X_1, ..., X_k]$ the value of the attributes $X_1, ..., X_k$ in the tuple *t*.

Definition 3 (Temporal Cartesian product $\times^T$): Given two periodic relations r and s defined over the schemas $R1^P = (A_1,...,A_n \mid VT_S, VT_E, Per, Per_{id})$ and $R2^P = (B_1,...,B_k \mid VT_S, VT_E, Per, Per_{id})$ respectively, the temporal Cartesian product $r \times^T s$ is a periodic relation q defined over the schema $R3^P = (A_1,...,A_n, B_1,...,B_k \mid VT_S, VT_E, Per, Per_{id})$ containing, for each pair of tuples ($t_r \in r$, $t_s \in r$), a new tuple t' which is the concatenation of the non-temporal attributes of t_r and t_s (i.e., such that $t'[A_1,...,A_n]=t_r[A_1,...,A_n]$, and $t'[B_1,...,B_k]=t_s[B_1,...,B_k]$), whose frame time is the intersection of the frame times of t_r and t_s (i.e., $t'[VT_S]=\max(t_r[VT_S], t_s[VT_S])$ and $t'[VT_E]=\min(t_r[VT_E], t_s[VT_E])$, with $t'[VT_S] < t'[VT_E]$), whose periodicity t'[Per] is

[1] Although such a representation is theoretically possible, for the sake of efficiency we store non-periodic data into standard TSQL2-like temporal relations, to avoid the use of unnecessary NULL values.

the least common multiple of t_r[Per] and t_s[Per], and whose periodicity identifier t'[Per_{id}] is a new system-generated identifier. The periodic pattern of t'[Per_{id}] in the table PERIODICITY is defined as the intersection of the periodic patterns associated with the identifiers t_r[Per_{id}] and t_s[Per_{id}], evaluated over a period of time which starts at t'[VT_S], and whose duration is t'[Per]. Of course, only tuples such that frame times and periodic patterns have a non-empty intersection are retained in q.

The definition of temporal Cartesian product given above can be extended to temporal definitions of theta join, natural join, outer joins, and outer Cartesian products, in a way similar that done in [15]. It is worth stressing that the consistent extension property also holds for our extended algebra:

Property 3 (consistent extension): Our temporal relational algebra is a "consistent extension" of the BCDM (and TSQL2) algebra [4].

Experimental results

In order to show the practical relevance of our implicit approach to efficiently manage periodic data, we have performed an extensive experimental evaluation. In particular, we have compared the performance of our approach with respect to the one of the standard explicit one. We remark here that, with the term "explicit" approach, we mean the approach in which periodic data are explicitly stored. For instance, the relation ACTIONS_Expl contains an explicit representation of the actions in example Ex.2.

Table 3- Explicit representation of the periodic data in Ex.2. The relation contains 30 tuples

ACTIONS_Expl

Action	Patient	VT_S	VT_E
A1	P1	100	100
A1	P1	102	102
A1	P1	104	104
A1	P1	107	107
....	....	....	....
A1	P1	167	167

Our results are computed on a four 450MHZ CPU - SUN UltraSparc II processor machine, running Oracle 10.2.0 RDBMS, with a database block size of 8K and SGA size of 100MB. At the times of testing the database server did not have any other significant load.

The RI-Tree [16] has been used to index both time intervals both in the implicit and in the explicit approach, since this indexing methodology has been proved to have has the best performance regarding interval data.

We compare our results considering space usage, CPU usage, query response time, and physical I/O, which is usually considered to be the most important parameter while evaluating efficiency of accessing data [17].
In absence of real data, based on our experience, we have generated periodic data to simulate real medical scenarios. The following parameters have been considered (we used hour as the basic granularity):

(1) Number of Patients: 16,824;
(2) Average number of periodic activities per patient: 8.30;
(3) Average number of periods in a periodical pattern: 4.86;
(4) Average duration of period of periodical patterns: 87.56;
(5) Average duration of the frame time: 1169;
(6) Distribution of the duration of periodical pattern: we have provided different durations, with a prevalence of actions to be repeated daily (about 40%), and weekly (about 30%).

In order to carry on the experiments, the same periodical activities concerning hospital patients have been represented both in the implicit and explicit model. In the implicit model, the representation of data required 353,367 records in the ACTIONS table and about 2 million records in the PERIODICITY table. In order to represent the same activities in the explicit model, more than 194 million records are required in the ACTIONS_Expl table, so that, globally, the space requirement of the explicit approach is more than 100 times greater (see Table 4).

Table 4- Comparing implicit vs explicit approach: space requirement

Table name	Number of records	Table Size (M Bytes)	Approach
ACTIONS	353,367	16.25	implicit
PERIODICITY	2,108,495	43.08	implicit
ACTIONS_Expl	194,671,463	7,331.82	explicit

Physical disk I/O's, CPU time and response time for range queries of type (i) for different query duration and different answer sizes are show in Tables 5, 6, 7, and 8. Different range queries duration are considered to investigate effect of the optimization in step (3) of our query answering algorithm. Different answer size is considered to see the effect of clustering the data, aging of database buffers and effect of trade off between Physical disk I/O and CPU usage.

Table 5- Evaluation of the implicit approach, for range queries lasting 1 hour

Answer Size	Disk I/O	CPU	Response Time
2,068	6,049	477	5
7,471	10,831	1,431	12
17,738	12,364	3,186	32

Table 6- Evaluation of the explicit approach, for range queries lasting 1 hour

Answer Size	Disk I/O	CPU	Response Time
2,068	3,031	73	3
7,471	12,872	315	30
17,738	31,904	930	154

Table 7- Evaluation of the implicit approach, for range queries lasting 1 week

Answer Size	Disk I/O	CPU	Response Time
2,887	1,838	200	3
4,620	2,114	260	5
29,455	9,490	1,375	26

Table 8- Evaluation of the explicit approach, for range queries lasting 1 week

Answer Size	Disk I/O	CPU	Response Time
2,887	7,970	601	52
4,620	12,913	1,232	116
29,455	183,073	26,460	944

As regards disk I/O (the most important parameter in the database context [17]), our approach is increasingly advantageous with respect to the explicit one. This is particularly true when the query range is bigger. This is because our approach can exploit the optimization at step (3) of the query answering algorithm. Also, with increased answer size our implicit approach outperforms the explicit method in the number of physical disk I/O's, which results in significant shorter query duration (more than 36 times shorter query response time in case of 168 hour range query and answer size of 29,455 as it can be seen comparing the last raw of Tables 7 and 8).

An extensive experimental evaluation of our algebraic operators is still ongoing. Preliminary results confirm the advantages of our approach with respect to the explicit one, similar to the advantages above as regards temporal range queries.

Discussion and conclusion

Temporal data play a fundamental role in medicine. Specifically, periodic data are frequent and important, so that their efficient treatment is a core issue in the area. We propose a new methodology based on an implicit representation, and on efficient query answering algorithms. We have experimentally shown that our approach outperforms the "traditional" explicit approach as regards disk I\O, CPU usage, and response time. The advantages of our approach increase with the increase of the answer size, and of the temporal range of the queries. As regards future work, we want to integrate our approach in GLARE (GuideLine Acquisition, Representation and Execution), a manager of clinical guidelines which strictly interacts with different databases, and devotes specific attention to the treatment of temporal data [18].

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Achieving interoperability for metadata registries using comparative object modeling

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Abstract

Achieving data interoperability between organizations relies upon agreed meaning and representation (metadata) of data. For managing and registering metadata, many organizations have built metadata registries (MDRs) in various domains based on international standard for MDR framework, ISO/IEC 11179. Following this trend, two pubic MDRs in biomedical domain have been created, United States Health Information Knowledgebase (USHIK) and cancer Data Standards Registry and Repository (caDSR), from U.S. Department of Health & Human Services and National Cancer Institute (NCI), respectively. Most MDRs are implemented with indiscriminate extending for satisfying organization-specific needs and solving semantic and structural limitation of ISO/IEC 11179. As a result it is difficult to address interoperability among multiple MDRs. In this paper, we propose an integrated metadata object model for achieving interoperability among multiple MDRs. To evaluate this model, we developed an XML Schema Definition (XSD)-based metadata exchange format. We created an XSD-based metadata exporter, supporting both the integrated metadata object model and organization-specific MDR formats.

Keywords:

Metadata registry, ISO/IEC 11179, Interoperability, Object model

Introduction

Metadata provide data with context and are used to facilitate the understanding, usage and management of data both by human and computers. Meta Data Registry (MDR) is a system for managing these metadata contents. For managing and describing metadata, ISO/IEC JTC 1/SC 32 established a standard for MDR, named ISO/IEC 11179 [1], on which many MDRs in various domains have been built and introduced. In biomedical domains, there are two representative MDRs, United States Health Information Knowledgebase (USHIK) from U.S. Department of Health & Human Services [2] and cancer Data Standards Registry and Repository (caDSR) from National Cancer Institute (NCI) [3]. For evaluating metadata functionality, we also developed an MDR, named Clinico-Histopathological Metadata Registry (CHMR), for describing and managing data elements related to clinical trial and research data [4].

Recently, several studies have shown semantic and structural limitations of ISO/IEC 11179 [5-7]. They are categorized into three problems. The first problem is the absence of semantic or syntactic linkage of shared concepts between components [6]. The second and third ones are structural limitations. ISO/IEC 11179 doesn't support a structure for metadata extension [5] and usage model [7]. To solve these problems and to satisfy organization-specific needs, most MDRs are built with indiscriminate extending. As a result, metadata inconsistency problem makes it difficult to support interoperability among MDRs. In other words, it results structural and semantic inconsistencies between MDRs. In this paper, we are focusing only on structural inconsistency between MDRs. To address the structural inconsistency problem, we propose an integrated metadata object model and metadata exchange format. Also we implement a metadata exporting system.

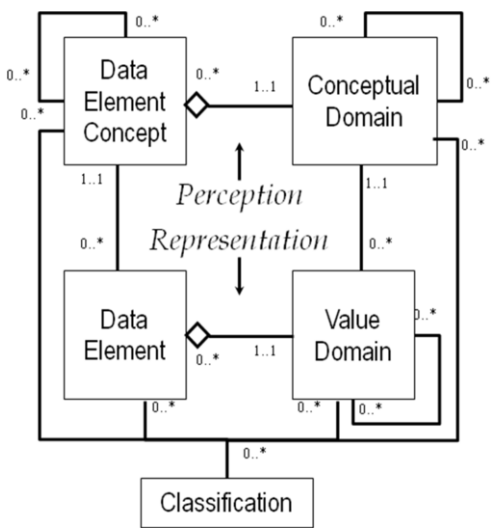

Figure 1- High-level meta-model of ISO/IEC 11179

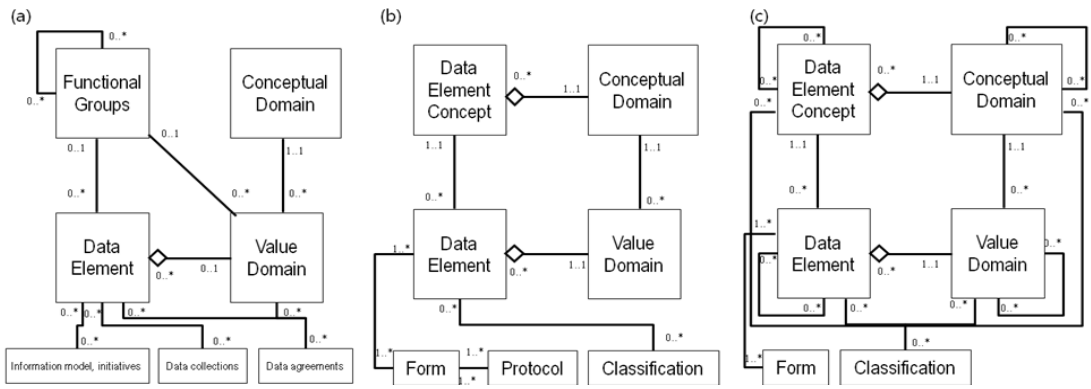

Figure 2- Reconstructed scheme for Metadata Registries (a) USHIK, (b) caDSR and (c) CHMR

Background: ISO/IEC 11179

ISO/IEC 11179 is an international standard for describing and registering metadata. Figure1 shows the most important five components of ISO/IEC 11179, Data Element, Data Element Concept, Value Domain, Conceptual Domain and Classification. The Data Element is foundational concepts in ISO/IEC 11179 model and an associated component between Data Element Concepts and Value Domain. Data Element Concept and Value domain is a set of attributes describing conceptual meaning and representational characteristics of data, respectively. Conceptual domain and Value Domain can be viewed as logical and physical code sets, respectively. Conceptual Domains support Data Element Concepts and Value Domains support Data Elements. Classification provides classification scheme to associate the components of ISO/IEC 11179.

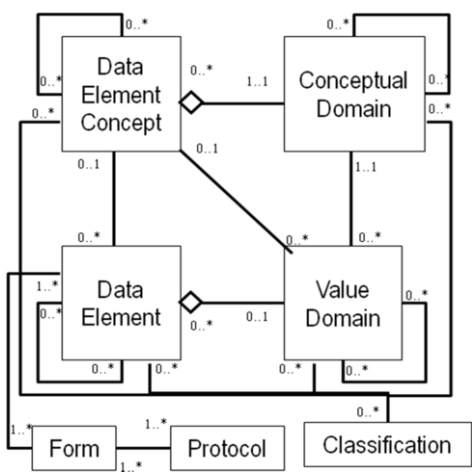

Figure 3- Integrated model

Materials and Methods

We select two public MDRs (USHIK and caDSR) with our own MDR called CHMR. USHIK and caDSR do not provide direct access to database schema or structure of metadata. For reconstructing the scheme of MDRs, we analyzed the XML files exported from caDSR and the metadata content structure of USHIK. Finally, we designed an integrated metadata object model (IMOM) and XML Schema Definition (XSD) to solve the structural inconsistency among MDRs. We downloaded 14,331, 39,572 and 13,835 data elements from USHIK, caDSR and CHMR, respectively, and stored them in an IMOM-enabled database, having 67, 738 data elements in total. We also implemented a system exporting metadata as XML files in organization-specific and IMOM formats regardless of the source of the metadata.

Results

Structural differences among MDRs

We reconstructed the scheme of MDRs (Figure 2) and compared the differences between MDRs. Relatively large number of modifications from the ISO/IEC definitions were found in USHIK and caDSR. Two of the most common modifications are as follows. First, most self associations are eliminated in USHIK and caDSR (Figures 2(a) and (b)). Second, newly defined component, named "Form," which is a set of data elements, is added in caDSR and CHMR (Figure 2(c)). Organization-specific modifications are as follows. USHIK renames Data Element Concept as "Functional Groups" and changes required associations to optional ones between Data Element and Functional Groups and Data Element and Value Domain. New associations were added between Functional Groups and Value domain (Figure 2(a)). caDSR added "Protocol" that represents a collection of "Form" (Figure 2(b)). CHMR added a self association in Data Element to describe the relationship between Data Elements (Figure 2(c)).

Integrated metadata object model and metadata exchange format

For covering all of the modifications in the three MDRs, we designed IMOM illustrated in Figure 3. The full object model represented in UML is available at http://bmesh.snubi.org/MetadataExchange/. There are two basic concepts of IMOM design. First, "do not eliminate organization specific extensions." Second, "basic attributes of ISO/IEC 11179 should be maintained." As a result, IMOM has 64 classes including five new classes related to the "Form" and "Protocol" components. Cardinalities of several associations were modified and four new associations were added.

To support metadata sharing among MDRs, we designed two types of XSD-based metadata exchange formats, one based on the full IMOM covering the entire attributes including organization-specific ones and the other covering the basic attributes only. The basic attributes are minimum specification for describing metadata defined by ISO/IEC 11179. Figure 4 shows a part of IMOM-based XSD file for metadata exchange. Both types of XSD files are available at http://bmesh.snubi.org/MetadataExchange/

Metadata Exporter

To evaluate IMOM and metadata exchange formats, we developed a metadata exporter (available at http://bmesh.snubi.org/MetadataExchnage/), supporting five XSD formats including the three organization-specific MDR formats and the two XSD formats based on IMOM and basic attributes.

Conclusion and Discussion

Recently, many organizations and research groups pay attention for extending and improving metadata contents [8-10]. Most efforts have been made for only one MDR or a domain. Achieving interoperability is important not only for an MDR but also for between MDRs. However, until now, research trends on metadata managing have been focused on just one MDR. The problem related to achieving interoperability among multiple MDRs should be researched.

In this paper, we proposed an integrated metadata object model and exchange format to solve the problem related to the structural inconsistencies among MDRs. We also implemented a metadata exporting system to support exchanging in multiple MDRs. To the best of our knowledge, none of the previous works have considered the interoperability among multiple MDRs. Our effort provides a basic framework to solve the structural inconsistency problems for achieving interoperability among multiple MDRs. In the next step of our research, we will focus on semantic inconsistency problems in multiple MDRs.

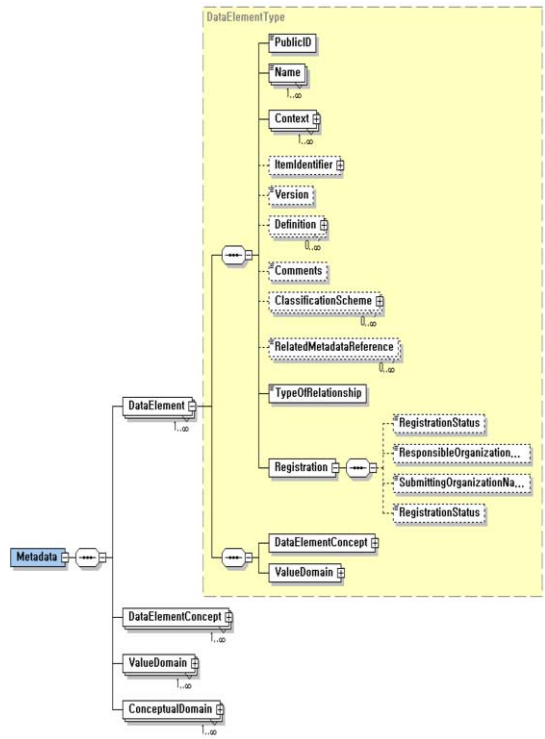

Figure 4- The fragment of integrated model XML Schema Definition file

Acknowledgments

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Verification & Validation of the Knowledge Base for the Hypertension Management CDSS

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Abstract

To implement a knowledge-based clinical decision support system for clinical information systems, it is crucial to verify and validate the knowledge base. This study developed and tested the hypertension management CDSS, named LIGHT. This study used a knowledge representation framework based on SAGE and developed a knowledge converter to translate knowledge encoded into the knowledge engine. To verify knowledge converted through the knowledge converter that is included in the knowledge representation framework, expected recommendations were made according to the knowledge encoded based on 201 test cases. The expected recommendations were compared to those generated by the knowledge engine. To validate the knowledge base, two physicians reviewed the test cases and made medication orders according to the knowledge base. These medication orders were compared to recommendations generated by the LIGHT. The concordance rates for compelling indication and absolute contraindication were 85% and 100%, respectively. Another senior physician reviewed and analyzed the discrepancy cases between the orders of the two other physicians and system recommendations. Accordingly, the authors conclude that the knowledge base for hypertension management became more accurate and practical through the testing process.

Keywords

Verification, Validation, Knowledge base, Hypertension Management, Clinical Decision Support

Introduction

Knowledge based-CDSS integrated with an electronic medical record can provide clinicians with evidence-based patient-specific recommendations at the point of care [1]. Clinical practice guidelines (CPGs) are usually used as resources of evidence based knowledge for Knowledge based-CDSS. However, in order to use CPGs for CDSS, there are a lot of tasks such as non-computer interpretable and non-executable narrative CPGs are translated into executable knowledge.

Research has been done on guideline ontology for knowledge representation to support more efficient knowledge authoring of computer interpretable guidelines (CIGs). There are several guideline modeling methods, such as EON, Asbru, GEM, GUIDE, PROforma, PRODIGY, GLIF, SAGE. SAGE is built upon previous work on another guideline modeling and has been evaluated as an effective guideline modeling framework, which provides a systemic way to create sharable clinical interpretable guidelines and standardized vocabularies [2, 3].

A knowledge based CDS service, named Lightening pressure with computer-Implemented Guidelines on Hypertension Treatment (LIGHT), as a part of the EHR project in Korea. The LIGHT system provides recommendations for hypertension management, and integration into a hospital information system as an interoperable and sharable CDSS [4]. An EHR knowledge representation framework based on SAGE was used. However it was not possible to use a practical execution engine for SAGE-based guidelines. To execute SAGE-based guidelines, the u-BRAIN execution engine is developed as a knowledge engine that is an integrated process engine and rule engine. In addition, a knowledge converter to translate SAGE based guidelines into u-BRAIN is also developed, which is applied as an "Export" plug-in on Protégé (Figure 1) [5. 6].

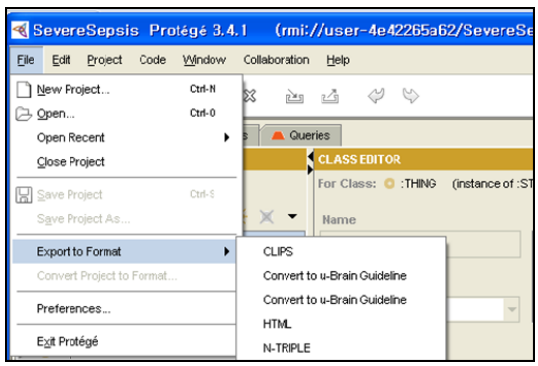

Figure 1 - The framework of EHR knowledge representation framework

It is possible to make wrong representation during the translation from narrative CPGs into computer interpretable guidelines. Clinical guidelines are often vague and incomplete with possible serious omissions and inconsistencies [7]. As well, newly developed software may have errors. It is essential to ensure that the recommendations generated by CDSS are accurate. One of the reasons for testing a system is to discover problems. The testing of the accuracy of the KB should be required at every step of the development of the system to ensure qualified software and to discover problems [8, 9].

The testing process was conducted in three phases (Figure 2). This paper focused on verifying knowledge converted (second phase) and validating the KB (third phase). Preece (2001) explained that *verification* is the process of checking whether the software system meets the specified requirements of the users, while *validation* is the process of checking whether the software system meets the actual requirements of the users [10].

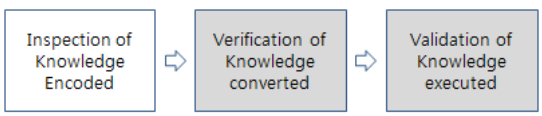

Figure 2- The process of testing the KB

The knowledge module for the LIGHT system is based on The Seventh Report of the Joint National Committee on the Detection, Evaluation, and Treatment of High Blood Pressure (JNC7) [11]. The knowledge module has 256 rules including the criteria of compelling indication and absolute contraindication for hypertensive medication. The LIGHT system makes recommendations for drugs of compelling indication or absolute contraindication. If blood pressure is not controlled (over goal BP), the system gives information about the maximum dose of the current medication.

The testing process in the development of the LIGHT system is described in this paper.

Materials and Methods

Test cases selection

This study used a set of 201 test cases selected from a data set of 430 patients with hypertension diagnosis (ICD 10 code; I10, Essential (primary) hypertension) in a general hospital. The inclusion criteria for the patient were history of two encounters from Dec 2007 to Dec 2008.

Verification of knowledge converted

The purpose of verification for the knowledge converted is to ensure that the knowledge converter correctly translates knowledge encoded into the u-Brain knowledge engine. The functional (black box) testing paradigm was used to verify the knowledge converted (Figure 3). Functional testing is concerned with the inputs and outputs of the LIGHT system [8].

The knowledge encoded based on our representation framework was inspected prior to the verification of knowledge converted. The semantic correctness and completeness was checked by two knowledge engineers who did not participate in the knowledge encoding. The research team including the knowledge encoders made the expected results in 201 real test cases, and compared them to the outputs of the generated knowledge executed through the knowledge converter in order to find errors of the knowledge converter.

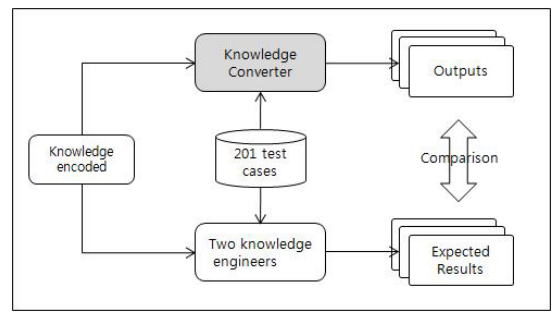

Figure 3 - The process to verify knowledge converted

Preparation of physicians for validation

Three physicians (internists) from a university hospital were involved in this phase. One physician had more experience and was regarded as the advanced physician. They had no previous involvement in the development of HT management KB. The document written 256 rules and the knowledge source of JNC7 were explained [9]. The documents were a semi-formal representation type such as excel and visio files. This study represented knowledge more explicitly on the documents than the CPGs.

Figure 4 - Screenshot for retrieving patient information and selecting medication for physicians

The LIGHT system was developed to present patient information and to obtain the recommendations from physicians. They reviewed patient information and prescribed medication according to information provided by the LIGHT system that would allow them to change the prescription after seeing the recommendation of system (Figure 4).

Patient information included age, most recent blood pressure measurement, previous blood pressure measurement, combined disease, signs and symptoms, most recent results of laboratory tests (potassium, sodium, glucose, urinalysis, lipid profile, creatinine, white blood cell count) and current medication. Physicians selected ADD, MAINTAIN, INCREASE and REMOVE 6 classes (thiazide, DHP and NDHP calcium channel blocker, ACE inhibitor, ARB, beta blocker) of hypertensive medication according to the current medication and the condition of the patient. These 6 classes of antihypertensive drugs were chosen because they were most frequently used in primary health care in Korea, according to the research that was conducted from May 2005 to Feb 2006 by R&D Center for Interoperable EHR.

Validation of knowledge executed

The medication recommendations generated by the CDSS were compared first with the medication selection made by physicians and then cases were searched for discrepancies. The advanced physician reviewed the cases and presented a third opinion about each test case. The KB was refined by consensus if the reason of the discrepancy originated form the HT management KB (Figure 5).

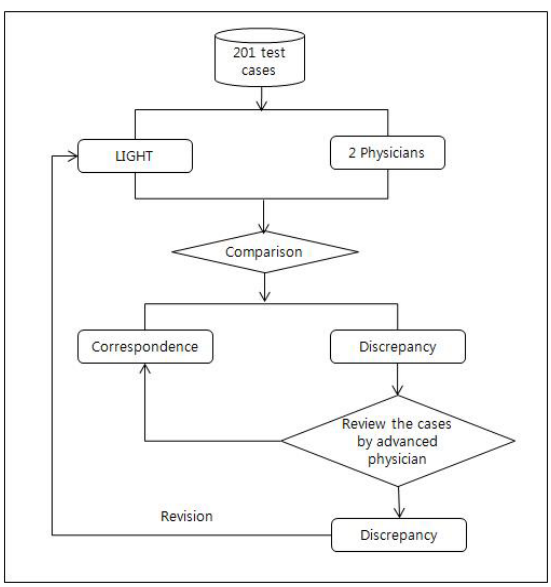

Figure 5 - The process to validate knowledge base

Framework to compare medication recommendations

An analysis of correspondence was made by compelling indication or absolute contraindication related to the condition of the patient.
The cases that were not matched according to the correspondence framework were regarded the cases as a discrepancy.

Table 1 - Framework of correspondence analysis

	Physician	LIGHT
Correspondence	Add	Compelling indication
	Maintain	Compelling indication
	Increase	Compelling indication and Not controlled BP
	Remove	Absolute contraindication

Evaluation of usefulness of recommendations

Two physicians were required to evaluate the usefulness of the patient specific recommendations generated by the LIGHT system. After the physicians prescribed medications for each patient, the system provided recommendations for the patient. And the system allowed them to change the prescription after seeing the recommendations and gave a user interface to evaluate the usefulness of recommendations.

Results

The correctness of knowledge converted

Outputs from the knowledge converter and expected results from the knowledge engineers based on knowledge encoded were exactly corresponded. The result showed that the knowledge converter could convert all knowledge elements used in SAGE into the knowledge engine [6]. To represent knowledge elements of CPGs, elements on SAGE were used such as activity graphs to represent the procedural knowledge, expression to represent rule based knowledge and virtual medical record (vMR) to identity the data of patients [2]. The knowledge converter used in this study can accept all these elements and convert correctly into the execution engine.

Analysis of the medication choice by physicians

For the 201 test cases, the LIGHT system made 537 medication recommendations with an average of 5.3 recommendations per test case (median 2, range 0-9). Physician A and B chose 279 hypertensive drug classes with an average of 2.8 for same test cases, respectively (physician A and B; median 1, range 0-4).

Among 279 drug classes, 164 classes selected from physician A and 176 selected classes from physician B came under the scope of the LIGHT system. The type of medication choice by physicians is shown in Table 2.

Table 2 – Type of prescription choice by physicians

	Type of Prescription			
	Add	**Maintain**	**Increase**	**Remove**
Physician A	30 (18.3%)	114 (69.5%)	17 (10.4%)	3 (1.8%)
	Subtotal		164(100.0%)	
Physician B	42 (23.9%)	116 (65.9%)	17 (9.6%)	1 (0.6%)
	Subtotal		176(100.0%)	

Result of comparison

In the case of compelling indication, correspondence rate for each physician was 85.1% respectively. In absolute contraindication, the rate was 100% respectively (Table 3). Two physicians were followed well by absolute contraindication from CPGs.

There were 27 test cases, when the medication recommendation discrepancies were classified by test case. These cases were characterized in three types; 1) A patient needed to increase the dose of a current medication or to add another medication, physicians did not choose a medication of compelling indication for ADD, INCREASE, 2) System recommended a medication of absolute contraindication, but physicians decided to ADD, MAINTAIN the medication or INCREASE dose, 3) The system recommended a medication of compelling indication, but physicians decided to remove the medication.

Table - 3 Correspondence rate of compelling indication

Classification	Physician A	Physician B
Correspondence	137 (85.1%)	149 (85.1%)
Discrepancy	24 (14.9%)	26 (14.9%)
Total	161 (100%)	175 (100%)

The reasons that led to discrepancies were analyzed through a review of the knowledge base and the opinion of an advanced physician. Medication recommendation discrepancies between physicians and the LIGHT system originated from the two reasons as follow; 1) The rule was on the document for semi-formal representation, however the rule was not encoded in the knowledge base. The relationship of a DHP-calcium channel blocker and angina was missed. The knowledge base was refined according to the results. 2) A physician did not recognize the condition of absolute contraindication. In this case, feedback was provided to the physician. 3) When blood pressure is controlled and the current medication is not absolute contraindication, physicians have a tendency not to change medications. This study did not regard as a discrepancy when the recommendation between them didn't correspond exactly.

Usefulness of recommendations of LIGHT

After physicians first chose recommendations were provided generated by the LIGHT system that gave the physicians a chance to change the selected medication. Physician A changed the choice in 14 cases and physician B did in 8 cases. In the evaluation of the usefulness of the recommendation given, physician A and B showed 96.1%, 77.4% respectively.

Physicians commented that the recommendation of the system would be very helpful for patients who required hypertension medication for the first time. However, in the case of a very complex patient, the LIGHT system did not consider all the parameters.

Discussion

It is difficult to make computer interpretable guideline in narrative CPGs when there are ambiguities and omissions [5, 7]. Newly developed software may contain errors [6]. The procedural testing method was conducted in order to search for errors in the knowledge base.

The EHR knowledge representation framework was used based on SAGE to make computer interpretable guidelines. The framework includes a knowledge converter that converts computer interpretable guidelines into knowledge execution engine. This study verified that the converter correctly all knowledge elements used in the SAGE framework with the converting knowledge base of HT management.

The validation of knowledge base is whether the content of the knowledge base accurately includes the knowledge of human experts [8], it is essential for human experts to participate. We could search one missing error and refined in the knowledge base through the testing process.

One of the limitations of this study is that the knowledge base didn't contain rules to cover all antihypertensive medications.

Conclusion

This study was conducted to verify and validate the knowledge base in every phase of developing CDSS. Through the verification and validation process, one omission in the knowledge base was found and refined to improved accuracy. The result showed that the testing process in every development phase contributed to an accurate and useful knowledge base and is useful for evaluating for other knowledge bases.

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A Self-organizing map based morphological analysis of oral glucose tolerance test curves in women with gestational diabetes mellitus

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Abstract

Gestational diabetes mellitus (GDM) makes women at risk of type 2 diabetes during their life. In order to predict this later abnormal glucose intolerance, several antepartum and postpartum predictors have been identified. In this study we conjecture that future evolution is predictable from morphology of the oral glucose tolerance test (OGTT) curves at baseline. To test our hypothesis, as a first step we evaluated the association between the curve morphologies of normal and diabetic patient condition at baseline. In particular, we analysed glucose and insulin curves of a group of women with a history of GDM. A Self-organizing map (SOM) was proposed to evaluate shape differences among control, normal, impaired glucose tolerance and diabetic curves shape. We compared our results with the currently applied clinical classification. We found that morphology contains information about the current status of the patient, because the SOM analysis clearly allows to discriminate subjects belonging to healthy or diabetic group. Moreover, SOMs highlighted additional information that could be used for prognostic purposes.

Keywords:

Gestational Diabetes Mellitus, Self-Organizing Map, Morphological analysis, Oral Glucose Tolerance Test

Introduction

Gestational diabetes mellitus (GDM) is defined as the diabetic condition with onset during pregnancy [1]. The prevalence of GDM seems to be proportional to the prevalence of type 2 diabetes; however, in general, GDM prevalence ranges from 1% to 14% of all pregnancies depending on the population studied [2]. In most cases, the onset of GDM is characterized by the symptoms of type 2 diabetes, i.e., an increased insulin resistance, and a decline in insulin secretion [3,4]. For this reason, gestational diabetes is often considered to be type 2 diabetes unmasked by pregnancy, also because they share common risk factors, such as obesity. In general, shortly after delivery, glucose homoeostasis is restored to the antepartum condition, but women with a history of GDM often show high blood pressure, atherogenic lipid profiles [5,6], and have a high risk of developing type 2 diabetes [7]. A systematic review showed that the incidence of diabetes among women with a history of GDM ranges from 3% to 65%, because of differences in the duration of the follow-up period and ethnicity [8]. This means that women who had gestational diabetes have at least a seven-fold increased risk of developing type 2 diabetes compared with those who had a normoglycaemic pregnancy [9]. Hence, women with a history of GDM represent a high-risk population and, since the risk of type 2 diabetes seems to be maintained for several years, they should attend regular assessments of their glucose tolerance condition. For these reasons, there is the need to develop appropriate preventive strategies and to identify reliable prognostic factors. In the last years, different antepartum and postpartum independent predictors of later abnormal glucose tolerance have been identified [10-14]. Several studies considered parameters or variables derived from the oral glucose tolerance test (OGTT) data as possible predictors of diabetes risk in the former GDM population, but a few studies considered the entire morphology of those curves.

In this study we hypothesize that the future evolution to a condition of normal glucose tolerance or type 2 diabetes is predictable from the morphology of the OGTT curves at baseline. In order to evaluate this potential predictor capacity, the first step is to evaluate if additional and useful information is contained into curves shape besides the two specific values used for current diagnosis of normal/diabetic condition. For this reason, we used a Self-organizing map (SOM), that is a neural network able to reduce high dimensional data into a low-dimensional topological map and display similarities, in order to cluster OGTT curves basing on their shape. Glucose and insulin curves derived from OGTTs of women with former GDM were considered. The SOM-based analysis was compared with the clinical, shape-independent classification of the glucose tolerance condition (i.e. the gold standard), in order to assess whether the morphology of the OGTT curves are (i) correlated to such condition, and (ii) maintain memory of the previous disease (GDM condition). Moreover, having a small number of curves at disposal, the other aim of this study is to find out an efficient method able to guide data mining in presence of small datasets.

Materials and Methods

Subjects

A group of 127 Caucasian women with GDM was investigated together with a control group (CNT) of 40 women without known risks for diabetes, and with normal glucose tolerance both during pregnancy and at the time of study. Gestational diabetes was diagnosed according to American Diabetes Association (ADA) criteria [15].

All women were recruited during pregnancy from the outpatient department of the University Clinic of Vienna, and gave written informed consent for participation in the study, which was approved by the local ethics committee. They were studied for a maximum of 5 years after delivery. All women underwent a standard 75-g OGTT every year. For each OGTT venous blood samples were collected at fasting and at 10, 20, 30, 60, 90, 120, 150 and 180 min afterward. In this preliminary analysis, however, only OGTT data at the baseline condition were used. According to the criteria proposed by ADA in 1997 [16], summarized in Table 1, the population was divided into a normotolerant group (NGT), a group with impaired glucose tolerance (IGT), and a group with type 2 diabetes (T2DM).

Table 1 – ADA classification of diabetes. G is the glucose concentration in blood measured at the beginning of the test and after 120 min

Glucose Values [mg/dL]	Clinical Classification
[G(0) < 100]	NGT
100 ≤ [G(0)] < 126 **OR** 140≤ [G(120)] <200	IGT
[G(0)] ≥ 126 **OR** [G(120)] ≥ 200	T2DM

As an example of the OGTT data, Figure 1 displays the measured mean glucose curves of NGT, IGT and T2DM subjects.

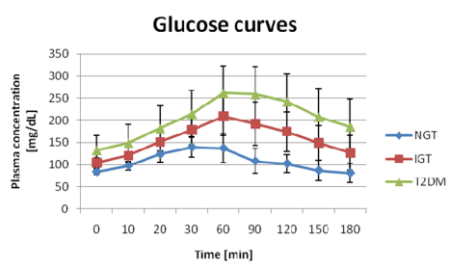

Figure 1 – Mean glucose curves and standard deviations of NGT, IGT and T2DM subjects

Morphological analysis

The Self-organizing map (SOM) is a subtype of artificial neural networks which uses a competitive learning technique to train itself in an unsupervised manner [17]. Competitive learning is an adaptive process in which the neurons of the neural network gradually become sensitive to different input categories, i.e., sets of samples in a specific domain of the input space. A division of neural nodes emerges in the network to represent different patterns of the inputs after training. The division is enforced by competition among the neurons: when an input x arrives, the neuron which is able to represent x better than the others wins the competition and is allowed to learn it even better. If there exist an ordering between the neurons, i.e. the neurons are located on a discrete lattice, the competitive learning algorithm can be generalized. Not only the winning neuron but also its neighbouring neurons on the lattice are allowed to learn: the whole effect is that the final map becomes an ordered map in the input space. This is the essence of the SOM algorithm. Technically, a SOM is made of m neurons located on a regular low-dimensional grid, usually one or two-dimensional. Each neuron i has a d-dimensional feature vector $w_i = [w_{i1},...,w_{id}]$, called prototype vector. At each training step t, a sample data vector $x(t)$ is randomly chosen for the training set, and the "distance" between $x(t)$ and each feature vector is computed. The winning neuron, denoted by BMU (Best Matching Unit), is the neuron with the feature vector closest to $x(t)$:

$$BMU = arg\min_i \| x(t) - w_i \|, \qquad i \in \{1,\ldots,m\}.$$

Once the winning neuron emerges, the weights of the neurons which are close to it are adjusted: because of the neighbourhood relationships, neighbouring neurons are pulled to the same direction, and thus prototype vectors of neighbouring neurons resemble each other. After the training is over, the map should be topologically ordered: this means that n topologically close input data vectors map to n adjacent map neurons or even to the same single neuron.

The morphological analysis was performed over all the glucose and insulin curves made available by the OGTT test. The analysis was conducted both on measured curves, and on curves obtained by the measured ones by removing their mean value. This was done in order to investigate whether curves can be someway classified exclusively in terms of their morphology, or the classification is biased by the exact value of each sample of the curve. For the SOM design, a hexagonal lattice map, a linear initialization of prototype vectors and a batch training algorithm was chosen, while the dimension of the grid depended on the size of the training sets used. The input sets were different, depending on what information we wanted to extract from the morphology of the considered curves. In detail, we investigated two different aspects:

- Curves belonging to CNT ($n = 40$) and NGT groups ($n = 43$) were used to construct a SOM with the aim of discovering whether a sort of memory of the previous disease (the GDM condition) is maintained in the morphology of the NGT curves (memory-of-disease-driven shape)
- Combination of curves belonging to CNT, NGT, IGT and T2DM groups (see Table 2) were used for training SOMs, aiming at evaluating whether there are substantial morphological differences among curves of subjects classified as having different glucose tolerance condition according to the ADA 1997 criteria [16].

Table 2 – Combination of curves used for training SOM

Combination of curves	Sample dimension
NGT vs. T2DM	($n_{NGT} = 43$) vs. ($n_{T2DM} = 37$)
NGT vs. IGT	($n_{NGT} = 43$) vs. ($n_{IGT} = 47$)
NGT vs. IGT vs. T2DM	($n_{NGT} = 43$) vs. ($n_{IGT} = 47$) vs. ($n_{T2DM} = 37$)

After training, the natural clustering tendency of curves was evaluated. Moreover, the available a priori knowledge about the input dataset was then used: each neuron was, in fact, afterwards labelled with class of the most numerous group of curves represented by that node. In this way, it was possible to understand how the current classification is represented by curves morphology and if SOM makes additional information come out.

The entire analysis was performed inside Matlab environment (The Mathworks, Inc., Natick, USA).

Results

First of all, there was any significant difference between results obtained with measured curves and those obtained with curves subtracted of their mean value (data not shown). For this reason, the following results are referred only to zero-mean curves.

A visual depiction of the analysis performed over glucose curves belonging to CNT and NGT groups is shown in Figure 2, where each colour is the result of the waveform classification performed by the SOM, i.e.: blue colour is associated to neurons representative of only CNT curves; yellow colour is associated to neurons representative of only NGT curves; green colour is associated to neurons with prototype vectors morphology is very close to both CNT and NGT curves. Notably, colours do not identify well separated regions in the map. This means that SOMs were not able to assign CNT and NGT curves to distinct regions of the map: neurons representative of only CNT curves were not confined in a particular region well separated from regions with neurons that recognized only NGT curves. Furthermore, about the 35% of prototype vectors was very similar both to CNT and NGT curves, and the corresponding neurons were quite randomly distributed in the SOM space. Also comparing different type of curves combined together (glucose and insulin) did not improve the SOM capability in discriminating among CNT and NGT curves (data not shown).

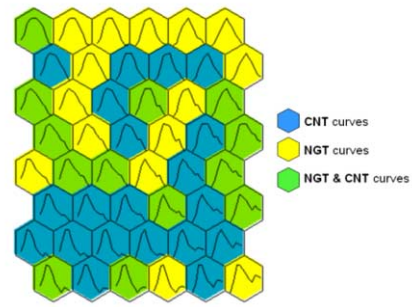

Figure 2 – CNT vs. NGT curves SOM: each neuron (hexagon) is characterized by its prototype vector (curve drawn inside the neuron). In this case, neurons representative of only CNT curves were not confined in a particular region well separated from regions with neurons that recognized only NGT curves

Concerning the morphological differences between NGT and T2DM groups, the SOM based analysis put in evidence a clear division in the morphology of the OGTT measured waveforms, as showed in Figure 3, in particular when only glucose curves were considered.

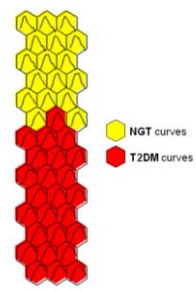

Figure 3 – NGT vs. T2DM curves SOM: upper region recognized only NGT patients, while lower area only T2DM curves

When the IGT group was included in the analysis, SOM analysis identified specific regions in the map referable to NGT, IGT and T2DM curves (Figure 4: glucose and insulin curves combined). However, when IGT curves were intro-duced in the analysis, the clear distinction observed between different group, such as Figure 3, was partially lost: transition regions appeared in the map because their prototype vectors were close enough to two different types of curve morphol-ogy. This is due to the fact that the inclusion of IGT curves in the analysis made less clear the distinction between NGT and T2DM curve morphology.

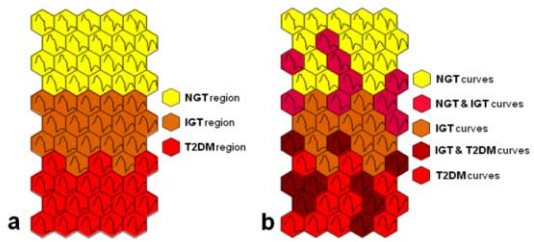

Figure 4 – NGT vs. IGT vs. T2DM curves SOM: it was possible to identify regions corresponding to different groups (a), however, some neurons had prototype vectors closed to two kind of curves, i.e. NGT and IGT or IGT and T2DM (b)

The distribution of the curves within neurons when the three clinically defined groups are included in the SOM analysis is summarized in Table 3. Notably, the number of NGT and T2DM curves falling into regions different from their clinical diagnosis was only the 2% and the 16%, respectively. In both the two cases, this happened because they were considered to belong to the same neurons as IGT curves.

Table 3 – Classification of curves using regions identified by SOM

Glucose tolerance condition	Areas identified by the SOM		
	NGT region	IGT region	T2DM region
NGT	42 *(98%)*	1*(2%)*	0
IGT	8 *(17%)*	30 *(64%)*	9 *(19%)*
T2DM	0	6 *(16%)*	31 *(84%)*

Discussion

To our knowledge, a few studies are present in the literature addressing the problem of the possible information contained in the shape of the OGTT curve [18]. In particular, in a population of women with a history of gestational diabetes, only a preliminary study [18] was carried out so far, based on a totally different approach from the SOM analysis used in this study.

Our results show that the whole morphology of the OGTT measured curves contain information about the current status of the patient with a history of GDM, because the SOM-based clustering clearly allows to discriminate subjects belonging to healthy or diabetic group even when the mean values is removed from the measured curves. Moreover, there are additional information that lead SOM to map nearer or not curves that currently belong to different groups. Exactly this topographic arrangement could be predictive of future evolution of patients.

Concerning the previous status of patient, OGTT measured curves of NGT women seem not to contain any memory of the previous GDM condition (that is, at this stage of analysis our method seems not to distinguish between NGT with former GDM and CNT). However, the other results presented here make us confident about the possibility of proceeding in our hypothesis verification: in fact, our preliminary findings show that OGTT curves morphology contains additional information about the current glucose tolerance condition that can be used for prediction of patient status evolution.

Conclusion

In conclusion, we succeeded in mining novel knowledge from our dataset even if it is relatively small: having not a large number of curves, through SOM, we have however extracted shape information that could be used for pattern recognition and feature selection in the next step, in which a relation between morphology characteristics and follow-up will be sought.

We also demonstrated the presence of additional information that, for example, leads some normal curve to be more similar to a diabetic one. The next phase will be to validate the hypothesis that these similarities or dissimilarities, recognized and underlined by SOM, are effectively prognostic factors of glucose tolerance evolution.

These results will be used to improve the follow up of women with a history of GDM. The fact that the whole morphology of the OGTT curves, and not only the absolute value of some glucose or insulin OGTT samples, depends upon the normal or diabetic condition of a subject allow for a more reliable identification of women that will develop type 2 diabetes.

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Temporal Clustering for Blood Glucose Analysis in the ICU: Identification of Groups of Patients with Different Risk Profile

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Abstract

Blood Glucose (BG) analysis and control in critically ill patients became an important research challenge in the last few years. Despite the big improvements that have been achieved both in research and in clinical practice, there are still many aspects that need to be elucidated. A first step towards a better comprehension of the phenomena underlying BG dynamics is represented by the study of retrospectively collected data. In this paper we propose an analysis of blood glucose time series through a combined temporal clustering and standard statistical analysis approach. The ultimate goal of the analysis is the identification of groups of patients showing different BG dynamics and evaluate their risk profiles, which is a very important issue in the Intensive Care Units. The method is applied to a set of patients treated at the Mediterranean Institute for Transplantation and Advanced Specialized Therapies in Palermo, Italy. We show that it is possible to identify two groups based on the initial blood glucose trends, and that the two groups significantly differ in terms of their future BG behaviour.

Keywords:

Blood glucose analysis, Temporal data mining, Clustering, Intensive care units.

Introduction

Blood Glucose (BG) analysis in critically ill patients has become a crucial issue over the last few years [1,2]. Recent studies have demonstrated that a tight glycaemic control in Intensive Care Units (ICUs) causes a significant reduction in mortality and in the development of post-operative morbidities in surgical ICU patients [3-5]. The use of standardized protocols is leading to better patients' outcomes, so that many tools have been proposed to improve the compliance of ICU departments to current guidelines [6]. Several "ad hoc" glucose variability indexes have been proposed in the literature to evaluate and compare the quality of BG control algorithms among patients [7-9]. Although a lot of progresses have been achieved in this field, many aspects of BG control in ICU patients still have to be deeply understood and there is certainly room for large improvement.

A first step towards a better comprehension of the phenomena underlying BG dynamics is represented by the analysis of retrospectively collected data resorting to statistical and data mining methods. In particular, since BG monitoring data are naturally collected over time, an interesting application is to study such data by exploiting Temporal Data Mining techniques. This can be useful for example to detect different risk profiles in the patients and to plan different therapies for different groups. To this end, temporal clustering techniques are particularly suitable to identify groups of patients showing similarities in glycaemic profiles. However, since ICU patients are usually characterized by severe conditions, the collected time series are often very noisy and irregular. Moreover, they are characterized by uneven sampling time and missing data. To tackle these problems, many researchers are starting to move towards methods that resort to a qualitative and abstract representation of temporal profiles, which are often based on the Temporal Abstraction (TA) technique [10-12].

In this paper we present a combined analysis through TA-based clustering [13] and classical statistical methods applied to ICU patients who underwent cardiovascular surgery at the Mediterranean Institute for Transplantation and Advanced Specialized Therapies (ISMETT) in Palermo, Italy. We show that it is possible to identify two risk groups based on the initial blood glucose trends, and that the two groups significantly differ on some important aspects of their future behavior.

The paper is structured as follows: in the Methods Section we describe the algorithms and analysis approach we used; in the Results Section we introduce the ISMETT ICU data set and we show the results obtained on the patients. The results are further commented in the Discussion Section. In the last Section we draw some final conclusions.

Methods

The analysis approach we adopted in this work is mainly characterized by three methodological issues. The first part of the

analysis deals with the extraction of a suitable representation of BG time series through Temporal Abstractions. Such representation serves as a preparation for the second step, which is temporal clustering. The third phase deals with knowledge extraction from clustering results. The aim of this last phase is to find significantly different groups of patients, focusing in particular on the risk of hypo and hyper-glycaemic events during ICU stay. The different analysis steps are described in the following sections.

Knowledge-based Temporal Abstractions

Knowledge-based Temporal Abstractions (TAs) were first introduced in [14]; they are a formalism that allows to move from a time-point to an interval-based representation of time series data. Such technique provides a description of a (set of) time series through sequences of temporal intervals corresponding to relevant qualitative patterns detected in their time courses. Following the model proposed in [15,16], TAs can be classified into two main categories, depending on the input and output data that are provided. *Basic* TAs are used to transform time-stamped data into a sequence of intervals, while *Complex* TAs are used to abstract intervals into other intervals applying suitable temporal operators [17]. In this paper we will mainly refer to Basic temporal abstractions, that we herein exploit to extract Increasing, Decreasing and Stationary trend patterns from blood glucose time series.

The algorithms that are used to detect TAs are known as TA mechanisms. We herein use a segmentation-and-labeling methodology to extract trends from the raw blood glucose time series. Time series are first processed through a stepwise linear segmentation and then a label is assigned to each segment on the base of its slope. For time series segmentation we use a bottom-up approach [18] suitably designed to deal with unevenly sampled and missing data. Once segments are extracted, the following step is to assign a label to each of them according to the slope of the segment itself. In this work we use a purely data-driven labeling approach, where a two-tailed t-test is performed on the slope parameter of the linear regression used for segment definition. A significance level α is established for the test, and the labeling criterion is the following:

- if |p-value|$\leq\alpha$ AND slope>0 then label = *Increasing*
- if |p-value|$\leq\alpha$ AND slope<0 then label = *Decreasing*
- if |p-value|>α then label = *Steady*

An alternative solution to the labeling issue is the knowledge based definition of a minimum slope threshold to which the segment slope value is compared.

As a result of this first analysis step, BG time series are represented by a qualitative label (or abstract pattern) made up of a set of consecutive basic trend TAs.

Temporal Clustering

The second analysis step concerns the application of a novel method to cluster time series data according to their qualitative behavior [13,19]. This method is called TA-clustering and, although designed to deal with gene expression data, well adapts to any time series with irregular sampling time. The TA-clustering technique is a generalization of template-based clustering [20] and it is based on a qualitative representation of profiles derived exploiting trend TAs (as described in the previous section). One of the most relevant features of TA-clustering is that it is based on a multi-level strategy that works on qualitative labels. In particular, we originally defined three abstraction levels for time series representation, that reflect different label aggregation. As a starting point we take the label deriving from the segmentation-and-labeling step; we will call this label the L_2-level label, since it represents the intermediate level from which the other two are then derived. L_1-level labels are obtained by removing all the *Steady* elements from L_2 labels and re-aggregating consecutive equal labels when needed. L_3-level labels are low-level abstractions obtained by assigning to each time interval of the original time series the corresponding qualitative label (consecutive labels can be duplicated in such representation). An example of the multi-level labeling system is depicted in Figure 1.

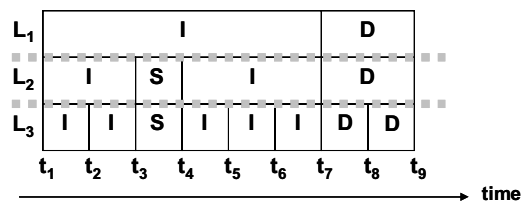

*Figure 1 – Example of the multi-level labeling scheme used for temporal clustering. Herein **I** stands for Increasing, **D** for Decreasing and **S** for Steady. At the bottom of the picture the time line is reported.*

Considering the high heterogeneity in sampling time, number of measurements and length of stay characterizing critically ill patients, in this work we will only refer to the most abstracted levels (L_1 and L_2).

Once the abstracted labels are created, the aggregation procedure for the two top levels is straightforward: time series with the same label are grouped into the same cluster. For L_3 labels a distance function is instead defined to group together time series that show similar qualitative behavior [13].

Evaluation and Comparison of Patients' Risk profiles

Relying on clustering results it is often possible to identify patients groups and to evaluate the clinical profiles of the members of such groups on the base of interesting characteristics. As regards BG monitoring, an interesting index to assess a patient's condition is to evaluate his/her risk of experiencing hyper or hypo-glycaemic episodes during the ICU stay.

To this end, for each patient we compute the risk profile following the indications proposed in [8]. In particular, for any BG measurement (*bg*) expressed in mg/dl, the risk function(*r(bg)*) is defined as follows:

$$r(bg) = 10 \times \left\{1.509 \times \left[(\ln(bg))^{1.084} - 5.381\right]\right\}^2 \quad (1)$$

Exploiting equation (1) it is possible to derive a risk time series for each patient. From this time series the average risk can then be calculated on a specific time window as required by the analysis purposes. We will exploit such solution on the groups of patients extracted through clustering. As we will show in the next section, comparisons between groups are performed towards standard statistical methods.

Results

Data Set Description

In this study we considered a group of 596 ICU patients treated by the Mediterranean Institute for Transplantation and Advanced Specialized Therapies in Palermo, Italy, from August 2006 to February 2008. The patients belonging to our sample underwent various types of cardiac surgery, as reported in Table 1. For 11 patients the information related to the type of intervention was not available.

Table 1 – Type of surgery and number of patients in our data set

Type of surgery	Number of patients
Single valve	216
Multiple valves	47
Aortic surgery	16
Ventricular surgery	24
Bypass	180
Bypass and Valve	78
Transplantation	15
Minor cardiac surgery	9

A set of 22 parameters was monitored over time for all the patients during the ICU stay. In this study we will consider blood glucose time series. BG was monitored for all the patients by means of BG fingerstick and venous measurements. The median of ICU stay was of 3 days (minimum: 1 day, maximum 31 days), with an average number of 14 measures per patient and an average inter-measurement time of 3.7 hours.

Data Analysis

Considering the median length of stay and the fact that patients staying at the ICU for 3 or more days usually show the most critical illness conditions, in our analysis we chose to take into account the first 3 monitoring days. As a first analysis step we performed TA-clustering using L_1 and L_2-level labels. The result of this step was a set of 14 L_1 clusters, that we further joined to form two macro-groups based on the initial trend of the glucose monitored values (*Increasing* and *Decreasing*)

In particular, we identified 300 patients starting with an initial increasing trend and 286 patients starting with a decreasing glucose trend. Figures 2 and 3 represent the two clusters with the average profile of the initial trend.

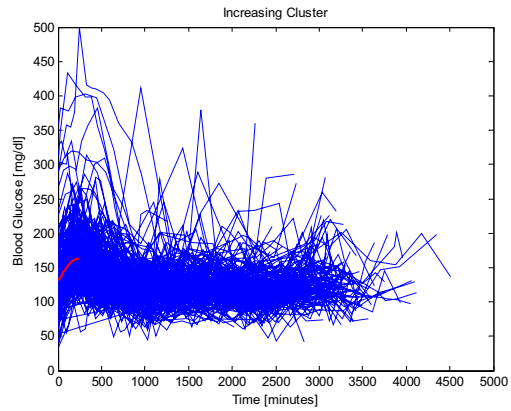

Figure 2 – Cluster of patients with an initial increasing trend

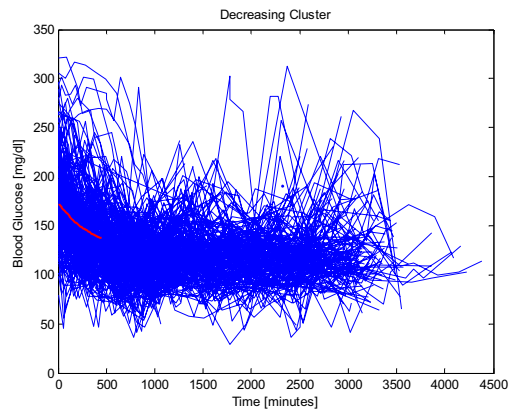

Figure 3 – Cluster of patients with an initial decreasing trend

The median time span of the initial increasing interval was found to be 4.03 hours, with an interquartile range of [1.9 - 8.4] hours. The median duration of the initial decrease was found to be 14.4 hours, with interquartile range [7.98–21.15] hours. The two medians are significantly different ($p << 0.01$). The duration of the increasing trend is significantly shorter than the duration of the decreasing BG trend ($p << 0.01$).

We also found a significant difference ($p < 0.05$) between the initial BG values in the two groups. Rather interestingly, the higher BG basal value is associated to the decreasing group, as it can be noticed by the boxplot in Figure 4.

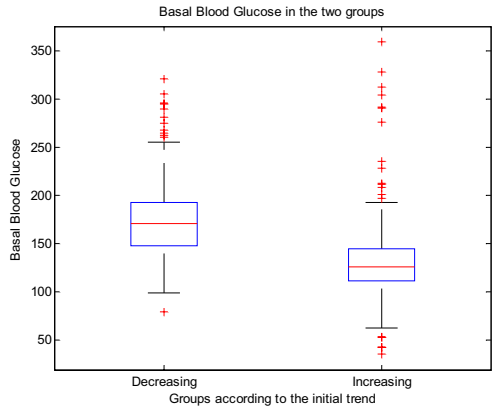

Figure 4 – Boxplot of the distributions of the basal BG value in the two groups

As a next analysis step, we have subdivided the BG time series for each patient into two periods to evaluate the patients' risk profiles. The first period was set to finish at the end of the initial trend (i.e. the increasing or decreasing period), while the second period was defined by the remaining monitoring time.

For each patient we computed the time series of the risks, and we calculated the average risk index on the two periods. We compared the average risk distributions for the second period in the two clusters, and we obtained a significant result ($p << 0.01$), being the decreasing group less risky. Besides the average risk index we also evaluated the standard deviation of BG measurements in the second period and compared it in the two groups. Also in this case the result showed a significant difference (p-value<<0.01) with higher values for the Increasing group. In particular the median value for standard deviations in the Increasing group was of 25.03, while for the Decreasing group it was 20.6.

To better evaluate the instability scenario that clearly characterizes the patients belonging to the Increasing group, we also analyzed the insulin intake in our set of patients with the goal of comparing the two groups. In particular, we compared the medians of the standard deviation of the insulin intakes after the initial trend in the two groups. The result is significant (p-value <<0.01), with a lower value for the Decreasing group. The median value of the insulin intake standard deviation for the Increasing group was found to be 1.24, while for the Decreasing patients it was found to be 0.95.

A further analysis also revealed that the duration of the increasing period is significantly positively correlated with the risk in the second period and that the duration of the decreasing period is negatively correlated with the risk in the second period ($p < 0.05$).

To better elucidate if the difference between the two groups is due to some clinical reasons not related to BG control, we performed an additional analysis to check the frequency of the surgery type and risk factors (comorbidities) in the two groups of patients. We didn't find clinically interesting differences in the distribution of clinical interventions; however, we found that in the Decreasing group there are significantly more Diabetes mellitus patients (76 vs 52, $p < 0.05$) while in the Increasing group there are more Valvular Heart Disease patients (148 vs 193 $p<0.05$)

Finally, we analyzed the distributions of clinical morbidities of the two groups, that showed significant differences only concerning Bleeding (Decreasing 15, Increasing 26, $p<0.01$) and the need of an Intra Aortic Balloon Pump (Decreasing 15, Increasing 3, $p<<0.01$).

Discussion

In the previous section we have shown that it is possible to divide ICU patients into two groups related to the initial BG trend and that these groups show significant differences in their risk profiles and in insulin treatment.

In particular, we have demonstrated that the basal BG values are significantly higher in the Decreasing group. This can be motivated by analyzing the post-operative patient management. Each patient gets an insulin drip starting immediately after surgery until they start to eat. If an high basal glycaemic level is observed, it is immediately treated to return to normal values, thus originating a decrease in BG time series. Higher basal glycaemic values lead thus to a more aggressive treatment in BG control at least in the first period.

Similarly, the resulting shorter duration of the increasing trend is clinically motivated by the fact that an increase in BG is often considered as an alarm. The procedures to go back to a normoglycaemic pattern are performed quite quickly in order to stop the increase and to avoid severe complications.

Broader glycaemic oscillations and higher average risk indexes were also found for the Increasing patients. This was coupled to an higher variability in the associated insulin therapy for such group, highlighting a clear relationship between the glycaemic temporal patterns and the clinical management of the patients.

Trying to further characterize the two groups of patients on the base of their clinical characteristics, we also compared the frequencies of surgery type and risk factors in the two samples. The aim of this analysis was to verify whether the group characterized by the higher instability and risk index (the Increasing group) was made up of patients who underwent major surgeries or characterized by important risk factors. However, our tests resulted in almost no significant differences into the distributions of surgeries and comorbidities among patients. Also the number of diabetic patients, that are usually characterized by a more aggressive insulin therapy and were thus expected to fall into the decreasing group, was only slightly higher in such group. The same conclusion can be drawn if we observe the distribution of the morbidities in our two samples. Besides the increase of the risk index and in the incidence of bleeding, the patients of the Increasing group don't show major morbidities if compared to the Decreasing group.

We might thus conclude that, at least in the clinical center under study, an increase of BG after surgery is a useful marker of

metabolic instability and of a critical evolution of the patient's condition which requires more frequent intervention of the health care providers. A further step of the analysis will be to include in the study also the other parameters that are monitored during the ICU stay.

Conclusion

In this paper we have presented a temporal data mining approach to the problem of analyzing blood glucose monitoring time series in ICU patients. In particular, we have applied a TA-based clustering technique to identify groups of patients showing similarities in their glycaemic profiles. We have been able to identify two macro-groups of patients characterized by a different initial trend in BG, namely Increasing and Decreasing trends. Such groups were found to significantly differ on some important characteristics, and in particular we found that the patients showing an initial increase in BG have an higher future BG risk and higher future oscillations. Moreover, the risk in the second period results to be correlated with the duration of the initial trend. These promising results lead us to conclude that evaluating the initial BG trend can be predictive of the future behavior of the patients' risk profile.

This paper showed that temporal data mining is a useful tool to better understand the data collected in routine clinic and to provide health care providers with useful advice and caveats.

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A Markov chain probability model of glucose tolerance in post gestational diabetes follow up study

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Abstract

Women with gestational diabetes mellitus (GDM) are at increased risk of developing type 2 diabetes (T2DM). However, the degree of risk and the timing of progression from normal to a pre-diabetic or diabetic state have not been clearly quantified. In this study we analyzed data from a longitudinal study on a group of women with a history of GDM, that were inserted in an oral glucose tolerance test (OGTT) annual screening program and followed up for 5 years after partum. A three state Markov chain model was proposed to represent the dynamics of changes between metabolic states. We used the data to empirically estimate the one-year transition parameters of the model and make predictions about the possibility that women with normal glucose tolerance or impaired glucose metabolism just after partum will develop overt T2DM in three or five years. Results show that subjects with an impaired glucose metabolism few months after partum will hardly (10%) be in the same state after three years. Women with normal glucose tolerance after partum will have a high probability (0.80) to be in the same state three years after.

Keywords:

Gestational Diabetes Mellitus, Markov chains, Follow-up studies, Oral Glucose Tolerance Test.

Introduction

Gestational diabetes mellitus (GDM) is the specific type of diabetes that may develop during pregnancy [1]. GDM is a quite common condition with a prevalence ranging from 1 to 14% of pregnancies, depending on the population under study. GDM represents nearly 90% of all pregnancies complicated by diabetes. The incidence of gestational diabetes is rising throughout the world [2,3], and the same holds for type 2 diabetes [4]. Women with previous gestational diabetes, after delivery (pGDM), often normalize their glucose levels, but they are at increased risk of developing type 2 diabetes [5,6], especially if they have other risk factors (i.e. obesity, hypertension, family history of type 2 diabetes). In this context, it is important to undertake follow up studies that can provide some insights about the actual risk and timing of possible onset of type 2 diabetes. Data analyzed in this paper refers to a 5 year follow up study of glucose tolerance in pGDM women. The analysis of the data was carried out using a three state Markov chain model to study the transition between different glucose tolerance conditions and making predictions about the onset of type 2 diabetes in the population after three years from the delivery. Markov chains have often been used to model disease's natural history, see [7] for an example of application in the context of diabetes.

Subjects

A group of 116 women participated in the study. They were selectively recruited from the outpatient department of the University Clinic of Vienna. Written informed consent was obtained from all subjects and the protocol was approved by the local ethics committee. For all women, GDM was found in their first pregnancy; repeated pregnancies were excluded.

Table 1 – Characteristics of the studied pGDM women at the basal state (mean ± SE).

	NGT	IGM	T2DM
Number of subjects	87	21	8
Age (years)	32.91 ± 0.51	34.66 ± 0.93	33.88 ± 2.25
BMI (kg m^{-2})	26.57 ± 0.55	30.97 ± 1.00	31.35 ± 2.15
Fasting plasma glucose (pmol L^{-1})	4.82 ± 0.05	5.89 ± 0.18	6.91 ± 0.35
Plasma glucose at 120 min (pmol L^{-1})	5.88 ± 0.11	9.77 ± 0.36	11.85 ± 0.63

GDM was diagnosed in all the participants according to the criteria of the 4th Workshop Conference of Gestational Diabetes [5], through a 75-g oral glucose tolerance test (OGTT). During pregnancy the GDM women were not subjected to any treatment; they received only dietary and physical exercise advertisements. The study started with a basal OGTT screen-

ing taken 4 to 6 months after partum and then the women were followed, with an annual OGTT screening program, up to 5 years later on. The characteristics of the pGDM women immediately after partum are described in Table 1. Subjects' conditions (or metabolic states) were classified, according to the American Diabetes Association (ADA) 1997 criteria, as: normal glucose tolerance (NGT); impaired glucose metabolism (IGM), including subjects with impaired glucose tolerance (IGT) and/or impaired fasting glucose (IFG); and type 2 diabetes (T2DM). A complete depiction of the data is given by Figure 1, where the distribution of the metabolic states at each year is reported.

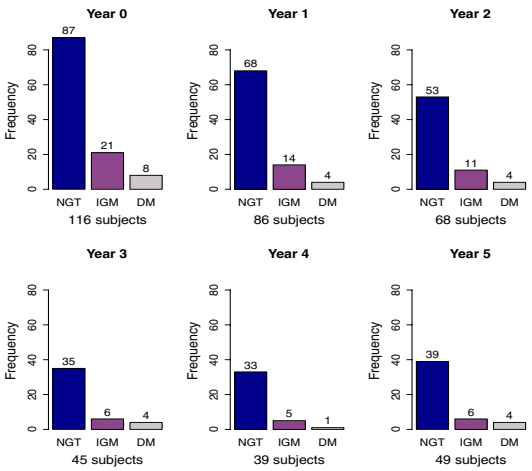

Figure 1- Frequency distribution of the three states (NGT, IGM, T2DM) at each year.

There were two main causes for ending the program: the natural deadline (5 years after partum), or the onset of type 2 diabetes. The data expected from the protocol are not complete, because some participants skipped one or more visits and then reentered the program subsequently.

Methods

Oral Glucose Tolerance Test

After an overnight fast, all women underwent a standard 75-g OGTT. Venous blood samples were collected immediately before glucose ingestion (fasting sample, $t=0$) and at 10, 20, 30, 60, 90, 120, 150 and 180 min afterwards for glucose, insulin and C-peptide measurements.

Data analysis

Markov chains

A Markov chain (MC) is a simple stochastic process often used to model uncertain phenomena evolving in time. In a stochastic process changes of state (value of the process) are governed by probabilistic laws. The laws describing present and future values of the process in terms of its past state history are called transition laws. A Markov chain, specifically, is characterized by transition laws depending only the most recent past state and not on the whole past history. More formally, consider a stochastic process $\{X_t, t=0,1,2,\ldots\}$ that takes values on a finite set S, called state space. Let the state space size be N, with $S=\{s_1,s_2,\ldots,s_N\}$. If $X_t=s_i$, then the process is said to be in state s_i at time t. Suppose further that the Markov property holds:

$$\Pr(X_{t+1}=s_j \mid X_t=s_i, X_{t-1}=s_{t-1},\ldots,X_0=s_0) = \\ = \Pr(X_{t+1}=s_j \mid X_t=s_i) \quad \forall s_0,\ldots,s_{t-1},s_i,s_j;\forall t. \quad (1)$$

Such a process is known as a Markov chain, and the above property reads that for a MC the conditional distribution of any future state given the past states and the present state is independent on the past states and depends only on the present state. If $X_t=s_i$ and $X_{t+1}=s_j$, then we can write

$$\Pr(X_{t+1}=s_j \mid X_t=s_i)=p_{ij}^{t+1} \qquad \forall t. \qquad (2)$$

The value p_{ij}^{t+1} represents the probability that the process, when in state s_i at time t will make a transition to state s_j at time $t+1$. Clearly we have that $p_{ij}^{t+1}\geq 0 \quad \forall i,j;$ and $\sum_{j=1}^{N} p_{ij}^{t+1}=1 \quad \forall i.$ We can arrange the transition probabilities into a $N\times N$ matrix, $P^{t+1}=\left\|p_{ij}^{t+1}\right\|$, obtaining the one-step transition matrix of the MC from time t to $t+1$. As the transition probability between any two states of the chain does depend of t, the chain is called time-inhomogeneous Markov chain.

Once the one-step transition probabilities are known it is possible to compute the conditional probability that the chain at time $t+T$ will be in state s_j given that at time t was in state s_i. As an example, we report the formula for the case $T=3$:

$$\Pr(X_{t+3}=s_j \mid X_t=s_i)=\sum_{k=1}^{N}\sum_{l=1}^{N} p_{ik}^{t+1} p_{kl}^{t+2} p_{lj}^{t+3}, \qquad (3)$$

$\forall s_i,s_j;\forall t.$

A state of the chain, say s_i, is called an adsorbing state if $p_{ii}=1$, that is once the process is entered in that state it will never leave it. A state is called transient, if, starting the process from that state, there is a positive probability that the process will never reenter that state. For further details on the basic concepts introduced in this paragraph, we refer the reader to

any book including an introduction on discrete time Markov chain, i.e. [7].

A Markov model for the transitions between metabolic states

Metabolic (or glucose tolerance) states can be defined for each subject - using ADA 1997 criteria - as NGT, IGM, and T2DM. We consider this simplified three state classification, even if the intra-class variability may be large in the IGM class (including both IFG and IGT subjects). Furthermore, we hypothesize that the dynamics of the glucose tolerance derived from the OGTT depends on the past screenings only through the previous year dynamics. Under this hypothesis and recalling that the subject state classification depends on the fasting and on the 2-h plasma glucose level during the OGTT, the future and the past subject's metabolic states are conditionally independent given the state in which the subject is at present, so the Markov property holds. Thus, we model the transitions between subject's glucose tolerance states as a one order time-inhomogeneous Markov chain with categorical state space $S = \{NGT, IGM, T2DM\}$. Let X_t be the metabolic state at year t, if $X_t = s_j$ and $X_{t-1} = s_i$, then $\Pr(X_t = s_j \mid X_{t-1} = s_i) = p_{ij}^t \quad \forall t.$

From the screening protocol, we know that women entering the T2DM state are no longer followed up because they might be treated with anti-diabetic drugs. This information allows us to define a Markov chain model with two transient states (NGT and IGM) and one absorbing state (T2DM). Thus the transition matrix, from year $t-1$ to t, has the following structure:

$$P^t = \begin{Vmatrix} p_{11}^t & p_{12}^t & p_{13}^t \\ p_{21}^t & p_{22}^t & p_{23}^t \\ 0 & 0 & 1 \end{Vmatrix},$$

where state 1 correspond to NGT, state 2 to IGM, and the absorbing state 3 to T2DM. In Figure 2 the graphical representation of the transition probabilities between any couple of states of the chain is reported.

Alternative Markov chain models with longer memory of the chain or with higher number of states might also be considered, but such models would not be suitable in the case of sample size of 116 (that is our case) because they would lead to many transition parameter estimates being zero for lack of empirical data.

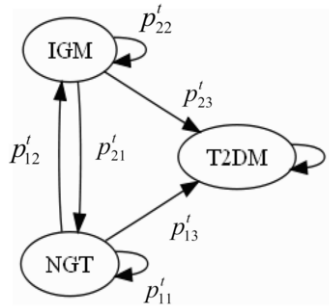

Figure 2 - One-step transitions between the states of the chain; labels on arrows are the transition probabilities.

Estimation of transition probabilities

Let denote by n_{ij}^t the number of women that were in state i at year $t-1$ and are in state j at year t after partum. We can empirically estimate the probability of a woman being in state j at year t after partum given that she was in state i at year $t-1$, $\hat{p}_{ij}^t$, using the formula

$$\hat{p}_{ij}^t = \frac{n_{ij}^t}{\sum_j n_{ij}^t}, \tag{4}$$

that corresponds also to the maximum likelihood estimator. This estimator is showed to be consistent but biased, with bias tending to zero as the sample size increases [9]. For the reader interested in further statistical properties of the transition probability estimator of a MC the paper just cited is a very good reference.

Thus, Equation (4) states that the estimated transition probability from any given state i to state j is equal to the proportion of women that started in state i and ended in state j with respect to all women that started in state i. As we are considering inhomogeneous Markov chains, these probabilities are different for different times.

Results

One year transition matrices

By using the procedure described in the data analysis section we have estimated the one year transition matrices for each possible transition (0 to 1, 1 to 2, 2 to 3, 3 to 4, 4 to 5). Due to the incompleteness of the longitudinal data (some screenings were skipped by the women or they had developed T2DM, thus they were excluded from further analysis) for the last two transition we had only few cases available to estimate some of the transition probabilities. Therefore we decide to stop our analysis at the third year.

As regards the estimated transition matrices for the transitions from 0 to 1, 1 to 2 and 2 to 3, we found the following results:

$$\hat{P}^1 = \begin{Vmatrix} 0.89 & 0.10 & 0.01 \\ 0.33 & 0.47 & 0.20 \\ 0 & 0 & 1 \end{Vmatrix},$$

$$\hat{P}^2 = \begin{Vmatrix} 0.88 & 0.12 & 0.00 \\ 0.36 & 0.45 & 0.18 \\ 0 & 0 & 1 \end{Vmatrix},$$

$$\hat{P}^3 = \begin{Vmatrix} 0.90 & 0.10 & 0.00 \\ 0.50 & 0.10 & 0.40 \\ 0 & 0 & 1 \end{Vmatrix}.$$

As can be appreciated, the transition from year 0 to 1 and from year 1 to 2 lead to approximately the same estimated transition matrix. In other words, we can claim that the differences in the first two transition matrices are negligible from a clinical point of view. In the transition from year 2 to 3 we notice a strong change in the behavior of IGM subjects. The percentage of women passing from IGM to T2DM is doubled with respect to the transitions occurred in the first 2 years after partum.

Predictions

The estimated transition matrices allow us to make predictions about the possibility that women with previous GDM will develop T2DM in three years after partum. Inserting into Equation (3) the estimated transition probabilities above, the ensuing conditional distributions of the metabolic state at year 3, given that the basal state was either NGT or IGM, are

$$\Pr(X_3 \mid X_0 = NGT) = (0.8, 0.1, 0.1),$$

$$\Pr(X_3 \mid X_0 = IGM) = (0.5, 0.1, 0.4).$$

Thus, a woman with pGDM who is NGT after partum, after three years from the delivery will remain NGT with probability 0.8, will become IGM with probability 0.1 and will develop T2DM with probability 0.1. The IGM condition appears as a temporary condition: in fact, in three years we expect that only the 10% of IGM subjects will remain in the same condition, while the remaining 90% will be split between the return to a condition of normal glucose tolerance (50%) and the development of the pathological condition of type 2 diabetes (40%).

Discussion

In this study we presented a Markov chain approach for population predictions about the transition between metabolic states of women with a history of gestational diabetes. The parameters of our model were estimated using data from a follow up study. We found that a woman in NGT condition immediately after partum has high probability (0.8) to be in the same condition three years later and will move to the condition of impaired glucose metabolism or become diabetic with the same probability: 0.1. The IGM condition appears to be a splitting condition from the normal and the pathological states. This may be due to the fact that in the IGM condition reversibility to the NGT condition is still possible, provided that the subject undergoes a change in the lifestyle, especially in terms of dietary habits and physical fitness. The quantification of the suitable energy intake and the possible degree of exercise are beyond the aims of this report; therefore, no specific suggestion is provided here. On the other hand, if no action is taken, it is known that the worsening of the metabolic condition with possible development of diabetes is likely to happen. Thus, in both cases, the IGM condition does not hold for long periods. Our results appear in fact consistent with this explanation: the 50% of IGM reversing to NGT may be the subjects that did take some actions for their health, whereas the 40% progressing to T2DM may be those not taking any significant action. Another interesting result was that, based on the estimated transition matrices, relevant changes in the probability of transition were noticed only between the second and the third year after partum. This observation indicates that in post-gestational diabetic women screening programs shorter than three years after the delivery may not be sufficient, since possible changes (worsening) in the metabolic condition are unlikely to happen before a period of at least three years after partum.

Conclusion

In this study we used a three state Markov chain model to analyze the dynamics of changes in the metabolic condition of women with a history of gestational diabetes. We found that possible transitions of the metabolic condition might not occur until three years after partum. We also found that the condition of impaired glucose metabolism is not likely to be maintained for a long time. The clinical implication of this finding is that a pGDM woman with IGM (easily detectable with a simple metabolic test) must be carefully followed in terms of lifestyle and perhaps appropriate pharmacological agents to yield in the following years a status of NGT. It will be necessary however the assessment of other parameters (such as for instance, insulin resistance, pancreatic secretion, lipid profile) to precisely identify the target for the intervention. With this regard, future works will be devoted to extend these preliminary results including considerations based on other measured variables (like plasma insulin and C-peptide), as well as on metabolic parameters describing fundamental processes such as insulin sensitivity and beta cell function.

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Development and Validation of Data Specifications for Nursing Problems in Maternal Nursing Care

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Abstract

The aims of this study were to develop data specifications for nursing problems related to maternal nursing care and to test the applicability of those data specifications. First, we identified focus concepts and characterizing concepts of nursing problems by analyzing nursing-problem statements from nursing records, reviewing the literature, and interviewing experts. Second, we identified relationships between the focus concepts and characterizing concepts. Third, value sets of characterizing concepts were identified and types and cardinalities of the characterizing concepts were defined based on those value sets. Finally, data specifications were evaluated by a group of experts and by applying them to published case reports. The adequacy of the characterizing concepts and value sets, and the types and cardinalities of the characterizing concepts were validated. In total, 58 data specifications were developed with 53 characterizing concepts, relationships, and value sets. Their validity was established by the experts and by their application to case reports. The data specifications developed in this study can ensure that electronic health records contain meaningful and valid information, and support the semantic interoperability of nursing information.

Keywords:

Medical information standards, Nursing diagnosis, Knowledge representation.

Introduction

The potential benefits of electronic medical records include improvements in patient safety and quality of care, and reducing the number of medical errors. These benefits depend on data interoperability; exchanging and sharing data is most effective if the data are exchanged and shared in a semantically interoperable manner.

Semantic interoperability means ensuring that the precise meaning of exchanged information is understandable by other systems or applications not initially developed for this purpose [1]. Data being exchanged must be structured and coded to facilitate their complete understanding by computer systems. Complete interoperability depends on a detailed clinical data model that is bound to terms and codes from a standard coding system.

Several different approaches have been used in the development of interoperable models. Intermountain Healthcare has been developing Clinical Element Models for over 15 years [2]. The Research and Development Center for Interoperable Electronic Health Records (EHRs) in Korea is developing a Clinical Contents Model [3]. The developers of the openEHR used archetypes and templates as interoperable models [4]. A group in the UK National Health Service is developing models using a process called the Logical Health Record Architecture. Within the Health Level Seven community, a detailed Clinical Document Architecture is being developed as an interoperable model [5]. However, these efforts in model development are limited to the domain of medical knowledge.

Whilst the importance of developing a nursing constraint model has been addressed by nurse informaticists [6], there are few reports on this topic in the nursing literature. Arche-types of nursing problems for breast cancer patients have been developed and tested in Korea [7], and data specifications for stroke patients have been developed in The Netherlands [8].

The aim of this study was to develop data specifications to represent clinical information in a meaningful way so that data can be accumulated and integrated in a clinical practice environment where the level of nursing-problem do-cumentation varies. We looked at the nursing problems of pregnant women who were hospitalized to give birth since this cohort is homogeneous in terms of gender and age and exhibits comparatively few comorbidities and complications. Once data specifications are developed, we plan to explore the possibility of expanding this work and applying it to other areas of nursing.

Materials and Methods

Extraction of focus concepts of nursing problems

We extracted nursing statements describing patient signs and symptoms, and nursing diagnoses from the electronic nursing records of the 118 women who were hospitalized to give birth from October 1 to October 31, 2008 at a tertiary teaching hospital in Korea. We identified focus concepts from these statements. For example, we extracted a focus concept ‘pain’ from

the nursing-problem statements 'mild back pain' and 'continuous back pain'. We also reviewed the maternal nursing literature to supplement the focus-concept list. The extracted focus-concept list was evaluated and confirmed by a group of experts that comprised a head nurse in maternal nursing, three nurses with master's degrees in maternal nursing, and four nurse experts each with more than 7 years of clinical experience in maternal nursing.

Identification of characterizing concepts

We identified the concepts needed to describe the focus concepts in more detail by analyzing nursing statements, reviewing the literature, and consulting staff nurses. For example, characterizing concepts such as 'anatomical site', 'severity', and 'frequency' were identified from the nursing statement 'continuous mild back pain'. These characterizing concepts were confirmed by 8 nurse experts and named using The Conceptual Framework for Patient Findings and Problems in Terminologies published by the ISO/TC 215 [9], Archetype by the *open*EHR [4], Attributes of SNOMED CT [10], and the Clinical Contents Model developed by the Research and Development Center for Interoperable EHRs [3].

Development of data specifications

Data specifications were developed using focus concepts, characterizing concepts, the relationship between focus concepts and characterizing concepts, and the types, value sets, and cardinalities of characterizing concepts.

Validation of data specifications

Data specifications were validated by experts and by their application to published case reports. A group of experts was asked to evaluate whether the focus concepts were adequate, the characterizing concepts were clearly represented, the relationships between core concepts and characterizing concepts were adequate, the value sets were complete, and the types and cardinalities of the characterizing concepts were correct. The expert group comprised three doctoral students in nursing informatics, one head nurse with experience in informatics and maternal care, two informatics nurse specialists, and two maternal nurses each with more than 7 years of clinical experience.

Data specifications were also evaluated using two case reports published in an academic journal. We identified focus concepts, characterizing concepts, and value sets from the case reports, and mapped them with the developed data specifications to evaluate their coverage. The cases we used for validation were aplastic anemia in pregnancy [11] and stimulating the onset of labor [12]. Data specifications of menstrual history, gravida, parity, abortion, Bishop Score, uterine contraction, and rupture of membranes were validated with the case reports.

Results

Extraction of focus concepts of nursing problems

Forty-one core concepts were extracted from 711 days of nursing records related to 118 pregnant women who were hospitalized to give birth. Examples of focus concepts identified from the nursing records included concepts unique to maternal nursing such as uterine contraction and lochia, and general nursing concepts such as gas emissions, constipation, and pain. In addition, 12 core concepts were identified from a literature review. Concepts such as Bishop Score, guilt, and inverted nipples were identified through a literature review. Five more concepts were identified from the experts' evaluation: two experts suggested body weight and abdominal circumference, and one expert suggested abscess, falling, and arrhythmia.

In total, 58 focus concepts were identified. These focus concepts included not only physical signs and symptoms such as dyspnea and seizure, but also psychosocial problems such as grief, guilt, depression, and parent role. Furthermore, there are complex focus concepts that comprise more than one focus concept, such as vital signs, which comprise systolic blood pressure, diastolic blood pressure, pulse, respiration, and body temperature.

Identification of characterizing concepts

Thirteen characterizing concepts were identified by analyzing nursing statements. For example, we identified 'severity' with a value set of 'absent', 'mild', and 'severe' by analyzing nursing statements such as 'severe pain', 'mild pain', and 'no pain'. The characterizing concept 'pain character' was identified with the value set of, for example, 'sharp', 'burning', and 'fulgurating', by analyzing nursing statements such as 'burning pain', ' sharp pain', and 'fulgurating pain'.

Thirty-four characterizing concepts were identified from a literature review, such as 'intensity' with a value set of 'strong' and 'weak'. In addition, six characterizing concepts were identified by the expert group, such as 'level' with a value set of '–', '±', '+', and '++' to describe the presence and amount of protein or ketone in the urine. In total, 53 characterizing concepts were identified.

Development of data specifications

Data specifications for 58 focus concepts were developed by relating focus concepts to characterizing concepts with data types, cardinalities, and value sets. The lochia data specification is listed in Table 1 and presented diagrammatically in Figure 1. Lochia has a 'has_amount' relationship with the characterizing concept 'amount,' and a 'has_odor' relationship with 'odor'. Data types of these characterizing concepts are coded text; cardinalities for 'amount' and 'odor' are optional.

Table 1 - Lochia data specification

Characterizing concept	Relationship	Type	Cardinality	Value
Amount	has_amount	Coded text	Optional 0..1	[almost none | a little | moderate | a lot]
Odor	has_odor	Coded text	Optional 0..1	[foul | none]
Color	has_color	Coded text	Optional 0..1	[rubra | serosa | alba]
Subject of information	has_subject of information	Coded text	Mandatory 1..1	[patient]

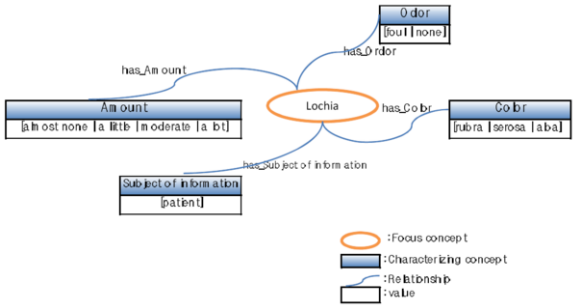

Figure 1- Schematic of lochia data specification

Validation of data specifications

Data specifications were validated by a group of experts, as described above, and tested by applying them to published case reports. Based on the recommendation of one expert, 'greenish' was added to the value set of the characterizing concept 'color' in the data specifications rupture of membranes and abscess. The characterizing concept 'interpretation' was removed from blood sugar, body weight, and pulse data specifications because two experts pointed out an overlap of information between the characterizing concepts 'numerical quantity' and 'interpretation' for the blood sugar, body weight, and pulse data specifications.

With the aid of case reports from the literature, data specifications unique to maternal nursing such as menstruation history, gravida, parity, abortion, Bishop Score, uterine contraction, and rupture of membranes were validated. In this validation, we verified whether the data specifications developed in the study cover data elements in the two case reports. Table 2 indicates how the section describing rupture of membranes was decomposed and mapped to values of characterizing concepts in the rupture of membranes data specification.

In this description, values of characterizing concepts of the data specification rupture of membranes, such as 'interpretation', 'occurrence', 'color', 'instrument', and 'subject of information' were identified. For example, 'M.S. reported a gush of clear fluid at 6:30 p.m.' has information about the time of rupture, the color of the fluid, and the subject associated with the information. All of these values were covered by the value sets of the characterizing concepts of data specification of 'rupture of membranes' developed in this study.

Table 2 - Validation of rupture of membranes data specification using case reports

Description of rupture of membranes in the case report	Extracted value	Characterizing concept
M.S. reported a 'gush of clear fluid' at 6:30 p.m. Ruptured membranes were confirmed by sterile speculum exam.	Were confirmed (positive)	Interpretation
	At 6:30 p.m.	Occurrence
	Clear (none)	Color
	Speculum exam	Instrument
	M.S. (patient)	Subject of information

Discussion

We developed data specifications to model the nursing problems of pregnant women who were hospitalized to give birth. These data specifications were validated by a group of experts and tested by applying them to case reports published in the literature. We identified focus concepts and characterizing concepts by analyzing electronic nursing records, reviewing the literature, and consulting nurse experts. We identified 58 focus concepts. Most of those identified by analyzing electronic nursing records were concepts describing physical problems such as pain, diarrhea, and constipation. Psychosocial concepts such as grief, guilt, and parent role were identified from the literature review and by consulting nurse experts. This implies that nurses do not document the psychosocial problems of their patients in their nursing notes as frequently as they document their physical problems. This concurs with what Min found in her work developing archetypes of nursing problems for breast cancer patients [7].

We found 53 characterizing concepts to describe focus concepts in more detail, of which only 13 were identified through analysis of the electronic nursing records. Most (54%) were identified from a literature review, and the remainder were suggested by the nurse experts. This implies that nurses do not document nursing problems in a structured way or as precisely as found in the literature or recommended by experts.

The data specification of nursing problems can be classified based on the characterizing concepts with value sets. For example, data specifications for flat nipple and inverted nipple have the same characterizing concepts ('anatomical site' and 'subject of information') with the same value sets. Other examples with the same characterizing concepts and the same value sets are the data specifications of constipation and diarrhea. However, there are similar focus concepts with different characterizing concepts. For example, after pain and labor pain are both types of pain, but they have different characterizing concepts from those of the data specification pain. For example, the data specification of pain has a characterizing concept 'anatomical site', whereas the data specifications of after pain and labor pain do not. If two focus concepts have different characterizing concepts and value sets, we classified them as different types of data specification.

Data specifications were modeled by linking the characterizing concepts to the focus concepts and specifying value sets, data types, and cardinalities of the characterizing concepts. There are two different types of relationship between the focus concepts and the characterizing concepts: associated and partitive. An example of an associated relationship is 'has_severity' linking the characterizing concept 'severity' to a focus concept such as pain. An example of a partitive relationship is 'has_part' linking a simple focus concept such as body temperature to a complex focus concept such vital signs.

A list of values for a characterizing concept was identified and presented in the data specification. For example, the characterizing concept 'severity' has a value set of 'mild', 'moderate', and 'severe'. The data type of the characterizing concept was also suggested in the data specification based on the value set. The cardinality of the characterizing concept, which indicates whether a specific characterizing concept is mandatory or optional to describe a focus concept, was also suggested in the data specifications.

The data specifications developed in this study can be used to guide the structured documentation of nursing records. If data are collected in a structured way using data specification, a richer and more granular database will be developed for use in research and education. In addition, if data are collected in a structured way using a value specified in the value set, data can be shared and exchanged between different information systems and different health-care institutions.

The data specifications developed in this study can ensure that electronic medical records contain meaningful and valid information, and support the semantic interoperability of information. The procedures and methods used here to develop data specifications could be expanded to other areas of nursing.

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A Model-Driven Approach for Biomedical Data Integration

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Abstract

A core challenge in biomedical data integration is to enable semantic interoperability between its various stakeholders as well as other interested parties. Promoting the adoption of worldwide accepted information standards along with common controlled terminologies is the right path to achieve this. Our paper describes a solution to this fundamental problem by proposing an approach to semantic data integration based on information models serving as a common language to represent health data coupled with technology that is able to represent the data semantics. We used the HL7 v3 Reference Information Model (RIM) [1] to derive a specific data model for the integrated data, the Web Ontology Language (OWL) [2] to build an ontology that harmonizes the metadata from the disparate data sources, the Unified Modeling Language (UML) [3] to model the data representation, and the Object Constraint Language (OCL) [4] to specify UML model constraints. To illustrate the approach, we use the Essential Hypertension Summary CDA document and related models from Hypergenes, a European Commission funded project [5] exploring the Essential Hypertension disease model.

Keywords:

CDA, Ontology, OWL, Modeling, UML, OCL

Introduction

Biomedical information repositories typically contain data related to a specific clinical domain with semantics unique to the originating systems [6]. These disparate data sources pose a challenge for data integration [7] that is paramount for improved patient-centric care [8], as well as for secondary use of the data for analysis of aggregated data in context of clinical research, public health surveillance, and decision support [9].

In this paper, we depict a complete solution to this fundamental problem by proposing an approach to semantic data integration using healthcare standard information models, ontology-based metadata harmonization, technology for creating and constraining data models, and an engine for instance generation.

The solution we present, as depicted in Figure 1, starts with a clinical domain expert creating an ontological representation of the information elements or variables of interest needed for a particular study. Based on past experiences, the clinical domain expert does not care about explicit data format, but only that certain data elements are required for further analysis.

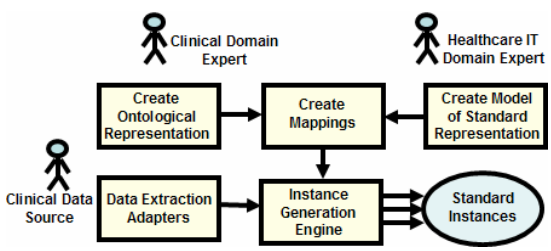

Figure 1 – Solution Activity Diagram

Our approach is intended to work over multiple, heterogeneous data sources by using models based on international standards for healthcare semantics and interoperability. Using standard exchange formats, along with a set of constraints, serves to unify data into a semantically unambiguous format that makes operations on the data straightforward from a technological standpoint. The healthcare IT domain expert, familiar with healthcare data representation methods and standards, creates healthcare interoperability models. Mappings between the ontological representation and healthcare interoperability models enable the instance generation engine to produce the standard instances in the last step.

IT industry-standard modeling languages form the bridge between the clinical and healthcare IT domains and user roles required for proper integration of healthcare data. The clinical domain expert works with a "more intuitive" ontology-based approach using semantic web technologies to represent the metadata needed for harmonization, while the healthcare IT domain expert uses software modeling languages to create model-based representations of the standard format, apply constraints to this format for a domain of interest, and, in collaboration with the clinical domain expert, create mappings between the ontological representation of the variables of interest and the standard-based information models. The annotated model created by the healthcare IT domain expert at design time, is then used by the instance generation engine at

runtime in order to transform the data to the standard format that conforms to the constrained model.

Background & Related Work

The HL7 v3 Reference Information Model (RIM) is used to derive consistent health information standards such as laboratory, problem and goal-oriented care, public health, and clinical research. It is an ANSI and ISO-approved standard that provides a unified health data 'language' to represent associations between entities who play roles that participate in acts. For example, a person entity plays a role of a surgeon who participates in a procedure act, and so forth. Acts may relate to other acts through "act relationships", thus providing a mechanism to describe complex actions.

Clinical Document Architecture (CDA) [10] is a constrained subset of the RIM that specifies terminology-encoded structure and semantics for clinical documents. These documents can be serialized to XML that conforms to a published W3C XML Schema. In most applications, the general CDA structure is further constrained by a set of templates that are standardized and published in an implementation guide, such as the Continuity of Care Document (CCD) [11]. Healthcare applications that produce or consume XML instances for CDA must include the appropriate template identifiers, as specified in the implementation guide. For example, a CDA instance that includes the template identifier "2.16.840.1.113883.10.20.1.28" indicates that the instance conforms to the CCD problem observation.

Most CDA template specifications, such as CCD, are written using structured English expressions that are based on the XML schema element relationships. These conformance statements are usually implemented using Schematron rules to augment the CDA XML schema. Our work, however, includes methods and open source software tools for representing CDA documents and template constraints using the Unified Modeling Language (UML) and the Object Constraint Language (OCL). Details and examples of this approach are described in the Methods and Results sections of this paper.

The UML modeling language is dominant among IT domain users, whereas clinical domain experts often work with formal ontology definitions. The Web Ontology Language (OWL) is a semantic markup language for publishing and sharing ontologies on the World Wide Web. It is endorsed by the World Wide Web Consortium (W3C) [12]. OWL is often used as the framework for converging distinctive terminologies into a single coherent ontology; many successful examples exist in clinical research and medical informatics domains [13, 14].

There has been some prior work in both using OWL ontologies in conjunction with instance generation [15], and in using OWL to add semantic annotations to UML information models [16]. These methods are applied and extended to support ontological mapping, representation modeling, formal constraining, and instance generation in our research.

Methods

Users

The use case diagram in Figure 2 illustrates the primary activities involved in our approach and the user roles required to perform these activities.

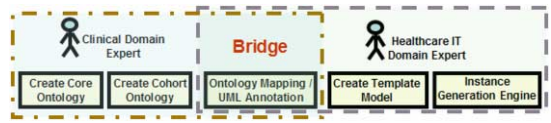

Figure 2 – Use Case Diagram

The clinical domain expert is responsible for creating the core ontology. The core ontology contains conceptual abstractions for a given clinical research domain and includes all the data elements required for secondary use by clinical researchers. The cohort ontology contains data elements and terminology specific to a data source. The cohort ontology is created by the clinical domain expert for each cohort that wishes to participate in the data integration. Using common ontology development tools such as Protégé [17], mappings are created between these cohort ontologies and the core ontology. This process is described in greater detail in the next sub section.

The healthcare IT domain expert is responsible for creating the CDA template model using a UML tool. The CDA template model contains classes, attributes, and relationships that are used to further constrain the CDA model to a particular clinical research domain. There are implicit relationships between classes in the template model and concepts in the core ontology. These relationships are made explicit by creating mappings on the CDA template model as UML annotations, providing the basis for generating the annotated template model.

The artifacts produced by these different users and the relationships between them are captured in Figure 3 below.

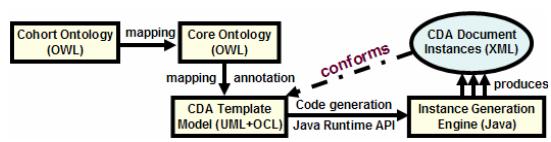

Figure 3 – Artifact Relationships

Data Integration

Healthcare data integration involves harmonization, validation, normalization, and transformation into standard structures that are accepted by the healthcare and medical research communities. Relationships between data items are often defined implicitly, e.g., in documentation or as tacit knowledge of experts. These implicit relationships must be expressed in an explicit and standard way so that analysis algorithms not aware of the implicit semantics can use them effectively.

Harmonization

Integration of data from dissimilar data sources must first undergo a process of conceptual harmonization, i.e. convergence of the sources metadata to a single and agreed-upon terminology. For example, blood pressure measurements from three different cohorts of essential hypertension are outlined in Figure 4. This outline depicts the underlying data model for the blood pressure measurements taken by the three cohorts.

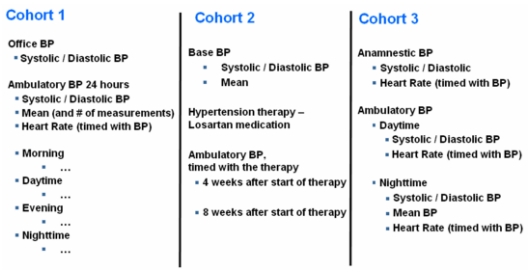

Figure 4 – Various blood pressure measurement schemes

Comparing data between the different cohorts is not a trivial task. The metadata is named differently, so how can one deduce that: Cohort 1 "Office BP", Cohort 2 "Base BP", and Cohort 3 "Anamnestic BP" all refer to the same conceptual data? Furthermore, looking at Ambulatory Blood Pressure findings one can see that Cohort 1 temporal divisions are to "Morning, Daytime, Evening, and Nighttime", whereas in Cohort 3 we find "Daytime and Nighttime" only; Cohort 2 blood pressure observations relate to four and eight weeks after start of therapy, thus completely incomparable to the above data.

Using OWL, we leveraged technology used for semantic web representation, to map all cohort variables to a core ontology able to represent the base conceptual terms for the target domain, e.g. Essential Hypertension. A schematic diagram is shown in Figure 5.

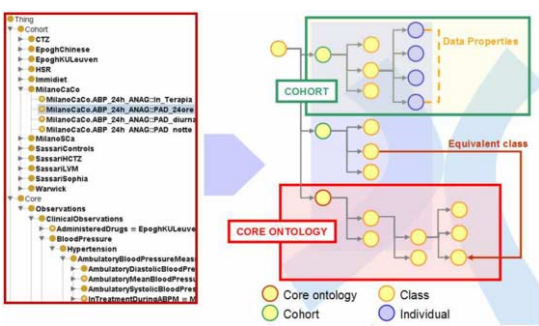

Figure 5- Ontology schematic diagram, left side is a screen capture of ontology using Protégé

The process starts by creating a cohort class (OWL class) for each metadata variable, thus each cohort contains a flat list of cohort classes. We then map each cohort variable in accordance with harmonization effort to a core ontology class by specifying an equivalent class relationship. In case of n:1 mapping, cohort instances (OWL individuals) are created, allowing the class to maintain 1:1 mapping, and additional parameters (as Data Properties) are added to capture the instance disparities. Thus, following the example shown in Figure 4, Cohort 2 Ambulatory Blood Pressure would contain one class with two individuals, having a temporal parameter to specify for four or eight weeks after therapy.

Normalization & Validation

Having crossed the hurdle of defining metadata in comparable terms, one is left with the challenges of deducing and validating data values for each metadata variable under the cohort's data model, as well as normalizing values in correspondence to harmonized standard units. This task is a complex one due to differences in units of measurement, classifications, and diversity of protocols. We do not elaborate here on these efforts.

Transformation to Intermediate Data Representation

Data is first extracted via a suitable adapter from data source proprietary formats, such as an excel file or MySQL database, and copied into a generic *data container*. The data container is conceptually a map where the *key* is a cohort variable and the *value* is the matching value. Additional inference is performed by the instance generation engine receiving both the data container and the ontology as input.

Capturing Data Semantics

Having similar sets of metadata represented in an agreed-upon terminology provides the basis for semantic interoperability [18]. Biomedical data is typically complex, consisting of associations and dependencies between discrete data items as well as between common structures. Consider the example in Figure 4. In Cohort 2, the Ambulatory Blood Pressure is measured while the subject is treated by a medication called Losartan. Associating the act of observing the blood pressure and the act of administering the drug will explicitly represent the semantics. This relationship is crucial to physician as the significance of high blood pressure while under a Losartan regimen is different than under other circumstances. To capture the full context of the data, these kinds of associations should be established during the data integration process when the experts responsible for the data source can provide the implicit semantics often hidden in unstructured documentation or in their minds.

As described in the background, the HL7 v3 RIM provides a unified 'language' to represent such relationships and context. CDA, as a RIM-derived domain specific standard, facilitates the explicit representation of the rich semantics of healthcare data. Referring back to the examples discussed above, the blood pressure measurements are represented as CDA observations and, when appropriate, these observations are associated with a substance administration of Losartan.

CDA Model

The CDA UML model was created as an implementation model that is primarily based on two artifacts: (1) the CDA Refined Message Information Model (R-MIM) from HL7 and

(2) the CDA XML Schema. This implementation model was developed to support the existing code generation and serialization mechanisms present in the Eclipse Modeling Framework (EMF) [19]. The model was imported into an EMF model and ultimately transformed into a set of Java classes. The Java classes in conjunction with a set of additional utility classes make up the base runtime API that can be used to produce, consume and validate instances of CDA.

Template Modeling &Annotation

The template model is a domain-specific model that constrains the CDA model. Classes in a template model extend those in the CDA model. Constraints are modeled using directed associations, property redefinitions, and OCL expressions. The CDA Profile for UML is used to capture additional metadata needed during model transformation and at runtime. Annotations on template model elements including UML classes and properties are used to describe all core ontology variables and their possible parameterizations, each appearing at a unique location in the template model. Annotations are used to map between the core ontology and the CDA template model. After an annotated template model has been created, it is transformed into an implementation model which leads to the generation of a domain-specific API for constructing and validating instances.

Instance Generation Engine

The instance generation engine takes a data container that contains data values corresponding to variables in the cohort ontology as input and produces CDA document instances that conform to the template model. Using the ontology mappings, which were specified by the clinical domain expert at design-time, it resolves each variable in the data container to a corresponding variable in the core ontology. Annotations from the template model are then used to map core ontology variables to unique paths in the output tree and store data values in the leaves of the tree. Values that were specified as default or fixed in the template model such as template identifiers and coded attributes are also generated automatically. Additionally, we support a registry of CDA templates that enables instance validation.

Results & Discussion

In the frame of Hypergenes, an FP7 European Commission funded project exploring the Essential Hypertension disease model, we had to deal with 18 historical cohort data sources with diverse clinical and environmental data. We chose HL7 v3 RIM meta-model and data types for data representation and CDA as our data model. Additionally we needed to apply a template to constrain CDA to a document specialized for describing an Essential Hypertension Summary document (EH-CDA). Needless to say it was a perfect opportunity to put theory to test. In this section we will describe how the technology was used as well as illustrate a concrete example based on work done for Hypergenes project.

Essential Hypertension Ontology

Hypergenes project assimilated clinical data from 18 cohort data sources. The harmonization process involved consulting with scientific experts in order to elucidate exact intention in each data element. The metadata was discussed at length in order to identify the list of variables, their meaning, variable associations, value ranges, and additional parameterization. The core ontology taxonomical structure was built based on data analysis of preliminary results and the macro-classes of intermediate phenotypes and environmental risk factors defined for Essential Hypertension. The core ontology was used as a reference for mapping the variables in each of the cohorts.

Essential Hypertension Template Model

Once metadata was fully accounted for, we created a template model that constrains CDA to Essential Hypertension report. Figure 6 depicts an excerpt pertaining to Blood Pressure Finding; the full model comprising of several hundred templates.

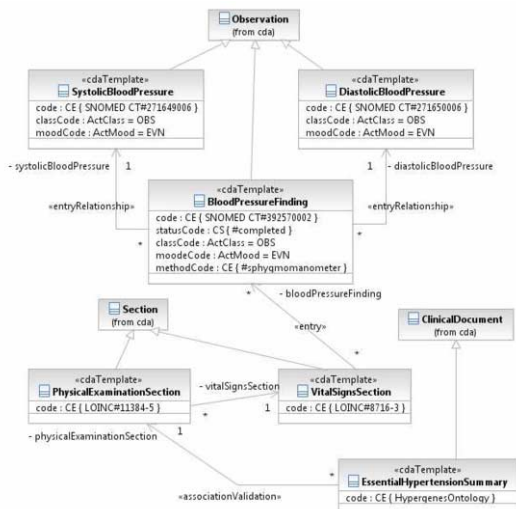

Figure 6 – Blood Pressure Observation in template model

The *BloodPressureFinding* class in the EH-CDA template model *extends* the *Observation* class from the CDA model. The template identifier was specified in a property of the <<cdaTemplate>> stereotype. Additionally, the code attribute was used to capture metadata about the specific code in SNOMED-CT. This gives the template precise semantics from a clinical perspective. The directed associations in the diagram (e.g. *VitalSignsSection* to *BloodPressureReading*) were converted into equivalent OCL constraints during the model-to-model transformation.

Instance Generation for Essential Hypertension

The model in Figure 6 was used to generate a runtime API that enabled the creation of the CDA XML instance of a Blood Pressure finding depicted in Figure 7 below.

```
<observation classCode="OBS" moodCode="EVN">
    <templateId root="2.16.840.1.113883.3.18.99.1.1.8.1"/>
    <code code="..." codeSystem="..." codeSysName="SNOMED CT" displayName="Blood pressure finding"/>
    <statusCode code="completed"/>
    <methodCode displayName="sphygmomanometer"/>
    <entryRelationship typeCode="COMP">
        <observation classCode="OBS" moodCode="EVN">
            <templateId root="2.16.840.1.113883.3.18.99.1.1.8.2"/>
            <code code="..." codeSystem="..." codeSysName="SNOMED CT" displayName="Systolic BP"/>
            <value unit="mmHg" value="171" xsi:type="PQ"/>
        </observation>
    </entryRelationship>
    <entryRelationship typeCode="COMP">
        <observation classCode="OBS" moodCode="EVN">
            <templateId root="2.16.840.1.113883.3.18.99.1.1.8.3"/>
            <code code="..." codeSystem="..." codeSysName="SNOMED CT" displayName="Diastolic BP"/>
            <value unit="mmHg" value="109" xsi:type="PQ"/>
        </observation>
    </entryRelationship>
</observation>
```

Figure 7 – EH-CDA Blood Pressure finding Observation

As the hypertension model contained hundreds of templates to model we used the Jena API, Eclipse UML2 API, and models for CDA, data types, and vocabulary from the MDHT project to programmatically generate the template model from a minimal complete, conforming instance [20]. The template model was decorated with annotations that map variable names from the core ontology to relative paths in the instance. We used a depth first traversal of the template model to convert these relative paths into a map of variable to absolute paths. Given an incoming record (i.e. data container), variables were extracted and used to look up the absolute path which was in turn used to construct the corresponding path of objects in the instance. We followed this approach for 11,472 records coming from 4,000 patients deriving from 18 historical cohorts of Hypergenes project. Each record contained up to 1500 unique data elements or variables that mapped to the same number of paths in the output instance.

Conclusion

In this paper we discussed a model-driven approach for integrating biomedical data using three complementary technologies. We used semantic technology in the form of an ontology definition language (namely OWL) to describe data elements of interest for a particular clinical research domain. We discussed the use of XML-based healthcare interoperability standards for clinical data and the role they play in semantic interoperability across multiple data sources. Finally, we discussed the use of UML to bridge the gap between the clinical domain expert and the healthcare IT domain expert and to facilitate the generation of a runtime that produces conforming instances. We validated our approach by using it to integrate clinical data in the EU-funded Hypergenes project.

Acknowledgments

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The Need for Standardised Documents in Continuity of Care: Results of Standardising the eNursing Summary

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Abstract

Continuity of care is a concept that is defined as the uninterrupted and coordinated care provided to a patient and that includes an informational dimension which describes the information exchange between the parties involved. In nursing, the nursing summary is the main instrument to ensure informational continuity of care. The aim of this paper is to present an HL7 Clinical Document Architecture based document standard for the eNursing Summary and to discuss the need for harmonizing these results at international level. The eNursing Summary proposed in this paper was developed on the basis of several internationally accepted concepts, primarily the nursing process, the ISO 18104 Reference Terminology Model for Nursing and various data sets. The standardisation process embraced several phases of involving nursing experts for validating its structure and content. It was finally evaluated by a network of 100 healthcare organizations. We argue that the eNursing Summary is a good starting point for standardising nursing discharge and transfer documents on a global level. However, further work is needed to bring together the different national and international strands in standardisation. .

Keywords:

Continuity of care, Nursing summary, HL7 Clinical Document Architecture, ISO 18104 Reference Terminology Model for Nursing

Introduction

Decreased length of stay in hospitals, early discharges from hospitals and the proliferation of fragmented healthcare services have contributed to a renewed interest in continuity of care as a concept for ensuring quality of care. Defined as the delivery of care to a patient by care providers "in an uninterrupted and coordinated manner" [1], it aims at bridging gaps between settings, institutions, healthcare professionals and between shifts. The non-attendance to continued care may lead to severe hazards for the patient such as adverse drug events [2] and is a clear risk factor in patient safety [3]. Continuity of care is a multi-dimensional concept which comprises of different levels referring to information, management, relationship and contact issues [4]. The informational dimension typically addresses the need for consistent, complete, up-to-date and timely patient information to be transferred between healthcare institutions or healthcare professionals in charge of providing care for the patients. New studies give insight into how technology and electronic health records (EHR) in particular can support a seamless flow of information within [5] and across institutions [6] without compromising privacy [7]. Sharing data between healthcare providers by means of an EHR is one approach of transmitting relevant information. In addition, messages can be exchanged between the health information systems concerned [8] or summary documents can be sent via electronic networks. Finally, summary documents can be also made available through shared document repositories with IHE XDS [9].

Nurses have had a long-standing interest in implementing continuity of care in their daily work [10], in particular in their role as discharge managers, case managers and community nurses. Their information needs have been clearly stated early on [11]. Only with the increasing prevalence of electronic nursing information systems in healthcare institutions [12] electronic exchange of nursing information across institutions becomes possible. National eHealth initiatives in many industrialized countries in addition have given momentum for including nursing information in the electronic healthcare information chain [13, 14]. Despite the definite need for an electronic nursing summary in many countries, national standards are rare (e.g. there is one in Finland [15]) and an internationally coordinated approach for standardising the nursing summary does not yet formally exist.

The aim of this paper is therefore to present the results of a standardisation process for the electronic nursing summary in Germany and hereby to stimulate the corresponding discussion at international level.

Materials and Methods

Defining the nursing summary and its core elements

By nursing summary we mean a document which summarizes all major health events of a given patient from the nursing perspective of the discharging or transferring institution. It makes use of the wealth of information from the maximum data set (nursing record) and is distinct from the nursing minimum data set. It is less aggregated than the minimum data set and focuses on the continued care of an individual patient.

A proposal for core elements of the nursing summary was derived from relevant standards, in particular the Continuity of Care Record [16], the Swiss "NURSING data" data sets [17], the Reference Terminology Model for Nursing [18] and the definition of HL7 nursing meta-observations [19]. The proposal also drew from our own previous work [20, 21]. It was further refined by members of the "Continuity of Care Network in the Osnabrück Region" (www.netzwerk-os.de) who established an eNursing Summary working group in 2006. The Network consists of healthcare institutions which represent the primary, secondary and tertiary healthcare sector and thus could provide a comprehensive overview of the information needs across the care continuum. Consensus was reached by means of a nominal group process. In 2007 and 2008 the results were presented in workshops at regional, national and multinational conferences (e.g. European Nursing Informatics ENI 2008 in Münster, Germany). Suggestions for modifications, e.g. biographical patient information, were incorporated in an updated version of the nursing summary. The developments took place under the auspices of the German Council of Nurses.

Building an information model of the nursing summary

HL7's Clinical Document Architecture (CDA) Release 2 [22] and the corresponding Reference Information Model (RIM) were utilized to structure the relevant data into a header and body section and to model the information. The document header was adopted to a great extent from the German discharge letter [23]. HL7 CDA classes, elements, data types and attributes were specified and modelled with the help of HL7-RIMDesigner in Microsoft Visio and RoseTree. LOINC-codes were used for coding the document sections. XML instances were created, drawn from the model and populated with example data.

Standardising and evaluating the nursing summary

The eNursing Summary undergoes the formal standardisation process of the HL7 German User Group in autumn 2009 and will subsequently be made available via its website (www.hl7.de). In parallel, contacts were established in 2009 to the Nursing Network Heilbronn, Germany, a regional network composed of 100 nursing care institutions, for evaluating the eNursing Summary data set and its structure by cross-mapping them to their paper-based nursing discharge letter. This discharge letter is the result of an internal standardisation process among the member institutions which all use it for exchanging patient information. The cross-mapping was performed by four experts (two of the authors [UH, DF], the chairman of the Heilbronn Network and a nursing expert from a software company).

Results

Information model of the eNursing Summary

The HL7 CDA based eNursing Summary is a structured clinical document. In contrast to its header, its body is specific to nursing. It has been broken down into the following sections (fig. 1): a) nursing process, b) social information, c) reference to legal documents, d) home care status and e) medical information. The "NursingProcess" section is the central part of the eNursing Summary (fig. 2). Nurses use the nursing process as fundamental concept to assess, identify nursing diagnoses, determine expected outcome plans, implement and evaluate patient responses to provide effective care [24]. The section is subdivided into the concepts *Nursing Score*, *Nursing Diagnosis*, *Nursing Goal*, *Nursing Procedure* and *Nursing Outcome*. *Nursing Score* summarizes the results of assessment scales used in the diagnostic process. The nursing diagnoses are described in *Nursing Diagnosis* which is further specified by the subconcepts *Etiology*, *Symptoms* and *Resources*. *Nursing Procedure* is always triggered by other nursing concepts, such as *Nursing Diagnosis*, and can be followed by a *Nursing Outcome*. Groups of scores, nursing diagnoses, nursing goals, nursing procedures and nursing outcomes may be clustered by themes, such as the activities of daily living (ADL), or by user-defined themes. The use of ADLs is not mandatory, neither is any other taxonomy because any predefined scheme would imply a specific nursing theory as default. Furthermore, studies showed a considerable amount of disagreement among specialty practice groups on what information was critically important for continuity of care [11]. We therefore favoured a more formal approach, i.e. using the nursing process as guiding structure, and left clusters of themes open for definition by user groups.

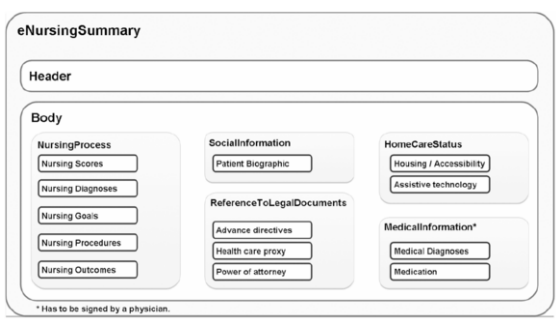

Figure 1- Structure of the eNursing Summary Body

Also at the level of entries the "NursingProcess" section does not propose any particular nursing terminology but is open to different controlled vocabularies. The eNursing Summary, however, recommends at least regional specifications of the terminologies preferred by the healthcare providers in that area.

The "SocialInformation" section covers a short non-structured note on the patient's or client's biography (CDA level 1 and 2). The "ReferenceToLegalDocuments" section allows legal and official documents to be referenced, i.e. meta-data of these documents to be communicated, such as date of issue, the depository and contact persons.

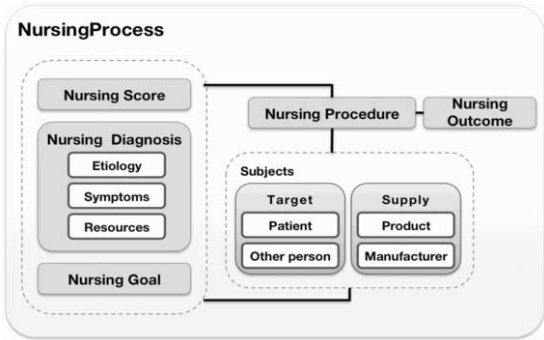

Figure 2- Concepts of the NursingProcess

These two sections were added pursuant to special requests from institutions that are in charge of the care of the elderly, in particular of dementia patients, e.g. nursing homes, geriatric clinics, geriatric hospital departments and ambulatory care services, and from psychiatric care institutions. The "HomeCareStatus" section describes the private and social environment where the patient lives, constructional issues of the home and the assistive technology that is available. Rehabilitation centers, home care providers (nurse specialists) and ambulatory nursing services particularly benefit from information of this section but also therapists in hospitals and other organisations. Information for the sections "SocialInformation", "ReferenceToLegalDocuments" and "HomeCare-Status" may be provided either by nurses or social workers depending on who is in charge of social care issues. Finally, the section "MedicalInformation" is a data container for medication data and medical diagnoses. It is copied from the medical summary or provided by physicians who are the authors and the signatories of this section.

The information model was checked for consistency and mapped into the proper CDA structures and corresponding domain message information models. The eNursing Summary concepts were represented by the use of specific terminology in the generic CDA classes.

Evaluation of the eNursing Summary

The results of the cross-mapping showed that all data fields of the Heilbronn nursing discharge letter could be translated into the eNursing Summary standard. The discharge form, however, differed from the standard with regard to the relations between diagnoses and interventions. Whereas the standard requires interventions to be linked to the cause of the intervention, typically the nursing diagnosis, the Heilbronn discharge letter consisted of a loose enumeration of unrelated problems and interventions. Furthermore, it did not specify any standardised nursing terminology to be used but rather preferred free text fields. Both can be represented in CDA documents and thus also in the eNursing Summary.

Discussion

The multidisciplinary nature of the nursing summary

The eNursing Summary is a communication instrument in ICT supported care delivery scenarios (fig. 3). Its main purpose is to warrant informational continuity of care across the spectrum of settings. The results of the standardisation process demonstrate that the nursing summary can be structured in a general way if the nursing process is utilized as the major guideline. Only then it is independent of the setting and the nursing specialty. When used in the context of the nursing summary the nursing process refers to critically important information and the patient status at discharge or transfer. It therefore does not contain the nursing assessment which is again carried out by the nurses who continue the care. In addition to the nursing process, the eNursing Summary also consists of medical, social and legal information that is needed by the institution or healthcare professional in charge of the follow-up care. As figure 3 shows the eNursing Summary may also contain information that is shared between nurses and therapists, e.g. information concerning the mobilization of a stroke patient. This fact hints at the interdisciplinary nature of the nursing summary and the role of nurses as generalists in the healthcare arena. It also raises the question of whether there is the need for a multi-professional summary to guarantee informational continuity of care. There is indeed critical overlap of information, notably in the medical area. There have been aivid discussions during the definition phase of the nursing summary on the need to know the medication and the medical diagnoses of a patient. This requirement can be met by two ways: either by referring loosely to the medical summary which would be (hopefully) sent in parallel or by copying these parts into the eNursing Summary. We finally decided for the latter solution in order to closely couple these pieces of information that need to be available at the same time for continuing the care. In the long run, the goal, however, should be to establish a multi-professional summary document. We made a first step towards this direction when adopting the content of the header from the medical summary.

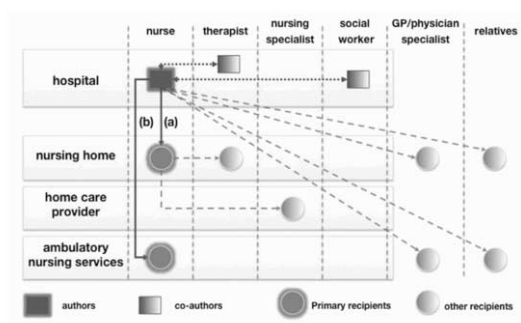

Figure 3- Continuity of care scenario; legend: patient discharged to (a) home, (b) nursing home

The need for harmonization at international level

There are several reasons that speak in favour of seeking to standardise the nursing summary at international level. First of all, the nursing process, which constitutes the backbone of the eNursing Summary, is an internationally accepted concept that is used – with variations – in many countries [25]. The second major contributor to the eNursing Summary is the Reference Terminology Model for Nursing [18], which is an ISO standard and ensures a common understanding of what is the essence of a nursing diagnose and a nursing intervention. Both approaches, the nursing process and the ISO standard, give the eNursing Summary a formal structure that makes it independent of a structure defined by content, e.g. by ADLs. This is paramount in an international context because the content may vary from country to country according to the culture and to the different task profiles of the nurses in different countries. The eNursing Summary allows so called themes to be included on an optional basis to make it flexible to the various demands and to enhance its readability.

There is also a need for standardising discharge and transfer documents from a European perspective. The European eHealth Action Plan [26] and the proposed European Directive on cross-border healthcare [27], both call for standardised procedures each from their own point of view. The eHealth Action Plan [26] addresses the need for developing interoperable health information systems, in particular electronic health record systems, as one of the most urgent challenges to be tackled. Interoperability is inseparably linked with the availability of accepted standards, also in nursing. The proposed EU Directive on cross-border healthcare [27] states that "ensuring continuity of cross-border healthcare depends on timely transfer of data concerning patient's health".

Finally, there is a growing interest among the health-IT vendors in internationally accepted standards as clinical health-IT-solutions are increasingly marketed on a global level, e.g. by international companies..

Need for action

Due to the critical importance of the electronic nursing summary in eHealth scenarios activities of international bodies for standardising the summary document are emerging. The concept and current implementation status of the eNursing Summary was presented at the 10th International HL7 Interoperability Conference 2009 in Kyoto [28] and HL7 is interested in further promoting the topic at international level. IHE (Integrating the Healthcare Enterprise) has taken the position that nursing is central to all patient care activities in terms of consistently providing and coordinating care. The IHE Patient Plan of Care (PPOC) profile is an individualized, framework intended for nurses to provide continuity of care across care settings and time [29]. These different strands which have emerged recently need to be integrated and participation from healthcare providers and industries must to be assured. International harmonization of an eNursingSummary should be addressed in the Joint International Council, where standardisation bodies and organisations like HL7, ISO, CEN, IHTSDO and others work together.

Limitations

The eNursing Summary standard we propose was developed using different international sources but has been evaluated so far in Germany only. Further work on mapping the structure and data fields with nursing and discharge letters used in other countries is necessary.

Conclusions

Implementing a standardised electronic nursing discharge and transfer document promises benefits for patients, relatives and healthcare professionals alike. Not only may patients with comorbidities [30], who frequently see different healthcare professionals during an acute episode of their illness, profit but also many other types of patients including elective [31] and emergency patients [32].

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Clinical Task-Specific Query Expansion for the Retrieval of Scientifically Rigorous Research Documents

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Abstract

To support the practice of evidence-based medicine (EBM), clinically relevant and scientifically sound articles should be easily accessible. Due to the huge volume of medical literature and the low performance of present retrieval models, clinicians could only get relevant documents in the order of publication time. This study propose a new clinical task-specific retrieval technique that improves retrieval accuracy by exploiting clinical task-specific EBM terms to query expansion using co-occurrence analysis technique. The idea is aimed at selecting query expansion terms that are relevant to a specific clinical-task using task-specific EBM terms. Focusing on treatment and diagnosis tasks, the new method which was performed on the OHSUMED collection showed a further improved result than the existing method.

Keywords:
Evidence-based medicine, Clinical task-specific query expansion, Local context analysis

Introduction

Evidence-based medicine (EBM) is the conscientious, explicit and judicious use of current best evidence in making decisions about the care of individual patients[1]. The exponential increase of the volume of medical literature requires the development of effective information retrieval strategies. Clinically relevant and scientifically sound articles (i.e., high-quality) should be accessible in a fast and easy manner, especially to support the practice of EBM.

In terms of clinical activity there are four main clinical task categories: treatment, diagnosis, etiology, and prognosis. EBM defines methodological criteria for the task categories in order to identify high-quality articles. For example, methodological criteria for treatment task is defined as "*random allocation of participants to comparison groups; Outcome assessment of at least 80% of those entering the investigation; analysis consistent with study design*" [2]. Based on the definition the main task of the information retrieval strategy is to search articles that meet the criteria for each clinical task.

Aiming at retrieving ranked relevant articles of high quality for a given clinical query, this paper describes a new information retrieval technique that uses EBM-related terms to improve retrieval accuracy in a clinical task-specific ranking system. Focusing on a treatment and diagnosis task, we suggest a new query expansion strategy based on co-occurrence analysis with clinical task-specific EBM terms as well as all query terms to restrict query expansion to terms that are relevant to a given clinical task in the principle of EBM.

Related Work

There have been different approaches to clinical task-specific retrieval.

Haynes and colleagues [2-7] developed optimal MEDLINE search strategies, called clinical query filters targetting four clinical task areas: treatment, diagnosis, etiology, and prognosis by validating diagnostic tests using proposed search terms and their manually-constructed gold standard. The filters were Boolean query strategies optimized for sensitivity and specificity that were added to the original user query. They were adopted by the U.S. NLM strategies for use in the Clinical Queries feature [8] in PubMed. However, since the query filter is Boolean form, it still retrieves thousands of articles from MEDLINE when a common clinical term is given as a user query ("*breast cancer*" for treatment task category, for example). It displays too many or too small number of articles depending on the user query. It also does not support ranking of the retrieved articles according to relevance to the user query.

Chu and colleagues [9, 10] proposed a knowledge-based query expansion to support clinical task-specific retrieval. In their retrieval system, the authors tried to expand the original user query with additional terms that are specifically relevant to the query's task using domain knowledge source such as UMLS Metathesaurus and semantic structure. Focusing on five types of tasks such as treatment, diagnosis, prevention, cause, and indication, they evaluated their approach on the OHSUMED test collection for a subset of 40 queries explicitly mentioning the tasks in the OHSUMED. Comparison of their approach with no-expansion and statistical expansion approach based on a co-occurrence thesaurus showed the effectiveness of their approach over the traditional approaches. Rather than using a knowledge source, we exploit clinical task-specific EBM terms to restrict query expansion to task-specific terms in the principle of EBM.

Recently, some researchers dealt with clinical task-specific retrieval using a text classification technique.

Aphinyanaphongs et al. [11] applied machine learning techniques to identify high-quality articles in internal medicine for the areas of treatment, diagnosis, etiology, and prognosis. Using inclusion or citations by the *ACP Journal Club*[12] for one specific time period as a gold standard, the authors constructed test corpus and automatically built machine learning models. They found support vector machine (SVM) classifier shows the best performance and machine learning techniques have better or comparable performance than the 1994 PubMed clinical query filters [13]. The results obtained by Aphinyanaphongs et al. [11] were tested for the generalizability to other gold standard used in the development of PubMed clinical query filters by the work of Kilicoglu et al. [14]. The authors confirmed that machine learning approaches can be used to recognize high-quality articles.

Materials and Methods

Text Corpus

We used OHSUMED [15] as a test collection. It is a subset of the MEDLINE database. It consists of 348,566 MEDLINE references from 1987 to 1991, and 106 topics (queries) generated by actual physicians in the course of patient care. Relevance judgments to each query are provided, with the scale of 'definitely relevant', 'possibly relevant', and 'not relevant'. In this study, we limit relevant documents to those judged as 'definitely relevant' to retrieve high-relevant documents.

For the new clinical task-specific retrieval, we reviewed the OHSUMED queries and selected 60 treatment-specific queries and 26 diagnosis-specific queries according to the definition of treatment and diagnosis task [2]. Among the 60 treatment-specific queries, we use 57 queries with at least one definitely relevant document for our treatment-specific experiments (see Table 1).

Table 1 - Queries used for our experiments

Task	Query IDs
Treatment	1,2,5,10,13,15,16,18,19,22,24,27,29,30,31,32, 33,35,37,38,39,40,42,43,45,52,53,56,57,58,60 ,61,62,63,64,67,69,71,72,73,74,75,76,77,78,7 9,81,84,85,88,89,91,94,98,100,102,104
Diagnosis	14,15,21,23,37,41,43,47,51,53,57,58,65,69,70 ,72,74,76,80,81,82,92,97,99,101,103

Text Representation

For the document representation, MeSH, title and abstract fields of each MEDLINE reference are used. For the index generation, we parse the three fields from each MEDLINE document as follows. First, all the texts in each field are tokenized into single words. Each word is then processed by the removal of stopwords identified by SMART stopwords. It is further stemmed by the Lovins' stemmer [16] and is case-folded. Finally, all single-stemmed terms are indexed in the form of inverted file.

A user query is represented by using *information need* field from OHSUMED queries since it is the most likely user queries issued in the information retrieval system, and is processed by the same text processing method mentioned above.

Document Ranking Model

As our baseline retrieval model for ranking retrieved documents according to relevance to the query, we implemented the well-known Okapi BM25 weighting scheme [17], which is a highly effective retrieval formula that represents the classic probabilistic retrieval model [18, 19].

In the Okapi BM25 formula, the top-ranked documents are retrieved by computing a measurement of similarity between a query, q, and a document, d, as follows:

$$sim(q,d) = \sum_{t \in q \wedge d} w_{d,t} \cdot w_{q,t} \quad (1)$$

$$w_{d,t} = \frac{(k_1 + 1) \cdot f_{d,t}}{K + f_{d,t}} \quad (2)$$

$$w_{q,t} = \frac{(k_3 + 1) \cdot f_{q,t}}{k_3 + f_{q,t}} \cdot \log \frac{N - n + 0.5}{n + 0.5} \quad (3)$$

where t is a term of the query q, $w_{d,t}$ is the weight of the term t in the document d, $w_{q,t}$ is the weight of the term t in the query q, n is the number of documents containing the term t across the document collection that contains N documents, $f_{d,t}$ is the frequency of the term t in the document d and $f_{q,t}$ is the frequency of the term t in the query q. K is $k_1((1-b) + b \cdot dl/avdl)$. k_1, b, and k_3 are tuning parameters set to 1.2, 0.75, and 1,000, respectively, by default. We use the default setting in this study. Document length and average document length, *dl* and *avdl* respectively, are measured in suitable units such as the number of terms or the number of bytes (in this study byte length is used).

Clinical Task-Specific Query Expansion by Exploiting EBM Terms

To retrieve topically relevant documents that pertain to a specific clinical-task and contain clinical evidence of high-quality, we use clinical task-specific EBM terms.

We focus on treatment and diagnosis task for this study. By employing and evaluating each task-specific EBM terms used in the PubMed Clinical Queries and their combinations in our preliminary experimentation, we define task-specific EBM terms *TASK-EBM* as follows.

Treatment: "clinical trials therapeutic"

Diagnosis: "sensitivity specificity diagnosis diagnostic"

The EBM terms are utilized following two ways in this study.

Method 1. Simple expansion with EBM terms (*SE-EBM*): The simplest way to use the EBM terms is to add these terms to the

original query before the query is submitted to the system. We refer this approach to *SE-EBM*.

Specifically, given a query q for a specific clinical- task such as treatment or diagnosis, input query to the system is built by appending the query q with the *TASK-EBM* terms of the clinical task that are not found in the query, and then submitted to the system. For the input query, the ranked retrieved documents are returned according to the score of Okapi BM25.

Method 2. Co-occurrence analysis with EBM terms (*CO-EBM*): By extending the local context analysis (*LCA*) [20], we propose a new query expansion approach to expand query with additional task-specific terms using task-specific EBM terms.

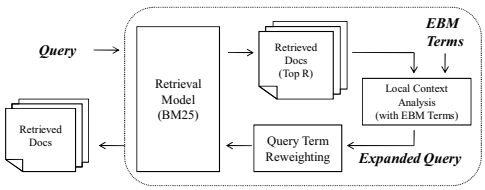

Figure 1 - Co-occurrence analysis with EBM terms

Given a query q for a specific clinical-task, our new query expansion is performed as follows. Let R be the number of pseudo-relevant document, and let E be the number of expansion terms that are appended to the original queries. First, query q is submitted to the system and documents are retrieved based on the Okapi BM25 for the given query. Then, the top-ranked R documents retrieved for the query q are assumed to be relevant and are used as a source of expansion terms. After extracting and merging all indexing terms from the top-ranked R documents, each term t is scored by:

$$score(t) = \prod_{k_i \in q \cup TASK-EBM} \left(\delta + \frac{\log_{10}\left(f(t,k_i)+1\right) \times idf_t}{\log_{10} R} \right)^{idf_i} \quad (4)$$

where the function $f(t,k_i)$ measures the degree of co-occurrence of term t with term k_i in the query q and the *TASK-EBM* terms of the clinical task, and idf_t and idf_i are inverse document frequency of term t and term k_i , respectively. Each factor is calculated by:

$$f(t,k_i) = \sum_{j=1}^{R} tf_{t,j} \cdot tf_{i,j} \quad (5)$$

$$idf_t = \min\left(1, \frac{\log_{10} N/n_t}{5}\right) \quad (6)$$

$$idf_i = \min\left(1, \frac{\log_{10} N/n_i}{5}\right) \quad (7)$$

where $tf_{t,j}$ is the frequency of term t in document j, $tf_{i,j}$ is the frequency of term k_i in document j, N is the number of documents in the collection, n_t is the number of documents in the collection containing term t, and n_i is the number of documents in the collection containing term k_i. The tuning parameter δ is set to default 0.1. The *TASK-EBM* terms are employed to reflect co-occurrence degree with those terms. All terms are then sorted in descending order by their scores. Lastly, the highly scored E terms are selected and added to the query q. The expanded query is automatically submitted to the system to get the final results. We refer this approach to *CO-EBM*. It is compared with the existing *LCA* method based on co-occurrence analysis with only query terms.

Query Term Reweighting

The expanded query produced by *CO-EBM* method is reweighted in the second-pass retrieval.

The standard Rocchio's feedback formula is a commonly used for (pseudo-) relevance feedback and term reweighting. It reweights terms in the expanded query by adding the weights from the actual occurrence of those query terms in the relevant documents and subtracting the weights of those terms occurring in the non-relevant documents [21]. In this study, we modify the formula so that all expansion terms are given the same weight for fair comparison of different query expansion approaches. Based on the positive feedback form of the standard Rocchio feedback formula, the new weight $w'_{q,t}$ of term t in the expanded query is assigned as:

$$w'_{q,t} = w_{q,t} + c \quad (8)$$

where $w_{q,t}$ is the weight of term t in the unexpanded original query q submitted to the system initially and c is a constant to give the same weight to all expansion terms (c is set to 1 in this study).

Results

We evaluate our experimental results using mean average precision (MAP), precision at given document cutoff value X (P@X). MAP is an average overall precision measurement for each relevant document in the ranking. It serves as a good measurement of the overall ranking accuracy. We measure the performance for the top-ranked 100 documents retrieved in our experiments. P@X is the percent of retrieved documents that are relevant after X documents have been retrieved. Since most users are interested in a few top-ranked documents, it is a good measurement in terms of users' perspective.

Table 2 - Performance of SE-EBM compared with no expansion for each treatment and diagnosis task.

Treatment (Average over 57 Queries)		
	No expansion	SE-EBM
MAP	0.2269	0.2175 (-4.14%)
P@5	0.3439	0.3333 (-3.08%)
P@10	0.2982	0.2772 (-7.04%)
Diagnosis (Average over 26 Queries)		
	No expansion	SE-EBM
MAP	0.2155	0.1877 (-12.9%)
P@5	0.3385	0.3462 (+2.27%)
P@10	0.3462	0.2885 (-16.67%)

Table 2 shows the performance of *SE-EBM* method compared with the one of unexpanded run for two clinical tasks of treat-

ment and diagnosis. As can be seen in the table, *SE-EBM* approach generally makes the performance decreases for both treatment and diagnosis tasks. It indicates that clinical task-specific EBM terms are not useful as additional expansion terms to retrieve task-specific relevant articles. Rather, these terms make relevant articles be retrieved in a lower rank. EBM terms would be not used as expansion terms in a ranking system.

On the other hand, the effectiveness of clinical task-specific EBM terms on improving retrieval accuracy is evaluated for selecting expansion terms. The performance of *CO-EBM* method is evaluated for a wide range of *R* (5 to100 by 5) and *E* (5 to 100 by 5) settings to see the sensitivity of the parameter settings, and is compared with *LCA* method based on co-occurrence with only query terms. Since 15 expansion terms generally provided a good performance on OHSUMED collection in our previous study [22], we present the performance of *CO-EBM* and *LCA* over a different parameter of *R* at a fixed E parameter of 15 in this paper. Figure 2 and Figure 3 display MAP percentage change of *CO-EBM* and *LCA* methods over unexpanded run for treatment and diagnosis task, respectively.

As can be seen, the maximum performance improvement is achieved using our *CO-EBM* method for both treatment and diagnosis tasks. On treatment-task experiments (Figure 2), our *CO-EBM* shows better performance than *LCA* when more than 50 documents retrieved are used for co-occurrence analysis. On diagnosis-task experiments (Figure 3), our *CO-EBM* shows better performance than LCA regardless of the number of pseudo-relevant documents used. It indicates that task-specific EBM terms can be effectively used for restricting query expansion to terms that are relevant to a given clinical task.

Conclusion

In order to support the practice of EBM, we have proposed a new information retrieval technique that exploits clinical task-specific EBM terms for the query expansion using co-occurrence analysis. Focusing on treatment and diagnosis tasks, our experimental results on the OHSUMED collection showed that our proposed method was performed best. The co-occurrence analysis with clinical task-specific EBM terms can select expansion terms more specific to a given clinical task. We believe that our method can be effectively used for clinical task-specific ranking system.

We plan to evaluate our approach for other clinical tasks including etiology and prognosis by preparing for new test collections since OHSUMED does not provide sufficient test queries for evaluation of other clinical tasks.

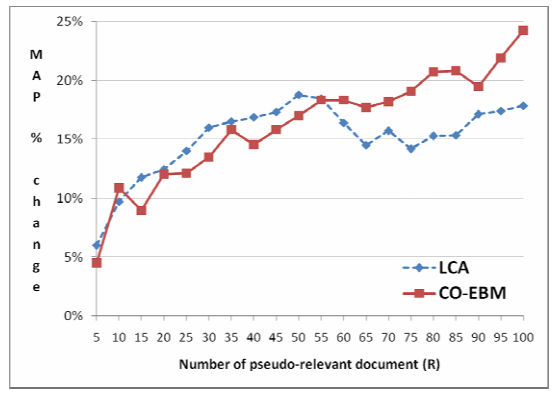

Figure 2 - Performance change of CO-EBM from no expansion compared with LCA when 15 terms are expanded using different number of pseudo-relevant documents for a treatment task.

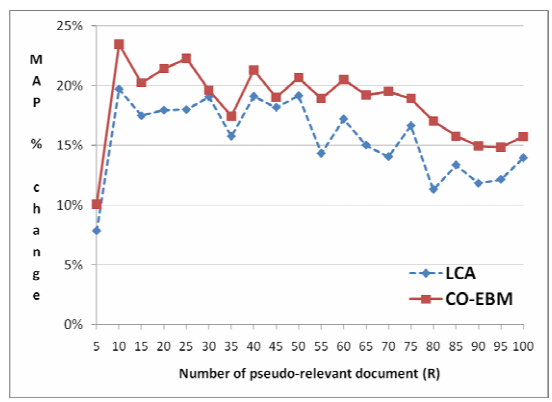

Figure 3 - Performance change of CO-EBM from no expansion compared with LCA when 15 terms are expanded using different number of pseudo-relevant documents for a diagnosis task.

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Finding Knowledge Translation Articles in CINAHL

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Abstract

Background: The process of moving research into practice has a number of names including knowledge translation (KT). Researchers and decision makers need to be able to readily access the literature on KT for the field to grow and to evaluate the existing evidence. Methods: To develop and validate search filters for finding KT articles in the database Cumulative Index to Nursing and Allied Health (CINAHL). A gold standard database was constructed by hand searching and classifying articles from 12 journals as KT Content, KT Applications and KT Theory. Main outcome measures: Sensitivity, specificity, precision, and accuracy of the search filters.
Results: Optimized search filters had fairly low sensitivity and specificity for KT Content (58.4% and 64.9% respectively), while sensitivity and specificity increased for retrieving KT Application (67.5% and 70.2%) and KT Theory articles (70.4% and 77.8%). Conclusion: Search filter performance was suboptimal marking the broad base of disciplines and vocabularies used by KT researchers. Such diversity makes retrieval of KT studies in CINAHL difficult.

Keywords:

Diffusion of innovation, Information dissemination, Evidence-Based Medicine

Introduction

Getting research into practice has become a focus for medical researchers and decision makers globally [1]. How to accomplish this is less clear. The field of research studying how best to implement new research findings is fairly new, with its origins in Roger's diffusions of innovations work in the field of agriculture[2]. Many disciplines are actively investigating theories, methods and frameworks to facilitate the movement of research into practice[3,4], each discipline with its own vocabulary and methods [5].

The process of getting research into practice in health care is often termed knowledge translation (KT). This is defined by the Canadian Institutes of Health Research (CIHR) as "*the exchange, synthesis and ethically-sound application of knowledge - within a complex system of interactions among researchers and users - to accelerate the capture of the benefits of research for Canadians through improved health, more effective services and products, and a strengthened health care system*" [6]. Terms used to refer to moving research into practice by other funding agencies include knowledge transfer, knowledge exchange, research utilization, uptake and dissemination [7].

Developing search filters for large databases can help researchers and decision makers optimize search retrieval, capturing articles of interest (true positives) and reducing the number that are not of interest (false-positives). Such search filters have been developed for methodological aspects of studies [8, 9], and also for content [10, 11].

We approached the KT literature as having 2 natural sub groups of articles, those related to interventions designed to change behaviors (KT Applications) and those related to the theory and understanding of KT (KT Theory). In this study, we sought to develop and validate search filters to retrieve articles with content related to KT in general as well as KT Applications and KT Theory. A large body of KT literature exists within the field of nursing so in this instance we focused our search strategy development for use in the CINAHL database via EBSCOhost.

Materials and Methods

To develop and validate the search filters, we used a diagnostic testing assessment framework. We created a gold standard database by hand searching the literature and classifying content as of interest to KT (KT articles) or not of interest to KT (non-KT articles). Search terms were tested using the database and the sensitivity, specificity, precision and accuracy with

which the terms retrieved the target articles (KT articles) were calculated. Sensitivity is the proportion of target articles retrieved, while specificity is the proportion of non-target articles that were not retrieved. Precision measures the proportion of retrieved articles that were on target, and accuracy measures the proportion of articles that were classified correctly.

Table 1 –Abridged inclusion criteria for articles with KT Content, KT Applications and KT Theory

KT Content includes the more specific areas of • Educational interventions • Peer-to-peer knowledge brokering • Finding information • Articles outlining barriers to providing care by clinicians • Application of Evidence-Based Medicine/practice • Quality of care and quality improvement strategies • Production of systematic reviews, guidelines, and other knowledge syntheses • Implementation of knowledge syntheses, guidelines or research findings • System modifications based on evidence • Setting policy using evidence • etc
KT Application: articles that are identified as KT and then describe a study or project in a specific setting or settings to implement a KT strategy eg. strategies that increase implementation, or a project to improve uptake of a specific intervention or knowledge area such as vaccinations, screening procedures, smoking cessation approaches, etc.
KT Theory: articles that describe or develop the general understanding of the KT process or theory. • Theories, models or frameworks of KT • Processes of KT • KT across disciplines, vocabulary and scope • Other theories contributing to our understanding of KT

Our gold standard database was constructed by careful reading of all articles published in 2006 in 12 journal titles. Our required sample size of on-target articles (KT articles) was between 110 and 150 [12] . To get a representative sample of the health literature, journals expected to have a high yield and a low yield of KT articles were included [12]. The method of journal selection is reported elsewhere [13].

Using a clear reading guide (developed with input from all authors who have KT expertise -NW, RBH, DC, MD, DAD, SES) articles were tagged as having KT content; those assessed as having KT content were further tagged as relating to a KT Application or KT Theory if applicable (abridged inclusion criteria -see Table 1). The reading guide was based on the full CIHR definition of KT [6] (the reading guide is available from the authors). Articles were read in duplicate by KAM and CL. Disagreements were adjudicated with consensus.

Table 2 – Number of articles classified as KT Content [KT Content- not instruments in square brackets], KT Applications (KTA) and KT Theory (KTT) in the 12 journals hand searched in 2006 (all 12 were indexed in CINAHL)

Journal	# Read	KT Content	KTA	KTT
High KT-yield journals				
BMJ	518	150[82]	31	23
Annals of Internal Medicine	260	109[39]	22	7
JAMA	310	87[28]	18	4
Social Science and Medicine	530	87[86]	47	57
Journal of Advanced Nursing	265	47[47]	35	27
Health Affairs	199	39[39]	15	11
Low KT-yield journals				
Journal of the Medical Library Association	59	16[16]	8	2
Addiction	168	13[13]	9	7
International Journal of Nursing Practice	48	9[9]	5	5
Journal of Occupational and Environmental Medicine	148	8[7]	4	1
Nursing Research	49	7[7]	6	7
Nursing Inquiry	31	1[1]	0	1
Totals	**2585**	**573[374]**	**200**	**152**

A posteriori we determined that a number of articles that were classified as KT Content only (not further classified at KT Application or KT Theory) presented information (ie content) for patient or clinician education. These articles included *JAMA*'s "Patient Page", *Annals of Internal Medicine's* "Summaries for Patients" and *BMJ*'s "ABC of [disease]" These tagged articles do not describe a KT intervention or theory, rather they are essentially a KT instrument for clinicians that can be printed and given to patients or articles educating clinicians on specific topics. As such, they represented a further subset of KT Content –articles to be used as KT instruments. We therefore created a further subset of articles for 'KT Content-not instruments' in an effort to improve the performance of search terms retrieving general KT Content articles. See Table 2 for the classification of articles.

Using KT published terms, Medline and CINAHL indexing terms, frequent terms in tagged articles (PubReminer (http://bioinfo.amc.uva.nl/human-genetics/pubreminer/) and terms suggested by KT researchers, we compiled a list of 3423 index terms and textwords to test their retrieval characteristics. The terms were submitted to CINAHL via EBSCOhost. Multiple spellings and endings were applied. Terms were tested as keywords and text words (TX). Keyword searches require no field codes and search title, abstract and subject headings. Textword searches are coded with TX and search all indexed fields and full-text. Index terms were searched using the MH field code. The retrieval characteristics were calculated for

each search term. All calculations were done by an automated online system developed at McMaster University. The system allows for the performance of single terms to be viewed as well as 'OR'ed combinations of terms that are computer generated. The system also allows the researcher to combine single terms using the Boolean 'OR'. Terms are 'OR'ed to maximize sensitivity and specificity.

The system generated 'OR'ed combinations of all terms and we selected the highest performing combinations to generate the 'best' search filter for detecting articles that were classified as (a) KT Content, (b) KT Content – not instruments, (c) KT Application and (d) KT Theory, while trying to keep the number of terms to a minimum. We report the best sensitivity filter keeping specificity ≥50%, best specificity filter keeping sensitivity ≥ 50% and best filter optimizing sensitivity and specificity using four term combinations (abs[sensitivity-specificity]<1%).

Our sample size was adequate for the KT Content and 'KT Content-not instruments' searches; for these we randomly divided the database into a 60:40 development/validation set of 1551 and 1034 articles respectively. Search strategies for KT Content, both with and without instruments, were developed in the development set and tested in the validation set. The proportions for sensitivity, specificity, precision and accuracy were compared between the two datasets as independent proportions using Arcus QuickStat.

Results

Our sample included 2585 articles, 573 tagged as KT Content, 374 KT Content-not instruments, 200 KT Applications and 152 KT Theory. Journals expected to have a higher yield of KT articles had a mean of 25.4% KT Content (95%CI 15.3 to 35.6) while low yielding journals had a mean of 12.8% (95%CI 3.2 to 22.3). The two groups of journals however were not statistically different in the proportions of articles tagged as KT Content, KT-not instruments, KT Application or KT Theory.

Table 3 – Combinations of Four Terms with the Best Sensitivity (keeping Specificity ≥50%), Best Specificity (keeping Sensitivity ≥50%), and Best Optimization of Sensitivity and Specificity (based on abs[sensitivity-specificity]<1%) for Detecting KT Content in CINAHL. Articles were assessed as all KT Content and then as KT Content with instruments removed. Values for the development data, the validation data, their absolute difference are given.

Search Strategy for KT content (EBSCOhost CINAHL)	Sensitivity (%) Development Validation Diff (95% CI)[a]	Specificity (%) Development Validation Diff (95% CI)[a]	Precision (%) Development Validation Diff (95% CI)[a]	Accuracy (%) Development Validation Diff (95% CI)[a]
KT Content including instruments				
Best Sensitivity – therapeutic* OR evaluation OR patient* OR polic*	62.9 59.1 -3.8(-4.4 to 12.0)	55.8 56.4 0.63(-5.0 to 3.8)	29.5 26.8 -2.7(-2.4 to 7.8)	57.4 57.0 -0.42(-3.5 to 4.3)
Best Specificity- patient education OR decision making OR therapeutic OR patient*	50.4 43.6 -6.8(-1.6 to 15.1)	70.0 68.2 -1.9(-2.2 to 6.0)	33.1 27.0 -6.1(-0.08 to 1.2)	65.6 63.0 -2.6(-1.1 to 6.4)
Best Optimization of Sensitivity and Specificity- clinical trial* OR therapeutic* OR patient* OR utilization	58.4 50.0 -8.4(-0.02 to 1.7)	64.9 64.5 -0.36(-3.9 to 4.6)	32.9 27.6 -5.3(-0.52 to 10.9)	63.4 61.4 -2.0(-1.8 to 5.8)
KT Content excluding instruments				
Best Sensitivity – evaluation OR evidence based practice OR health service* OR patient*	75.2 68.8 -6.5(-2.8 to 1.6)	50.6 52.9 2.4(-6.6 to 1.9)	20.9 19.1 -1.8(-2.6 to 6.1)	54.2 55.1 0.90(-4.8 to 3.0)
Best Specificity –evaluation OR evidence based practice (TX) OR health services (TX) OR health services administration (TX)	61.3 52.8 -8.5(-1.8 to 18.8)	67.8 71.2 3.4(-7.3 to 0.52)	24.9 22.9 -2.0(-3.9 to 7.7)	66.9 68.7 1.8(-5.5 to 1.9)
Best Optimization of Sensitivity and Specificity- patient OR utilization (TX) OR evaluation (TX) OR evidence based practice (TX)	71.7 59.0 -12.7(2.9 to 22.6)[b]	61.5 62.8 1.3(-5.4 to 2.9)	24.5 20.4 -4.1(-1.1 to 9.1)	63.1 62.3 -0.77(-3.0 to 4.6)

[a] Comparing the development and validation data sets. [b]Statistically significant differences at p<.05. EBSCOhost CINAHL fields: TX=text words, searches all searchable fields in full-text and citation record; ?=wildcard; *=truncation character; no field code=default title, abstract and subject heading search.

Table 4 – Combination of Terms with the Best Sensitivity (keeping Specificity ≥50%), Best Specificity (keeping Sensitivity ≥50%), and Best Optimization of Sensitivity and Specificity (based on abs[sensitivity-specificity]<1%) for Detecting KT Application and KT Theory Content in CINAHL

Search Strategy for KT content (EBSCOhost CINAHL)	Sensitivity (%) (95% CI)	Specificity (%) (95% CI)	Precision (%) (95% CI)	Accuracy (%) (95% CI)
KT Applications				
Best Sensitivity – evaluation OR evidence based practice (TX) OR health services (TX) or patient (TX)	78.5 (72.8 to 84.2)	50.7 (48.7 to 52.7)	11.8 (10.0 to 13.5)	52.9 (51.0 to 54.8)
Best Specificity – randomized controlled trial OR pretest-posttest design OR decision making OR evaluation	50.5 (43.6 to 57.4)	80.0 (79.3 to 82.4)	18.1 (14.9 to 21.3)	78.5 (76.9 TO 80.0)
Best Optimization of Sensitivity and Specificity- physician OR utilization OR evaluation OR evidence based practice	67.5 (61.0 to 74.0)	70.2 (68.3 to 72.0)	16.0 (13.5 to 18.4)	70.0 (68.2 to 71.7)
KT Theory				
Best Sensitivity – research OR evaluation (TX) OR evidence based practice (TX) OR social work (TX)	80.3 (73.9 to 86.6)	52.0 (50.0 to 54.0)	9.5 (7.9 to 11.1)	53.7 (51.8 to 55.6)
Best Specificity- change* OR evidence-based medicine OR decision making OR knowledge	53.9 (46.0 to 61.9)	85.1 (83.7 to 86.5)	18.4 (14.8 to 22.0)	83.2 (81.8 to 84.7)
Best Optimization of Sensitivity and Specificity- theoretical OR decision making OR change* (TX) OR evidence based practice	70.4 (63.1 to 77.7)	77.8 (76.1 to 79.4)	16.5 (13.7 to 19.4)	77.3 (75.7 to 79.0)

Search Filters

No single terms were able to retrieve KT, KT Application or KT Theory articles with 50% sensitivity and 50% specificity. Multiple term filters were derived by 'OR'ing top performing single terms together to form 4-term combinations.

For KT Content articles, sensitivity of filters ranged from 50-62%, specificity from 56-70%, precision from 30-33% and accuracy from 57-66% (Table 3). Development and validation sets did not differ in search performance. When KT instruments were removed, sensitivity increased by ~10%, but the other performance measures did not change or were lower (Table 3). Development and validation sets performed similarly except for sensitivity of the optimal search.

KT Application filters peaked at 80% specificity, but with low sensitivity of 50% (Table 4). Similarly, sensitivity peaked at 78.5% but with low specificity. Overall the KT Application filters performed better than the general KT Content search. Performance of KT Theory filters were similar to KT Applications, maximizing sensitivity or specificity at the expense of the other, The optimal search performed with 70% sensitivity and 78% specificity, the best overall (Table 4).

Precision was low, which is not surprising since it is dependent on the prevalence. KT Application and KT Theory filters also had low precision. Accuracy improved for the KT subsets (Application and Theory) compared to the KT content filters.

The search terms that are included in the best performing filters tend to be fairly common and widely used (evaluation, evidence-based medicine or practice, research or patient) and not necessarily KT specific.

Discussion

Ideally a search filter will allow retrieval of a large proportion of the target articles with a minimum number of non-target articles, maximizing sensitivity while maintaining specificity. Our research group has published a number of such filters, relating to methodological aspects and content. Generally speaking, performance values of 90% sensitivity and 90% specificity are markers of effective search filters.

In the case of KT, we find that sensitivity and specificity do not reach high levels. For the filters focusing on the KT subsets, we were able to develop filters that performed slightly better than the general content area of KT.

From the search terms, we see that the content purpose of the search is often reflected in the filter search terms, for example, the term 'theoretical' in the optimal KT theory filter. KT Application filters included more methods terms like "randomized controlled trial" and "pretest-posttest design". But many of the other terms are not specific to the field of KT (research, patient, evaluation) and this likely explains the poor performance of the filters. Yet few KT related terms that we compiled were able to effectively detect KT articles. For example, research utilization, dissemination, and translational research did not contribute to effective retrieval of KT material Also, when maximizing specificity, sensitivity is compromised, at times leaving many target articles undetected.

Given the range of disciplines engaged in KT and the lack of a consistent vocabulary, the low performance of the search filters is not surprising. When moving forward it is important for those in the field of KT consider how we can improve our communication and understanding, for example, by agreeing on our use of KT terms. Perhaps then more effective search filters could be devised.

Alternatively, other approaches to data mining such as semantic web technologies could be studied in relation to KT litera-

ture search and retrieval. Use of these technologies could circumvent the call for a standardized terminology for the field.

Strengths

Our study sample of 2585 articles represents a sufficient sample to develop and validate KT search filters. Our journal titles cover a broad range of health fields from nursing to internal medicine, and library science to environmental science and business. The search filters performed similarly in the development and validation datasets suggesting that the performance of these searches can be generalized for use in the entire CINAHL database or other similar subsets.

Limitations

Classifying articles as KT is not a simple task. The development of the reading guideline went through many iterations with continuing input from all authors. We tried to be as systematic and consistent as possible, but it is possible that other researchers would classify some of the articles differently based on their own views and values for KT.

Statistical limitations include not having development and validation data sets for the KT Application and Theory categories. Also we were unable to perform cross-validation studies on the KT Content dataset.

Conclusions

Retrieval of KT literature from large databases remains a challenge. Our search filters do not have high enough sensitivity and specificity to allow a researcher to effectively retrieve KT articles of interest. They would be left with too many non-target articles to sort through and miss many target (ie KT) articles. A consensus regarding the use of KT terms would be one way to improve retrieval going forward. In addition, work with the large database producers such as CINAHL would likely show benefits from implementing new index terms related to KT and their consistent use.

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Pediatric Pain Management Knowledge Linkages: Mapping Experiential Knowledge to Explicit Knowledge

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Abstract

The goal of this project is to augment clinician communication by connecting it to evidence-based research, providing explicit knowledge to corroborate the experiential knowledge shared between health care practitioners. The source of tacit knowledge sharing is the Pediatric Pain Mailing List (PPML), a forum for practicing clinicians to contact peers on the subject of pain in children. The messages, dating back to 1993, are processed for pertinent information and gathered together into threads. They are then parsed and connected to a set of MeSH keywords, which is used to search Pubmed and return a set of papers that correspond to the subject being discussed. The results are presented in an online forum, providing clinicians with an arena in which they can browse the archives of the PPML and connect those conversations to pertinent medical literature.

Keywords:

Information retrieval, MeSH headings, Natural language processing, Pediatrics, Pain, UMLS

Introduction

Pediatric pain management is a complex subject, as children lack the cognitive ability to properly express their pain [1], which at times leads to incorrect interventions. The problem is exacerbated due to lack of specialized knowledge and formal training in pediatric pain management [2]. The emergence of Web 2.0 technologies has provided alternate knowledge dissemination mediums, such as online discussion forums, mailing lists, social networks and so on, that allow pediatric pain practitioners to converge and share their knowledge through problem or topic specific discussions. One successful initiative is the Pediatric Pain Mailing List (PPML) which brings together over 700 pediatric pain practitioners from around the world to share their clinical experiences and seek clinical advice. The PPML not only overcomes temporal and geographical barriers to connect pediatric pain practitioners, but the archives of the mailing list, containing over 13,000 messages, represent an invaluable resource of the experiential knowledge of the pediatric pain management community spanning more than 15 years. The archives contain experience based recommendations, educational materials, tools, case solutions, practice critiques and research ideas.

Experiential knowledge is not evidence-based rather it is practice-based, nevertheless it provides vital and pragmatic insights into *what worked*, *what did not work* and *what are the best practices* in specific clinical situations, especially beyond the realm of accepted norms and established beliefs. We argue that to generate comprehensive healthcare knowledge for a specialized health topic it is important to augment this tacit experiential knowledge with evidence based explicit knowledge, i.e. to establish knowledge linkages between online discussions with published medical literature.

In this paper, we present our approach to establish knowledge linkages between pediatic pain management discussions in the PPML and corresponding published literature at Pubmed. The rationale for the project is driven by the observation that practitioners need to reaffirm the practice-related recommendations on the PPML with evidence reported in the medical literature. The exercise of finding evidence corresponding to the exact theme and content of a PPML discussion is challenging for practitioners, as the incorrect choice of keywords (as per the PPML discussion) results in sub-optimal research articles, which in turn affects the perceived validity of the PPML messages and the subsequent uptake of the experiential knowledge at the PPML.

Our solution is a knowledge management framework that leverages (a) Web 2.0 based communication and collaboration to gather clinical experiential knowledge through an active interaction within a virtual community of practice, and (b) knowledge interoperability to establish linkages between the unstructured experiential knowledge and structured explicit knowledge stored in an accessible knowledge repository. The research challenge is (i) to organize the unstructured email messages containing the experiential knowledge into meaningful topics/discussion threads so that specific knowledge items can be easily found and used by the practitioners; and (ii) to process the content of the email messages to derive medically salient keywords to search a medical literature repository for related research articles.

In this paper, we present our knowledge linkage framework featuring our literature search strategy that implements an ex-

tended Boolean Information Retrieval (eBIR) algorithm [3]. Our framework allows users to (i) search through the PPML archives to find interesting discussion topics, (ii) select interesting discussions threads within the discussion topics, and finally (iii) retrieve a set of related research articles from Pubmed, through a 'single-click' evidence retrieval mechanism, based on our literature search strategy.

Methods

Our knowledge linkage framework followed the following steps: (i) Filter the email archives to extract medically useful email messages; (ii) Associate a series of emails to realize a *thread* that represents an online discussion between multiple practitioners around a specific topic; (iii) Parse the discussion thread to identify its constituent medical terms in terms of the MeSH lexicon (because Pubmed is indexed using MeSH); (iv) Apply the search strategy to find related research articles; (v) Present the search results to the user.

The task of processing free text and connecting it to a formal medical lexicon is an active research subject in the medical community [4-6]. Previous projects have approached the problem using natural language processing (NLP) algorithms to try and extract the semantics of the text, representing the semantics using a formalized lexicon. One example is the program Metamap [7], a NLP based medical language processing system that scans medical text and links it to formal terms from MeSH. However, Metamap's precision and recall in previous projects have varied depending on the format of the text being processed, from values as high as 0.897 and 0.930 respectively [6] to values as low as 0.56 and 0.72 [4]. Projects that reported low recall and precision with Metamap acknowledged that many of the problems come from the inherently ambiguous nature of the text being processed: in processing medical residents' voice recordings, it was noted that Metamap failed to recognize abbreviations, acronyms or complex phrases that omitted key terms [5].

For this project, we expect some degree of inaccuracy in the list of medical terms returned by Metemap given the unstructured nature of the PPML. We decided to use Metamap as the medical text processing application due to its ability to provide MeSH terms together with concept and semantic types. We improve the output of Metamap through our literature search strategy that uses a modified eBIR algorithm to rank the MeSH terms by assigning them a score, and then determining the optimal subset of terms based on their scores. Below, we discuss the workings of the individual steps of our knowledge linkage framework.

Processing the PPML Archives

The archives are stored in simple ASCII text files, organized by month, starting June 1993, and ending December 2008. The messages were processed to extract the sender, date, subject line and content of the message. The extracted information was used to filter out irrelevant and noisy messages. For experimental purposes we selected the set of emails from 2007 and 2008; we believe that the recent two years of the PPML reflect the current nature of the mailing list.

The goal of the project is to extract the substantive content of the messages and use that to link pertinent literature. This means that the messages need to be parsed to remove content such as user signatures, replies and useless messages. The purpose of parsing these elements is to restrict the recorded content of the message to the subject being discussed, in order to properly link the conversation to literature. Any medical terms in the user's signature, or the content of the previous messages, could confuse the mapping process and ultimately lead to inaccurate results.

Discussion Thread construction

Using the extracted data the messages are assigned to discussion *threads* that are the embodiment of experiential knowledge in the PPML. A thread can be thought of as a conversation, or a series of messages around a certain topic. It generally contains a question, problem or novel idea posed by a list member, and is followed by a series of responses that attempt to solve the problem. Within a thread experts in the field can provide their own knowledge or recount their own experiences in response to a certain problem. A thread is built using the subject line of the email messages—all messages with a matching subject are grouped within a thread.

Converting Threads to MeSH Vocabulary

Given that the Pubmed database is indexed by the MeSH vocabulary, to optimize the search results we convert the content of the PPML messages to the MeSH vocabulary via the Metamap program [7].

Connecting Threads to MeSH terms

Metamap uses a special NLP parser called SPECIALIST [7] to find all the nouns and noun-phrases in a discussion thread, and maps them to one or more MeSH terms. Each mapped MeSH term is assigned a score that is a measure of how strongly the actual term mapped to the MeSH vocabulary. The score is a weighted average of four metrics measuring the strength of the matching, with an overall range in [0,1000], with higher scores indicating a better match. The formal equation for calculating the scores is:

$$1000\text{x}(\textit{Centrality}+\textit{Variation}+2\text{x}\textit{Coverage}+2\text{x}\textit{Cohesiveness})/6 \quad (1)$$

1. *Centrality*: An indicator of whether the matched (source) term is the head of the phrase. The head of the phrase is the root; in the phrase *pain medication medication* is the head and *pain* is a modifier.
2. *Variation*: A measure of the distance between the matched term and the root word. For example, if the source word is eye and the match is to the term ocular, the distance is 2, as ocular is a synonym for eye
3. *Coverage and Cohesiveness*: Measures of how well the source term and the MeSH term match each other: if the source and MeSH terms are both "pain" then the match is perfect, but if the source term ocular matches to the MeSH term Ocular Vision then the coverage and cohesiveness are less than perfect.

For our purposes, the Metamap scoring system provides a baseline measure of how well the mapped MeSH term represents the original term in the PPML discussion thread.

Managing MeSH Terms

Metamap produces certain MeSH terms that are not appropriate for this project, either due to generality or complexity of the phrase being mapped. The problem of generality arises when the MeSH term provided is not a formal member of the MeSH lexicon. Metamap returns the MeSH term *stress*, which is not technically part of the MeSH vocabulary. MeSH contains many terms that are more specific forms of stress, but the term itself is not present. These terms must be dropped from the MeSH mapping, as their generality makes them useless in connecting the content to literature.

The second problem relates to complex matches, and can be best explained using a sample message. Consider the following message "*The report stated that when* ***music therapy*** *is used,* ***the babies*** *required* ***less pain medication****. Does anyone know* ***of any published reports*** *of* ***empirical research*** *demonstrating the effect?"* Table 1 lists the mappings and their associated scores for this example.

Table 1- Sample message and its associated MeSH mappings

Source	MeSH	Score
music therapy	Music Therapy	1000
the babies	Infant	966
less pain medication	Pain	660
less pain medication	Pharmaceutical Preparations	827
of any published reports	Publishing	694
of empirical research	Empirical Research	1000

Consider the two mappings in table 1 for "less pain medication" which is an example of a *Complex Match* [7], where a single noun-phrase maps to a combination of MeSH terms. In this case the word "pain" maps to *pain* and "medication" to *pharmaceutical preparations*. The formal solution proposed by Metamap for complex matches is to combine these two mappings and take the average of their scores, resulting in the term "less pain medication" mapping to two MeSH terms, with a score of (827+660)/2=743.5. This is a logical solution, but for this project we do not use such a strategy, as it requires two MeSH terms to represent a single concept. Our strategy for complex matches is to leave the multiple mappings separate and allow their reduced scores to reflect the fact that neither MeSH term completely represents the concept in the message.

We also incorporated a filtering strategy to remove undesired MeSH terms. This is achieved through a *stop* list (a set of noun-MeSH combinations) that is based on terms that are consistently mapped incorrectly. Terms appearing in the stop list will be removed automatically from the list of MeSH terms produced after parsing the PPML message. In Table 1, the last two mappings belong to the stop list and will be removed.

At the end of the step, we have a set of MeSH terms (with a score evaluating the strength of each mapping) corresponding to the terms in a discussion thread.

Literature Search Strategy

The first step in the literature search process is to generate a *literature search vector* from the set of MeSH terms found in previous step. This is done by combining any duplicate MeSH terms in the set and adding their scores together. The result is a set of k unique MeSH terms, each of which has a *MeSH Score* associated with it. Let M be the unique set of MeSH terms from the thread, and let s_i be the MeSH score for term i.

$$\{m_1, m_2, m_3, \ldots, m_k\} \in M \quad (2)$$

M can potentially be used to query Pubmed through a simple Boolean Information Retrieval (BIR) algorithm that would perform a search of Pubmed for all the MeSH terms, and return a set of papers that feature each term in M. The problem with this approach is that if we keep the size of M unrestricted (and often quite large) Pubmed may have no papers that have all the associated MeSH terms. A modified BIR solution would be to drop the lowest scoring MeSH term(s) from the search vector and redo the search, reiterating until a set of papers is returned. Let $M_{(j)}$ be the MeSH search vector with the lowest j scores removed ($M_{(0)}$ is the full set), let $f(q)$ be the number of papers in Pubmed with the set of MeSH terms q, and let Q be the set of papers returned. The set of papers returned would be:

$$Q = min_j(f(M_{(j)}) > 0) \quad (3)$$

Again, there are several problems with the above search strategy: (i) it provides no ranking of the returned papers; (ii) it uses the MeSH scores only to sort the MeSH terms, and not as absolute values; (iii) it does not differentiate between those papers that contain all but one of the terms in the search vector from those that contain none; and (iv) it does not address the most pressing issue of this project, the potential inaccuracy of the MeSH terms.

To address these limitations, we developed an algorithm similar to the extended BIR algorithm (eBIR) [3]. Our algorithm differs from the BIR algorithm by using the MeSH scores as weights for each of the MeSH terms in M. For each MeSH term Pubmed has a set of papers that use that term as a keyword. Let p_j be an individual paper, P_i be the set of papers associated with MeSH term i, and l_i be the number of papers in P_i.

$$P_i = \{p_1, p_2, \ldots, p_{li}\} \in m_i \quad (4)$$

For every MeSH term there is now a vector of associated papers along with the MeSH score. A *paper score* is derived from these MeSH scores, and we use the paper score to order the results. Let t_i be the paper score for paper i. The paper score can be calculated using the following:

$$\forall m_i \in M(\forall p_j \in P_i | t_j = t_j + s_i) \quad (5)$$

Take every MeSH term m_i in the set of MeSH terms M, and for every paper p_j associated with that MeSH term, add the MeSH score, s_i, to the paper score t_i. Paper j has a score that is the sum of its MeSH terms' scores. Finally, let the set Q be the union of all the papers, and return the set Q sorted by the paper scores.

$$Q = \bigcup_{i=1}^{k} P_i \quad (6)$$

We argue that our literature search algorithm is superior to a traditional BIR algorithm as it provides an absolute ordering of the papers, and is not a susceptible to high scoring MeSH terms that are incorrect mappings.

PPML Forum: Linking Explicit and Experiential Knowledge

We have developed a PPML forum that allows practitioners to interact with the PPML discussions and review the retrieved research articles for a selected discussion thread. The forum allows the following functionalities:

(a) Navigating the discussions using a standard search function that allows users to perform a search of discussion threads for desired content, returning a list of threads sorted by relevance to the search query.

(b) Navigating the discussions using search functions based on MeSH terms. Two search algorithms have been provided for the MeSH-based search. The first search method uses a simple BIR algorithm and takes MeSH terms as input and returns all the discussion threads that contain all those terms, sorted by the date they were posted in the thread. This method has the advantage that it returns recent messages first, as it is expected that recent messages are what clinicians are most interested in. The second search method uses our search algorithm (i.e. terms with their MeSH scores) to retrieve discussion threads. The threads are assigned a score that is a sum of the MeSH terms that match the terms in the query. If we define C as the set of MeSH terms in the query, and M_i as the set of MeSH terms for thread I, then the query score e_i for each thread is calculated as follows:

$$e_i = \sum_{j \in C \cap M_i} s_j \quad (7)$$

The query score returns the threads sorted by search score, and any ties sorted by date of last communication. Future testing will provide an answer as to which method is more effective.

(c) Organizing the discussion threads into a hierarchy, based on the 135 UMLS semantic types, for users to browse the threads.

(d) Retrieving a set of citations for a given thread, along with direct links to each of the referenced papers.

The three different navigation methods provide the users with different approaches to finding their desired thread, and once there they can browse the content of the conversation and retrieve the pertinent medical literature with a single click.

Results

We give below an example discussion thread to demonstrate the linkage of PPML discussions with research articles. This thread, the first thread ever on the PPML, is from 1993, on the subject of music therapy.

```
Sender: 1
Subject: Music Therapy
Date: Mon Jun 28 21:19:36 ADT 1993
The last several days, the local NBC station
aired a "medical report" about the use of
music therapy.  The report was from Miami and
included a short report on the use of music
therapy in a NICU.  The report stated that
when music therapy was used, the babies
required less pain medication.  Does anyone
know of any published reports of empirical
research demonstrating this effect?
..........
Sender: 2
Subject: Music Therapy
Date: Tue Jun 29 08:25:12 ADT 1993
I would suggest that you might contact [name
removed]  in  Pediatrics  at  Washington
University Medical School.  Her research is on
neonatal pain and she might know where the
local station picked up the report. I haven't
seen any data on the topic.
..........
Sender: 3
Subject: Music Therapy
Date: Tue Jun 29 10:20:41 ADT 1993
I'm not aware of specific studies conducted
using music therapy to reduce the need for
pain medication (i.e., music therapy to manage
pain).  However,  several  cognitive
interventions have been used quite effectively
to manage pain.  Donald Meichenbaum developed
a technique in the early 1970s called stress
inoculation training which combines aspects of
self-instruction  training  and  relaxation
training.
```

The example has been parsed and threaded correctly, and is ready to be converted to MeSH terms. Table 2 lists a sample of the MeSH terms that have been for retrieved after parsing the thread using Metamap.

Table 2- A sample of the mappings for a thread in PubMed. (The thread has 18 total MeSH terms)

MESH	SCORE	# OF PAPERS
Music Therapy	4802	1621
Pain	4215	237890
Pharmaceutical Preparations	1688	254813
Infant, Newborn	1660	438290
Education	1654	422011
Teaching	1320	429705

The returned set of MeSH terms for the thread seem to be appropriate, with the exception of the terms *education* and *teaching,* which are examples of terms added to the stop list. Table 3 contains a sample of the citations for the papers linked to the thread by our literature search strategy.

This example demonstrates the efficacy of our knowledge linkages framework. We took a thread containing the experiential knowledge of practitioners and retrieved corresponding published literature to supplement that experiential knowledge.

Table 3- The first three papers connected to the thread with MeSH terms, cumulative score and citation, and link to the paper, or the PubMed entry

MeSH: Music Therapy;Pain;Infant, Newborn;Behavior: *12609 Bo LK, Callaghan P.* **Soothing pain-elicited distress in Chinese neonates.** Pediatrics:2000,105(4).
MeSH: Music Therapy;Pain;Infant, Newborn;Behavior: *12609 Kemper KJ, Danhauer SC.* **Music as therapy.** Southern medical journal:2005,98(3).
MeSH: Music Therapy;Pain;Infant, Newborn;Behavior: *12609 Tagore T.* **Why music matters in childbirth.** Midwifery today with international midwife:2009,(89).

Pilot Study

A pilot study was conducted on a sample of the archives, using all messages on the PPML in 2007 and 2008. The threads were reviewed by the project authors to determine (a) the accuracy of the message parsing, (b) the accuracy of the thread assignment, and (c) the accuracy of the papers returned.

The results of the pilot study were promising. The message parsing was successful on 76% of the messages, with problems arising only from MIME and HTML formatted messages. These problems can be rectified using more sophisticated message parsing algorithms, and we plan to fix them in the next version. The organization of messages into threads was achieved accurately over 90% of the time, which is very promising. The problems arose when users changed the subject line of a message when replying to a previous problem, or replied on a thread about a new topic. Some of these problems can be dealt with more sophisticated parsing algorithms, but when there is no obvious connection between the original and the modified version of the subject lines it is impossible to connect the two automatically. Future work will incorporate an override of the threading function to allow messages to be connected manually if a mistake is found in the thread reviews.

The correct linkages of the discussion threads with corresponding articles was achieved with an overall success rate of 65%. The linkage success rate can be improved by better filtering the content of the threads. Many of the messages on the PPML, such as job postings or advertisements for conferences, are not proper candidates for knowledge linkage and hence their presence compromised the retrieval rate of corresponding articles.

The results revealed some potential problems in the literature search strategy due to the functionality of Metamap, as it tends to miss key terms. The most common example was a lack of an age group indicator to represent children (ages 0-18). This age group is represented by the MeSH terms *Infant*, *Child* or *Adolescent*. Several of the threads that had problems with knowledge linkage were discussions about complex material, but within the thread Metamap did not recognize any MeSH term related to children, which resulted in papers that were not restricted to the proper age group. Following the lead of Abidi et al. [8] the next step in the project will apply an age group filter to restrict all the queries to include the MeSH term C*hild*, restricting the searches to papers about pediatric medicine.

The pilot study was successful enough to warrant future research. Once the changes recommended from the pilot study are completed a formal study using clinical experts will be conducted to evaluate both the conversion to MeSH, the linkage to publications, and the online presentation format.

Conclusion

This project has demonstrated the potential of a system to supplement the experiential knowledge contained in a medical mailing list with explicit, evidence-based research from published journals. It has also demonstrated the potential of a system to leverage archived medical text to provide a novel knowledge-based tool. Using the Metamap system and a novel information retrieval algorithm, the conversations have been processed and linked to pertinent medical literature, presenting the results in an online forum. The forum provides an arena through which clinicians can browse the archives of the PPML and reaffirm the experiences they shared with evidence-based literature.

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Retrieving Similar Cases from the Medical Literature –The ImageCLEF experience

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Abstract

An increasing number of clinicians, researchers, educators and patients routinely search for relevant medical images using search engines on the internet as well as in image archives and PACS systems. However, image retrieval is far less understood and developed compared to text-based searching. The ImageCLEF medical image retrieval task is an international challenge evaluation that enables researchers to assess and compare techniques for medical image retrieval using test collections. In this paper, we describe the development of the ImageCLEF medical image test collection, consisting of a database of images and their associated annotations, as well as a set of realistic search topics and relevance judgments obtained using a set of experts. 2009 was the sixth year for the ImageCLEF medical retrieval task and had strong participation from research groups across the globe. We will provide results from this year's evaluation and discuss the successes that we have had as well as challenges going forward.

Keywords:

Image retrieval, Information storage and retrieval, Content analysis and indexing, Systems and software

Introduction

Image retrieval is a burgeoning area of research in medical informatics [1, 2]. With the increasing utilization of digital imaging in all aspects of health care and medical research, there has been a substantial growth in the number of images being created every day in healthcare settings. Consequently, there is a critical need to manage the storage and retrieval of these image collections, whether they are stored in Picture Archival and Communication Systems (PACS), in patient health records, or on the web. Effective image annotation and retrieval can be useful in the clinical care of patients, education and research [2, 3]. Image retrieval can be used by clinicians to generate differential diagnoses, monitor patient response to therapy, and for quality control. Medical students and residents have also indicated that effective image retrieval can be useful for self-education [4], and other practitioners report using image retrieval systems for patient education, as well. Data-mining of large image collections can provide useful information for researchers. Examples include prevalence of certain findings including polyps during routine screening [5], visual characteristics associated with malignancy in mammography [6, 7], and prediction of response to radiation therapy based on FDG-PET [8].

Many areas of medicine, such as radiology, dermatology, and pathology are visually oriented, yet surprisingly little research has been done investigating how clinicians use and find images. In particular, medical image retrieval techniques and systems are under-developed in medicine when compared with their textual cousins. In particular, the field has suffered from a lack of evaluation opportunities and avenues for researchers to use to compare and measure their systems' performance. The lack of standardized test collections is an especially large problem facing medical image retrieval researchers.

Text retrieval, on the other hand, has a long history of evaluation campaigns, in which different groups use a common test collection to compare the performance of their different methods. The best-known such campaign is the Text REtrevial Conference (TREC), which has been running continuously since 1992. There have been several offshoots from TREC, including the Cross-Language Evaluation Forum (CLEF). CLEF operates on an annual cycle, and has produced numerous test collections since its inception in 2000. While CLEF's focus was originally on cross-language text retrieval, it has grown to include multimedia retrieval tracks of several varieties. The largest of these, ImageCLEF, first began in 2003 as a response to the aforementioned need for standardized test collections and evaluation forums and has grown to become today's pre-eminent venue for image retrieval evaluation.

ImageCLEF itself also includes several sub-tracks concerned with various aspects of image retrieval; one of these tracks is the subject of the present paper: the medical retrieval task. This medical retrieval task was first run in 2004, and has been repeated each year since.

The medical image retrieval track's test collection began with a teaching database of 8,000 images. Since then, it has grown to a collection of over 66,000 images from several teaching collections, as well as a set of topics that are known to be well-suited for textual, visual or mixed retrieval methods. In 2008, images from the medical literature were used for the first time, moving the task one step closer towards applications that can be of interest in clinical scenarios. Several user

studies have been performed to study the image searching behavior of clinicians. These studies have been used to inform the development of the task over the years, particularly to help identify realistic search topics. In 2009 we introduced a case-based retrieval task as we continue to strive for scenarios that more closely resemble actual clinical work-flows.

A major goal of ImageCLEF has been to foster development and growth of multimodal retrieval techniques: i.e., retrieval techniques that combine visual, textual, and other methods to improve retrieval performance. Traditionally, image retrieval systems have been text-based, relying on the textual annotations or captions associated with images [9]. Several commercial systems, such as Google Images (images.google.com) and Yahoo! images (http://images.yahoo.com), employ this approach.

Although text-based information retrieval methods are mature and well-researched, they are limited by the quality of the annotations applied to the images. There are other important limitations facing traditional text retrieval techniques when applied to image annotations: 1) image annotations are subjective and context sensitive, and can be quite limited in scope or even completely absent; 2) manually annotating images is labor and time intensive, and can be very error prone; 3) image annotations are very "noisy" if they are automatically extracted from the surrounding text; and 4) there is far more information in an image than can be abstracted using a limited number of words.

Advances in techniques in computer vision have led to a second family of methods for image retrieval: content-based image retrieval (CBIR). In a CBIR system, the visual contents of the image itself are mathematically abstracted and compared to similar abstractions of all images in the database. These features could include the color, shape or texture of images. Typically, such systems present the user with an ordered list of images that are visually most similar to the sample (or "query") image.

Materials and Methods

The traditional system-oriented IR evaluation process depends on a test collection made up of three parts: a "collection" of content items (articles, images, videos, etc.) that are to be retrieved; a set of "topics" representing potential queries or information needs that are to be answered by searching over the collection's content items; and a set of "gold standard" relevance judgments describing an expert's (or several experts') opinion as to which content items are relevant for each of the search topics.

ImageCLEF Medical Image Retrieval Test Collection

For the first several years, the ImageCLEF medical retrieval test collection was an amalgamation of several teaching case files in English, French, and German [9, 10]. In both 2008 and 2009, the Radiological Society of North America (RSNA) made a subset of its journals' image collections available for use by participants in the ImageCLEF campaign. The 2009 database contained a total of 74,902 images, the largest collection yet.

All images were taken from the journals *Radiology* and *RadioGraphics*, both published by the RSNA. The ImageCLEF collection is similar in composition to that powering the "ARRS GoldMiner"[1] search system [11]. This collection constitutes an important body of medical knowledge from the peer-reviewed scientific literature, and includes high quality images with annotations. Images are associated with specific published journal articles, and as such may represent either an entire figure or a component of a larger figure. In either event, the image's annotations in the collection will contain the appropriate caption text. These high-quality annotations enable textual searching in addition to content-based retrieval using the image's visual features. Furthermore, as the PubMed IDs of each image's article are also part of the collection, participants may access bibliographic metadata such as the MeSH (Medical Subject Headings) terms created by the National Library of Medicine for PubMed.

Creation of Realistic Search Topics

Our goal in creating search topics for the ImageCLEF medical retrieval task has been to identify typical information needs for a variety of users. In the past, we have used search logs from a different medical websites to identify topics. This year again search topics were identified by surveying actual user needs. The starting point for this year's topics was a user study conducted at Oregon Health & Science University (OHSU) during early 2009. This study was conducted with 37 medical practitioners in order to understand their needs, both met and unmet, regarding medical image retrieval. During the study, participants were given the opportunity to use a variety of medical and general-purpose image retrieval systems, and were asked to report their search queries.

In total, the 37 participants used the demonstrated systems to perform a total of 95 searches using textual queries in English. We randomly selected 25 candidate queries from the 95 searches to create the topics for ImageCLEFmed 2009. We added to each candidate query 2 to 4 sample images from the previous collections of ImageCLEFmed, which represented visual "queries" for content-based retrieval. Additionally, we provided French and German translations of the original textual description for each topic. Finally, the resulting set of topics was categorized into three groups: 10 visual topics, 10 mixed topics, and 5 semantic topics. This classification was performed by the organizers based on their knowledge of the capabilities of visual and textual search techniques, prior experience with the performance of textual and visual systems at ImageCLEF medical retrieval task, and their familiarity with the test collection. The entire set of topics was finally approved by a physician. An example of a "visual" topic can be seen in Figure 1 while that of a "textual" topic is shown in Figure 2.

[1] http://goldminer.arrs.org/

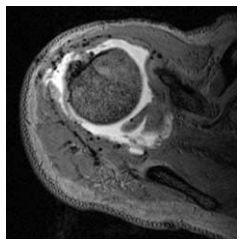

Figure 1-A "visual" topic: "MR Images of rotator cuff"

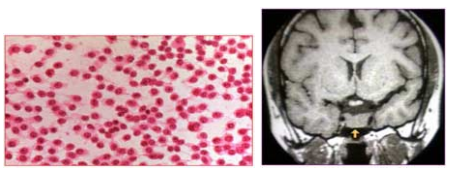

Figure 2-A "semantic" topic: "Pituitary adenoma"

In 2009, we also introduced "case-based" topics as part of an exploratory task whose goal was to create search topics that are potentially more aligned with the information needs of an actual clinician in practice. These topics were meant to simulate the use case of a clinician who is diagnosing a difficult case, and has information about the patient's demographics, list of presenting symptoms, and imaging studies, but not the patient's final diagnosis. Providing this clinician with articles from the literature that deal with cases similar to the case (s)he is working on ("similar" based on images and other clinical data on the patient) could be a valuable aide to creating differential diagnosis or identifying treatment options.

These case-based search topics were created based on cases from the French teaching file Casimage, which contains cases (including images) from radiological practice. Ten cases were pre-selected, and a search with the final diagnosis was performed against the 2009 ImageCLEF data set to make sure that there were at least a few matching articles. Five topics were finally chosen. The diagnoses and all information about the chosen treatment were removed from the cases to simulate the aforementioned situation of a clinician dealing with a difficult diagnosis. However, in order to make the judging more consistent, the relevance judges were provided with the original diagnosis for each case.

Relevance Judgments

During 2008 and 2009, relevance judgments were made by a panel of clinicians using a web-based interface. Due to the infeasibility of manually reviewing 74,900 images for 30 topics, the organizers used a TREC-style "pooling" system to reduce the number of candidate images for each topic to approximately 1,000 by combining the top 40 images from each of the participants' runs. Each judge was responsible for between three to five topics, and sixteen of the thirty topics were judged multiple times (in order to allow evaluation of inter-rater agreement).

For the image-based topics, each judge was presented with the topic as well as several sample images as shown in Figure 3. For the case-based topics, the judge was shown the original case description and several images appearing in the original article's text. Besides a short description for the judgments, a full document was prepared to describe the judging process, including what should be regarded as relevant versus non--relevant. A ternary judgment scheme was used, wherein each image in each pool was judged to be ``relevant'', ``partly relevant'', or ``non-relevant''. Images clearly corresponding to all criteria were judged as ``relevant'', images whose relevance could not be safely confirmed but could still be possible were marked as ``partly relevant'', and images for which one or more criteria of the topic were not met were marked as ``non-relevant''. Judges were instructed in these criteria and results were manually verified during the judgment process.

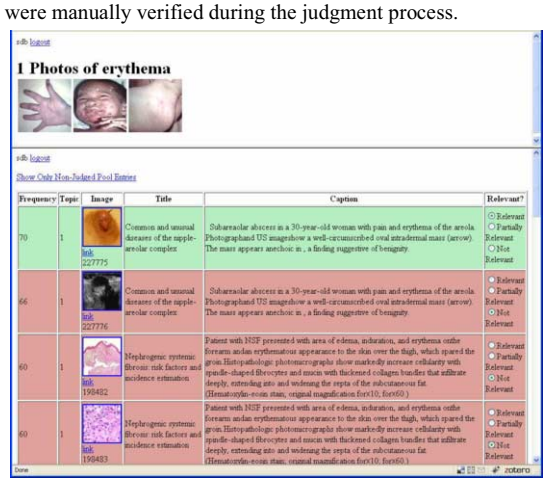

Figure 3-Web interface used for creating relevance judgments

As mentioned, we had sufficient judges to perform multiple judgements on many topics, both image-based and case-based. Inter-rater agreement was assessed using the kappa metric, given as:

$$\kappa = \frac{P(A) - P(E)}{1 - P(E)} \quad (1)$$

where $P(A)$ is the observed agreement between judges, and $P(E)$ is the expected (random) agreement. It is generally accepted that a $\kappa < 0.7$ is good and sufficient for an evaluation. The score is calculated using a 2x2 table for the relevances of images or articles. These were calculated using both "lenient" and "strict" judgment rules. Under the lenient rules, "partly relevant" judgment was counted as "relevant"; under strict rules, "partly relevant" judgments were considered to be "not-relevant".

In general the agreement between the judges was fairly high (with a few exceptions), and our 2009 overall average κ is similar to that found during other evaluation campaigns.

Participation

For the medical retrieval task, the participation remained similar to the previous year with 37 registrations. 17 of the participants submitted results to the tasks. We had six first-time participants in 2009, which we consider to be a very positive development.

A total of 124 valid runs were submitted, 106 of which were submitted for the image-based topics, while 18 were submitted for the case-based topics. The number of runs per group was limited to ten per subtask and case-based and image-based topics were seen as separate subtasks in this view. Participants were requested to provide information about each run that they submitted. Runs could be classified as "textual", "visual" or "mixed" depending on the type of search engine used. They could also be classified as automatic, manual or feedback depending on the level of user interaction. The number of runs by run type can be seen in Table 1 below.

Table 1 – Number of runs by run type

Number of Runs		Run Type		
		automatic	feedback	manual
Retrieval Type	Textual	52	7	
	Visual	15	1	
	Mixed	25	3	2
	N/A	1		

Results

The metrics used to evaluate the runs include the mean averge precision (MAP), early precision (e.g. P@5, p@10) and bpref), measures that have historically been used for TREC and other challenge evaluations [12]. As was the case in the recent past, the focus of many participants in this year's ImageCLEF was primarily on text-based retrieval methods (as opposed to visual techniques). Almost half the runs submitted were automatic and textual. The increasingly semantic topics, combined with a database containing high-quality annotations, produced an evaluation environment better-suited for text-based image retrieval, and this fact was not lost on the participants. Only a few participants submitted visual runs, and those runs that were submitted were small in number and generally performed poorly, as can be seen from the average of the MAPs of the runs in Table 2.

Table 2 – Mean average precision by run type

Average MAP		Run Type		
		automatic	feedback	manual
Retrieval Type	Textual	0.27	0.26	
	Visual	0.01	0.01	
	Mixed	0.20	0.26	0.19

Mixed-media runs performed similarly to textual runs in terms of mean average precision. That said, mixed runs that effectively combined visual and textual retrieval approaches typically outperformed the corresponding purely textual runs when considering metrics such as early precision, as can be seen in Table 3 where some mixed automatics runs demonstrated high early precision.

Case-based topics were introduced for the first time, and only a few groups participated. Runs submitted for case-based topics performed slightly worse than those submitted for image-based topics.

Table 3 – Maximum precision@5 by run type

Maximum P@5		Run Type		
		automatic	feedback	manual
Retrieval Type	Textual	0.73	0.61	
	Visual	0.09	0.06	
	Mixed	0.71	0.74	0.62

A kappa analysis between several relevance judgments for the same topics showed that there were differences between judges but that agreement was generally high. There were, however, a few judges that had significant disagreements with other judges. Additionally, feedback that we received from the judges indicated that the level of expertise of the judge in the specific area being searched affects their leniency with the relevance judgment process. The relevance judgments from judges with markedly different opinions were not used for calculating the final results. Interestingly, as has been found in the text retrieval domain, the overall rankings of the systems remain relatively stable even with using relevance judgments from different judges. However, the topic of relevance judging and the role of the judge (student, resident, general practitioner, expert radiologist, etc.) while evaluating the relevance of an image is of significant interest to us and one that we are investigating further.

Very few participants submitted interactive and manual runs as most participants seem to prefer batch processing with automatic text-based approaches, leading to primarily system-based evaluation. However, the role of the user in the retrieval process is important and we continue to encourage participants to introduce interactivity into their search systems and runs.

Conclusion

The ImageCLEF medical image retrieval campaign have been quite successful in attracting international researchers by providing a test collection that can be used to evaluate the performance of both text-based and content-based image retrieval systems. The test collection has grown from 8,000 images in 2004 to over 74,900 images in 2009. The participants in ImageCLEF have had interesting but diverse approaches to the addressing the problem of effective image retrieval in the medical domain. However, the collaborative nature of the forum and the annual workshops have fostered a community of participants that have willingly shared their techniques and

even resources to the common goal of improving access to clinical images.

This work has some limitations. First, like all test collections, the topics were artificial. However, since they grew out of the results of a user study, we feel that they are reasonable and valid examples of clinician information needs and language use. Another limitation is the pools uses for relevance judgments reflect the runs submitted by the participants. Images that may have been retrieved by other techniques or were not the top hits would not be evaluated.

Going forward, we plan to expand the case-based topics as we believe that they more closely simulate the experiences of real user. We will continue to encourage participants to improve their multimodal techniques by making available the best visual and textual runs from past years in an effort to identify optimal ways of combining them. We are also continuing our user studies to better understand the needs of real users and to assess the validity of the performance measures used in these evaluation campaigns. The role of the user in assessing relevance continues to be of interest to us.

Acknowledgements

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Chapter 17.

Usability & Evaluation

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Computerization of a Preanesthetic Evaluation and User satisfaction evaluation

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Abstract

Preanesthetic evaluation purpose is to reduce morbidity and mortality through the review of the patient's medical history, clinical examination, and targeted clinical studies, providing referrals for medical consultations when appropriated. Changes in patient care, standards of health information management and patterns of perioperative care, have resulted in a re-conceptualization of this process where the documentation of patient medical information, the efforts in training and maintaining the integrity of the medical-legal evaluation are areas of concern. The aim of this paper is to describe the design, development, training, and implementation of a computerized preanesthetic evaluation form associated to the evaluation of the user satisfaction with the system. Since the system went live in September 2008 there were 15121 closed structured forms, 60% for ambulatory procedures and 40 % for procedures that required hospital admission. 82% of total closed structured forms had recorded a risk of the procedures of 1-2, according to the American Society of Anesthesiologists classification. The survey indicates a positive general satisfaction of the users with the system.

Keywords:

Preoperative care, Computerized medical records systems, Perioperative procedures, User satisfaction

Introduction

Preanesthetic evaluation is a clinical assessment process that precedes the accomplishment of surgical and non surgical procedures, which will be carried out under general or local anesthesia or sedation. This process includes review of the medical records of the patient, current medical history, clinical examination, test results and referrals to other specialists when appropriate[1]. The purpose of the evaluation is to reduce preoperative morbidity and mortality [2]. The detection of risk factors influences the choice of the anesthetic technique, the complexity of required actions and the need of specific anesthetic postoperative care [3].

Changes in patient care, standards of health information management and patterns of perioperative care, have resulted in a re-conceptualization of every aspect of preoperative preparation, where the documentation of patient medical information, the efforts in training and maintaining the integrity of the medical-legal evaluation in preanesthetic are areas of concern and research [4, 5]. The registration of this assessment is often done on paper.

A study compared the efficiency of a new computerized preoperative evaluation system against one paper based and the waiting and examination periods were analyzed. The computerized system required less examination time than the manual system and the authors presumed that time is saved at other points of patient care by the legible, instantly retrievable preoperative evaluations that the computerized system produces. The computerization of clinical records improves the quality of patient care by transforming this information into data which is easily readable and accessible [6, 7].

The implementation of a computerized version of a structured Preanesthetic evaluation questionnaire in obstetric patients reduced time-consuming tasks, captured far more detail and provided immediately available data for quality assurance activities[8].

The purposes of this study are 1) to describe the design, development, training and implementation of a Preanesthetic Evaluation Electronic Form (PEEF) included in an Electronic Health Record (EHR), 2) results of system use since implementation and 3) to assess the user satisfaction with the new system. This is done within the framework of a new Center for Preanesthetic Evaluation (PEC) in the Hospital Italiano of Buenos Aires.

Materials and Methods

Design

This is a descriptive study of a Preanesthetic Evaluation Electronic Form implementation.

Setting

The Hospital Italiano of Buenos Aires (HIBA) is a non-profit health care academic center founded in 1853. HIBA has a network of two hospitals with 750 beds, 500 home care pa-

tients under care, and 23 outpatients care centers. There are more than 2,400,000 outpatient visits annually, each year over 38,000 inpatients are admitted to its hospitals and 23,000 surgeries in the last year.

In 1998 HIBA began the implementation of a Healthcare Information System (HIS) to manage clinical information with preexisting administrative applications. It is an in-house project that currently handles all the information related to health care both clinical and administrative from capture to analysis.

The EHR is a full-implemented web based, problem oriented, patient centered record with customized functionalities depending on the level of care (outpatient, inpatient, emergency care and home care) This EHR system includes a computerized provider order entry (CPOE), available throughout the HIBA network. The terminology server [9, 10] has allowed the mapping of local vocabulary (thesaurus) to reference vocabulary SNOMED CT, allowing the auto-codification of 80 % of diagnosis.

Computerization of the preoperative process

The computerization of the preoperative process was planned and included the following stages: the computerization of the Preanesthetic Evaluation Form, the appointment for surgery, and the Surgery & Anesthesia Form. In addition to this, and in the context of the proposed creation of the PEC, a multidisciplinary working team was established enabling the development of the PEEF (Figure 1).

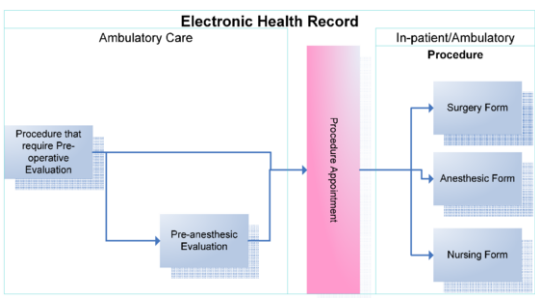

Figure 1- Computerization of the preoperative process

Multi-disciplinary working team

An anesthesiologist, a pediatrician, a clinician, a cardiologist, norms and procedures area specialist and two medical informatics residents integrated the working team. The medical informaticians were in charge of preparing the functional requirements, the implementation and user satisfaction survey using QUIS ™.

Evaluation Process pre go live

The Preanesthetic Evaluation (PE) for adults and pediatric populations was carried out in HIBA in a decentralized manner in several locations, with different methods of coordination and evaluation. An average of 1500 patients per month was evaluated.

The PE began with the ordering of a surgical procedure or any other that is carried out under anesthesia. To record the steps during the evaluation, a paper form was used. This form was given to the patient, in the majority of cases by clerks during scheduled visits or by the surgeon´s secretaries that was going to execute the procedure.

The paper form had specific data fields, depending on the circumstances. It was completed by the patient, the clerk or the secretary, the clinician, the cardiologist, the anesthesiologist and the nurse.

Finally, the form consisted of a summary generated through the participation of multiple key users involved. Sometimes, the records were illegible. Anesthesiologists highlighted the most important data evaluated in the paper so that the anesthesiologist at the operating room could quickly visualize it. At that time a copy was given to the patient with the fasting schedule, the preparation for surgery, the procedure explanation and an informed consent.

Preanesthetic Evaluation Electronic Form (PEEF)

The PEEF was included in the ambulatory EHR (AEHR) and was developed entirely in Java.

Every PEEF starts with the input of the problem or a procedure coded by the terminology server [10, 11]. While the PEEF is opened the user can navigate between modules and add or modify information, when the PEEF is closed the final print version of the structured form could be given to the patient with the highlighted data chosen by the physician.

This new structured form was divided into the following sections or modules:

- Relevant Diseases: there is a predefined list of diseases and pathologies, as shown in Figure 2. If any of these were already in the problem list of the AEHR, it automatically appears highlighted (underlined) in this module. This helps to avoid duplication of information and enabled integration of a structured data into a longitudinal patient record. Also contains the vital signs and tetanus immunization data.

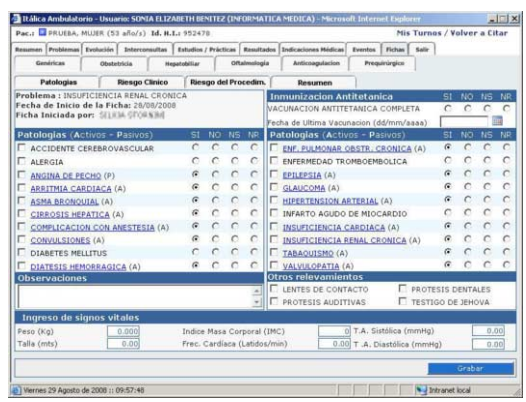

Figure 2- Snapshot of the EHR: pre-defined relevant diseases list in the Preanesthetic Evaluation Electronic Form.

- Clinical risk: in this section clinical, respiratory and renal risk is evaluated; laboratory test can be ordered; referral can be made as well as to order the medication suspension. If respiratory risk is marked an alert suggesting ordering a test is triggered (Figure 3)

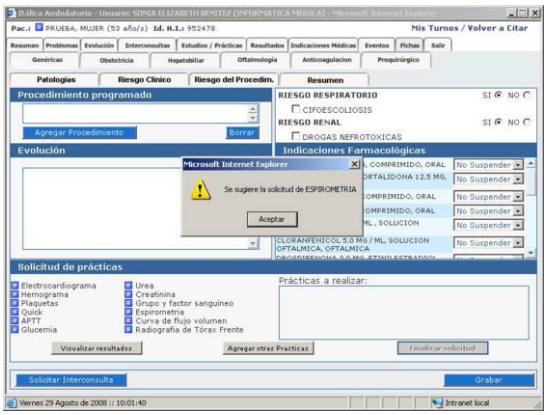

Figure 3- Snapshot of the EHR: Section for Clinical Risk evaluation in the Preanesthetic Evaluation Electronic Form.

- Risks of the procedure: the risk of bleeding and the difficulty on intubation is evaluated by the anesthesiologist. The result of this is expressed using the ASA (American Society of Anesthesiologists) score.
- Summary: In this module all the records made are visible in a summarized form.

Training in the use of the PEEF

During the pre go live stage a virtual training space was created and online reading material was made available to the users. The training course had interactive material and assessment activities. The implementation process was accompanied by a face to face support made by medical informatics residents.

Databases analysis

Secondary databases were analyzed to evaluate the amount of PEEF created and closed, the most frequent diagnosis and procedure and the prevailing ASA classification.

The ASA Score is a five category physical status classification system for evaluating a patient before surgery. The categories are: 1)The healthy patient, 2)The patient with mild systemic disease, 3) The patient with severe systemic disease, 4) The patient with severe systemic disease that is a constant threat to life 5) The patient who is not expected to survive without the operation.

QUIS: Evaluation of User Satisfaction

The Questionnaire for User Interaction Satisfaction (QUIS ™)[12] is a standardized usability testing instrument for interactive computer systems. An adapted Spanish edition of the short version was used supplemented by free-text comments.

The survey contains a demographic questionnaire with the identification of the physician specialty, a measure of general satisfaction and an organized evaluation of four specific interface factors: screen, terminology and system feedback, learning, and system capabilities. The global satisfaction with the interface are measured, as well as the factors that are part of that aspect, on a 9-point scale, where 1 (one) correspond to the worst and 9 (nine) characterize the best evaluation.

When the survey was completed, each area was analyzed separately and grouped by medical specialties. Central tendency of data was summarized by the median and the dispersion by range.

Results

Databases analysis

Since the system went live in September 2008 there were 15121 closed structured forms, 60% for ambulatory procedures and 40 % for procedures that will require hospital admittance. The prevailing ASA was 1-2 with 82% of total closed structured forms.

Currently 20 general practitioners (GP), 5 anesthesiologists and a variable number of cardiologists are working in the Center.

Evaluation of User Satisfaction

Between 29/09/09 and 10/10/09, 18 users completed the survey. 66 % of them have been working with the system between 6 month up to a year and 53 % worked between 4 hs. to 10 hs. 61% of users who completed the survey were general practitioner with a response rate of 55% and the 16 % corresponding to anesthesiologists with a response rate of 60%.

QUIS categories were compared between the user's specialties as shown in Table 1.

Table 1 - Results of Category[1]

Categories	GP	Anesthesiologist	Global Median
General Satisfaction	7 (5-8)	7 (3-8)	7
Learning	8 (7-9)	8 (8-9)	8
Screen design	8 (7-9)	8 (7-9)	8
Use of terminology	7,5 (6-8)	7,5 (7-9)	7,5
Capacity of system	7 (6-7,5)	8 (8)	7,5
Users manuals & Help desk	7 (6-8)	7 (6,5-8)	7

Due to the variability number of the cardiologist that used the form, they were not included.

The majority of items were scored up to 7, except two items of General satisfaction (Flexibility and Adequacy of power) and

[1] The results of Table 2 related to GP and Anesthesiologist are expressed in median (range).

one item of Help desk & user manual (Clarity of User Manual) as is shown in Figure 4.

Learning to use PEEF was appraised as easy by the anesthesiologists.

Characters on the screen were easy to read and sequence of screen was considered very clear. Anesthesiologists rated more positively the system's capabilities in contrast with GPs. The help desk service was helpful and the support more appreciated for both GP and Anesthesiologists.

Free-Text Opinion Space

In addition to the above mentioned 71% (10/14) of the physicians who completed the questionnaire also contributed with narrative responses about different problems or features of the PEEF. The problems mentioned were the downtime of the system, problems and procedures correction, rigidity of tetanus vaccination data entry and medication suspension. Alerts and more amount of free text were solicited, among others.

Three of the cardiologists wrote their opinion. Only one of them asked about a specific section for cardiologists' record.

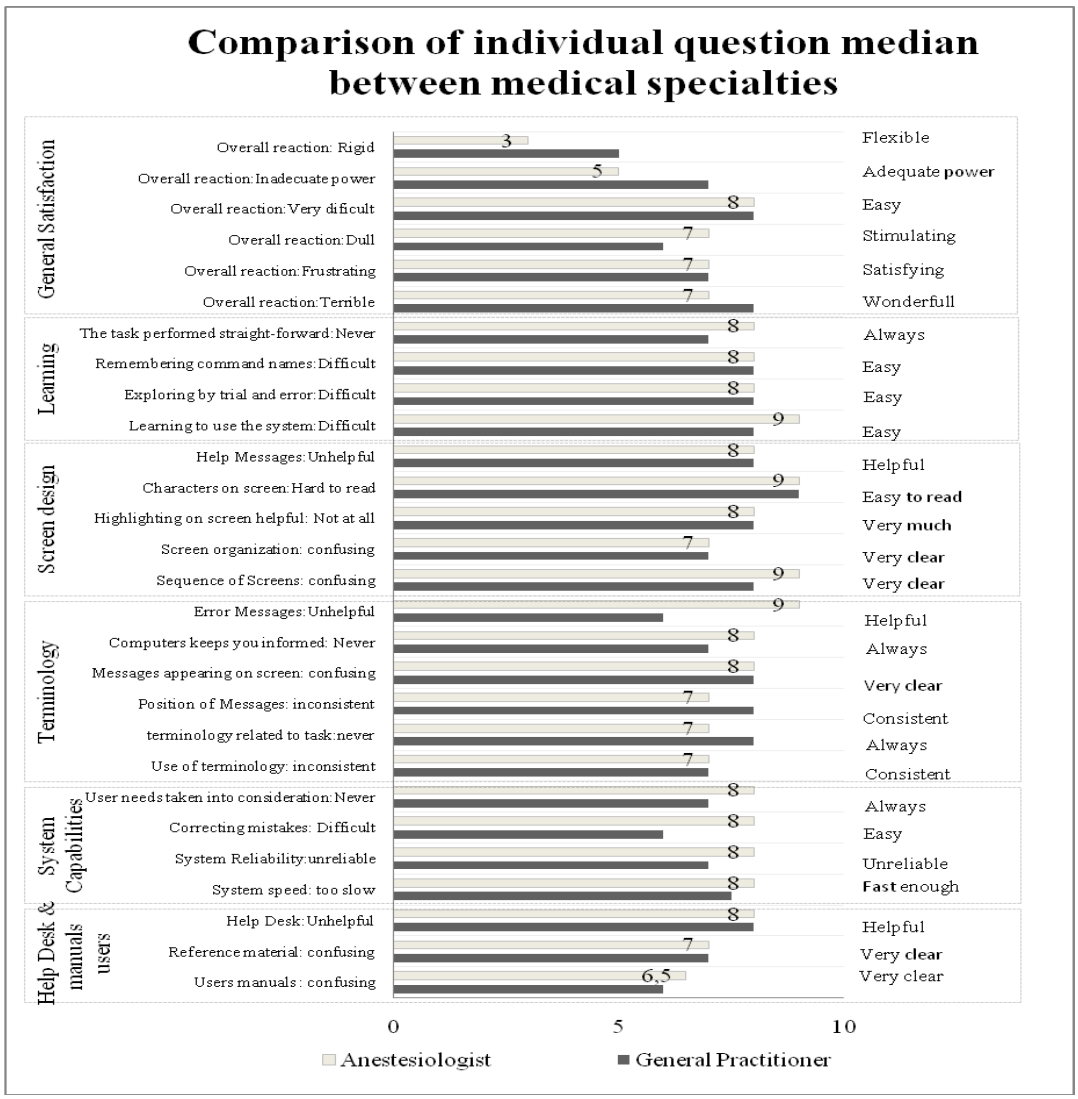

Figure 4 – Comparison of individual question median between medical specialties

Discussion

In this study we described the experience of the implementation of an integrated computerized preanesthetic evaluation form in an academic center and the evaluation of user satisfaction of the new form.

User interface of systems has been evaluated by QUIS™ in other opportunities. Using QUIS™, 75 primary care physicians where surveyed about the Brigham and Women's Integrated Computing System (BICS). The system scored highest in the area of screen design and lowest in the area of system capability. General satisfaction was most highly correlated with screen design and layout [13]. Also was the instrument used for comparing the physician satisfaction with two order entry systems. User satisfaction differed significantly between the two systems, the Veterans Affairs CPRS had a mean of 7,06 in General Satisfaction against the Commercial System evaluated [14].

The survey results indicated a positive general satisfaction on the PEEF. It scored highest particularly in the area of screen design. The system was globally considered as stimulating, with adequate capacity and ease of use.

The lack of flexibility expressed in the results is associated to a pre-defined list of problem and rigidity of tetanus vaccination data entry and medication suspension

The limitation of this user survey can be summarized in the following points: the overall response rate was low and the cardiologists were not included due to the variability of number of them.

Conclusion

A PEEF was successfully implemented, used and accepted by the end user.

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Usability of Clinician Order Entry Systems in Singapore: An Assessment of End-User Satisfaction

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Abstract

Objectives: To gather end-user feedback and evaluate factors that influence end-user satisfaction of order entry systems used in the hospitals under National Healthcare Group, Singapore. Design: Questionnaires were sent to a randomly selected group of 100 doctors and nurses. Results & Conclusions: 52 doctors and nurses responded to the survey. The users' satisfaction with the clinical systems was average. (Mean satisfaction score is 3.85 on a scale of 1 to 7). Users generally agree that the systems could help reduce patient care errors and improve delivery of quality care to patients. System reliability, intuitive navigational capabilities and ease of use are strongly and positively correlated with user satisfaction. System response time however, is found to be strongly but negatively correlated with user satisfaction with a correlation coefficient of -0.717 ($p<0.001$). These findings suggest that more efforts should be made to improve these aspects in order to improve user satisfaction. These elements should also form important considerations in all future clinical systems development.

Keywords:

Medical informatics, Medical order entry systems, Attitudes of health personnel, Consumer satisfaction.

Introduction

Computerized physician order entry (CPOE) systems have been shown to significantly reduce medication errors and improve quality of care in many studies [1, 2]. However despite the benefits of CPOE systems, many implementations have failed or met with high levels of user resistance [3, 4]. Studies have shown that it is vital to understand the needs of clinical users, the various system and human factors that can impact user satisfaction [5- 7]. A study by Bailey [8] found that user satisfaction is an important predictor of a system's success.

In Singapore, despite the increasing number of implementations over the years in public tertiary hospitals, there is a paucity of studies covering user satisfaction and perceptions of CPOE. One recent study in Singapore reported generally high user satisfaction levels with an electronic prescription system used by a group of general practice clinics [9].

In National Healthcare Group (NHG), Singapore, a CPOE user feedback survey was planned in early 2009 as part of a post-implementation review. The CPOE system for laboratory, radiology and medication orders was designed, custom-built and implemented over four years in several of its tertiary hospitals. To date, there are more than a thousand doctors and nurses using them daily.

The aim of this study is to: (a) determine the overall satisfaction level of NHG users (doctors and nurses) with respect to their order entry systems; and (b) identify the constructs that are associated with user satisfaction

This study will contribute an Asian perspective into the current body of knowledge around CPOE implementation, and the findings should help hospitals learn about the factors that influence clinician user satisfaction. The results may also provide further insights into how order entry systems should be designed to improve adoption and reduce user resistance.

Methods

Fifty doctors and fifty nurses from various institutions under the National Health Care Group (NHG) were randomly selected and requested to complete a pretested questionnaire based on the study of Lee et al [10]. The doctors and nurses were from both medical and surgical departments. The only inclusion criterion was that the users (doctors and nurses) must have worked for at least six months in the group. This was to ensure that the user surveyed has sufficient experience with the systems to give effective feedback.

The questionnaire is composed of 16 questions respectively attached to a seven-point Likert scale, where '1' corresponds to 'never'; '4' corresponds to 'it varies'; while '7' corresponds to "always' . There was also an inclusion of 6 open ended questions in the questionnaire to ensure that the exercise can capture important user feedback that may not be reflected by the 16 standardized questions.

The initial draft questionnaire was tested with 2 doctors and 2 nurses from both medical and surgical disciplines for face validity. The final questionnaire was then derived subsequently for use.

The survey tool is designed to measure the users' perception of reliability, speed of the systems, ease of use of the applications, adequacy of training to use the system, impact on productivity, impact on patient care and overall satisfaction with the clinician order entry systems. The questionnaire is made available in hard copy which is hand-delivered to those selected participant. At the same time, the selected participants are sent emails to introduce them to the study as well as to instruct them on how they can participate either through the hard-copied questionnaire or through a web-based survey tool.

The questionnaire contains a simple introduction and instructions. The survey responses were anonymous and participants were told that no individuals will be identified in the study. All doctors and nurses selected in our random sample had the right to refuse to participate without prejudice. This study was further reviewed and endorsed by the NHG Electronic Medical Records committee as a form of post-implementation user feedback.

Once the questionnaire was completed, the data was validated, edited for consistency and encoded into a spreadsheet for analysis.

Results

A total of fifty-two users handed in their questionnaires. About 98% of these responders were doctors and nurses with a ratio of 1:1. These health care professionals come from Alexandra Hospital, NHG Polyclinics, The National University Hospital and Tan Tock Seng Hospital representing both the Inpatient and the Outpatient sectors of the medical group.

Cronbach alpha of the data collection tool is measured to assess internal consistency of the questionnaire, i.e. 0.656. Factor analysis of the data collection tool suggests four statistically significant components present in the questionnaire. These components pertain to the following user satisfaction constructs: ease of use; facilitating efficiency of work; promotion of quality of care and patient safety; and availability of prompt assistance whenever the users need it.

Further assessment of the tool likewise reveals that the consistency of responses are much more homogenous among nurses than among physicians ($p<0.001$). There is no sufficient evidence to say however that internal consistency of the questionnaire varies across gender, across institutions and whether the user is either in the in-patient or outpatient setting.

The mean overall satisfaction score of the study population is estimated to be 3.85 ± 1.39. Figure 1 illustrates the distribution of satisfaction levels among users.

It can readily be seen in Figure 1 that about 33% of the respondents (those who answered "Frequently" or "Almost Always") find the clinical systems to be consistently satisfactory. There is no evidence that the satisfaction levels are different between doctors and nurses. There is likewise no evidence to suggest that satisfaction levels vary across institutions from where the samples are selected.

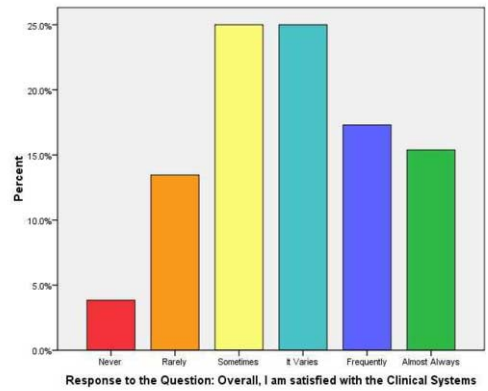

Figure 1- Distribution of Overall Satisfaction of Users on the Clinician Order Entry Systems, NHG Singapore, 2009.

Looking into some of the details, the study population has provided a good contrasting feedback, i.e. from good comments to areas of improvement. On one hand, the data suggest that the order entry systems are perceived not only to reduce patient care errors but also to improve delivery of quality of care to patients. As such, responders feel that the systems provide the necessary information for the health care providers to do their respective jobs better. Qualitatively, doctors like the fact that they can access clinical information remotely and that they can find information in "one place." Nurses likewise highlighted that with the clinical systems in place; they can readily access old laboratory results as well as monitor laboratory requests with pending results

On the other hand, the responders feel that the opening of multiple windows while using the applications can be quite annoying. They also said that the system response time has a lot of room for improvement. As the doctors are very adept in their habits in ordering, they are of the opinion that computerized order entry for tests and medications slow down their respective processes. Nurses, however, love the fact that they can readily and legibly read instructions from doctors. They also like the fact that they are being prompted by their respective systems when medications are due to be administered.

Correlation analysis is done to determine which facets of the order entry systems are strongly associated with user satisfaction. Table 1 shows the four factors with the strongest correlation found. System reliability, intuitive navigational capabilities and ease of use are strongly and positively correlated with user satisfaction. Correlation coefficient are estimated to be 0.736, 0.741 and 0.731, respectively ($p<0.001$). System response time however, is found to be strongly but negatively correlated with user satisfaction with a correlation coefficient of -0.717 ($p<0.001$). Test of heterogeneity suggest that inasmuch as the direction of correlation is the same for doctors and nurses, responses solicited from nurses are more homogenous than responses elicited from the physicians ($p<0.05$).

Table 1- showing the facets of the order entry systems that are strongly associated with user satisfaction (p <0.001)

Facets of the systems	Correlation coefficient
System reliability	0.736
Intuitive navigational capabilities	0.741
Ease of use	0.731
System response times	-0.717

Interestingly, there is no sufficient evidence suggesting that training of users for the systems of interest is associated with user satisfaction.

The summary scores of the responders are presented in Table 2 below.

Table 2 - Summary Table of Responses of Clinical System Users, NHG Institutions, 2009. (based on the 7 point Likert scale)

Question	Mean	SD
Q1 The systems are reliable - it does its job consistently.	4.35	1.14
Q2 The systems improve my productivity.	4.35	1.27
Q3 Navigating through the systems is intuitive and easy	4.13	1.44
Q4 The systems have a negative impact on patient care.	3.17	1.48
Q5 The systems reduce patient care errors.	4.71	1.27
Q6 The systems are easy to use.	4.25	1.40
Q7 Compared to paper ordering, computerized order entry for tests and medications slow me down	5.18	1.68
Q8 The systems give me information I need to do my job better.	4.87	1.34
Q9 I feel that I had adequate training on the systems	4.50	1.50
Q10 The systems improve the quality of patient care.	4.60	1.27
Q11 System response time is slow.	5.75	1.36
Q12 Opening multiple windows to access different applications can be annoying.	5.88	1.32
Q13 When I have a problem with the systems, I just ask someone for help.	4.81	1.34
Q14 I feel that I can benefit from refresher classes on the clinical systems.	3.79	1.63
Q15 When I need help on the system, I can find it.	3.96	1.30
Q16 Overall, I am satisfied with the systems.	3.85	1.39

Discussion & Conclusions

The relatively low response rate of this study can lead to some selection bias and thus be considered as one of its significant limitations. A number of non-responders told their department secretaries that they could not spare the time to answer the questionnaire. The implication of this response is that if the lack of time to answer the questionnaire is associated with non-satisfaction of the users, then the estimated overall satisfaction rate of the users will be significantly diminished. The converse is also true. If the lack of time to answer the questionnaire is associated with satisfaction of users, then the estimated overall satisfaction rate of the users will be significantly increased. Considering that the slowness of the system has been cited as one of the pain points and is associated with adequacy of time, it can be reasonable to assume that the study results can swing towards more user dissatisfaction. Future studies should consider the use of incentives eg. vouchers to improve response rates.

Moreover, the fact the Cronbach alpha of the questionnaire varies between doctor (0.514) and nurse (0.757) responders suggest that either the doctors have a different concept of user satisfaction compared to nurses or the data collection tool with its contents are more effective in measuring nursing constructs than doctor mindsets --- at least as far as assessing user satisfaction of the clinician order entry systems. Doctors and nurses have different job scopes which lead to different needs and expectations of the clinical systems. Therefore in healthcare IT development, it is imperative to involve both physicians and non-physicians.

Based on our correlation analysis, end-user satisfaction is strongly associated to four key system elements – reliability, intuitive navigation, ease of use, and system response time. These findings suggest that more efforts should be made to improve these aspects in order to improve user satisfaction. These elements should also form important considerations in all future clinical systems development.

Beyond optimizing clinical software design, hospitals need also to improve and maintain good IT infrastructure like hardware and network to improve the overall system performance.

While there are numerous studies [11-13] showing that proper user training can improve the success and acceptance of electronic medical records, our results do not show any correlation between training and user satisfaction. The is likely due to the fact that the last CPOE training session was conducted more than six months ago, and the impact of training on user satisfaction have waned with time.

In light of the study's findings, recommendations have been made to the software team for future enhancements, particularly the need to optimize system performance and usability. A further study on clinical users may be warranted to explore in-depth the issues uncovered here.

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Mini Stare-HI: Guidelines for reporting health informatics evaluations in conference papers

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Abstract

Background: To improve the quality of reports of health informatics evaluations we recently devised and published a guideline named STARE-HI, now formally endorsed by IMIA. Objective: To develop a prioritization framework of ranked items (a mini-STARE-HI) to assist authors when reporting health informatics evaluation studies in a restricted space conference paper. Method: We invited 111 editors of health informatics conference proceedings and reviewers and authors of health informatics evaluation studies to score 106 reporting items on a scale ranging from "0 - not necessary" through to "10 - essential" by a web-based survey. Results: The response rate for the survey was 63% (70 out of 111). The most important items (score >9) were "Interpret the data and give an answer to the study question", "Whether it is a laboratory, simulation or field study" and "Description of the outcome measure/evaluation criteria". Four items had a mean score <6. Conclusion: It has been possible to produce a ranking of reporting items from STARE-HI according to their prioritized relevance for inclusion in space-limited conference papers. We believe that this prioritization framework can improve quality and utility of conference papers on health informatics evaluation studies.

Keywords:

Standards, Reporting, Evaluation studies, Conference papers, Evidence

Introduction

Modern healthcare tends increasingly to depend on health informatics applications such as electronic patient records, order entry and image processing systems. Within the last two decades, the viewpoint that interventions in healthcare should be evidence-based has become the accepted norm. In this context it is more than ever imperative to also assess the impact of health informatics investments, as concluded in [1,2]. Until now this has seldom been the case, and in those cases where health informatics applications have been assessed reports on these evaluations are often of limited value because essential information is not properly communicated – possibly because reporting standards were missing. High quality reporting is essential as it serves the target audience better and assists in the build-up of a robust evidence base. To improve reports of health informatics evaluations we recently devised and published a Statement on Reporting of Evaluation Studies in Health Informatics - STARE-HI [3]. This is now endorsed by IMIA, and listed by the EQUATOR initiative [4].

About half of all health informatics evaluation studies are published in health informatics journals and conference proceedings as shown by [5]. Too many studies report their results in a conference paper without a full journal report, as noted by [6]. Therefore, conference papers provide valuable information for systematic reviews about studies that are not otherwise published, the exclusion of which from the review would seriously weaken the evidence base as well as possibly introduce publication bias. For these reasons, conference papers should contain sufficient information about the evaluation study to serve as an accurate record of its conduct and findings, providing optimal information about the study within the space constraints of the conference paper format so that they are of sufficient quality and utility to contribute to the evidence base. However, they are inevitably constrained by prescribed limits on length, providing authors with a severe challenge in meeting the STARE-HI guidelines. This paper describes the development of a prioritization framework, called Mini STARE-HI, to assist authors in considering which items to include, and which to exclude on space grounds, when reporting health informatics evaluation studies in a conference paper.

Materials and Methods

The scope and purpose of the full STARE-HI is to provide guidelines for reporting evaluations in Health Informatics, independent of the evaluation method used. Therefore, these guidelines have a general character, with a main focus on the description of the context in which the study took place including a description of the system being evaluated, the description of the methodology, the systematic reporting of results, and the structuring of the discussion [3]. STARE-HI formed the basis for the development of this Mini STARE-HI, which had two steps.

First, all members of the core editorial team of STARE-HI independently identified in STARE-HI all items in the various reporting (sub) areas that they believed authors should consider when reporting an health informatics evaluation study. For example, the sub area "system details" contains items such as "type of system", "aim of the system", "profession and number of users", etc. We included in the next step all items identified by one or more editorial team members.

Next, a total of 111 participants, consisting of authors of health informatics evaluation studies, reviewers with an interest in health informatics evaluation and editors of Medical Informatics conference proceedings, were invited by email to participate in a web-based survey and rate the importance of each of the checklist items. Respondents were asked to score the items with the common limitation of a 5-6 pages conference paper such as MIE, Medinfo and AMIA in mind. The scoring system was a scale ranging from "0 - not necessary" to "10 - essential" to include the item in a report of a health informatics evaluation study in a conference paper. Furthermore, respondents were invited to provide any items per reporting (sub) area they felt important but were missing in the checklist.

Results

One-hundred-and-six items were identified in the STARE-HI guideline in step one and included in the survey. After the original invitation and two reminders the response rate for the survey was 63% (70/111).

Table 1 shows the items per reporting area ordered on their mean score. The most important items (score >9) were "Interpret the data and give an answer to the study question" (in the discussion section), "Whether it is a laboratory, simulation or field study" (in the methods/study design section) and "Description of the outcome measure/evaluation criteria" (in the methods/study design section). In contrast, the items "Name of the health care organization" (in the methods/study context section), "Authors' contribution", "Formal permission and ethical concerns" (in the introduction) and "study limitations" (in the abstract) were considered the first candidates to ignore in case of lack of reporting space (score <6). The overall mean score per reporting area was highest for the discussion (8.3).

In total 19 different comments were given for adding new or "how to" items, rephrasing items, or for rearrangement of order. The latter group counts for more than half (11/19) of the comments.

Table 1- Survey results on the prioritization score of health informatics evaluation items derived from the STARE-HI guideline when applied to a conference paper.

Reporting area (mean score)	**Reporting items (generated from STARE-HI, [3], re-ordered per reporting area based on the mean score)**	**Mean score (SD)**
Content of Title (7.1)	Study question	7.5 (2.8)
	Type of information system	7.5 (2.9)
	Study design	6.6 (2.9)
	The term "evaluation" or "assessment"	6.6 (3.1)
Abstract (8.0)	Describe the major results	9.0 (1.1)
	Include the objective	8.9 (1.4)
	Include a conclusion	8.7 (1.7)
	Describe/define the outcome measures	8.5 (1.6)
	Describe the methods - study design	8.5 (1.6)
	Describe the setting	7.7 (2.1)
	Describe the participants	7.6 (1.9)
	Be structured	7.6 (2.4)
	Describe study limitations	5.2 (2.8)
Keywords (7.1)	Refer to the type of system being evaluated	7.8 (2.3)
	Include "evaluation" or "assessment"	7.3 (2.8)
	Refer to the outcome measure	7.1 (2.4)
	Based on MeSH terms	6.9 (2.4)
	Refer to the study design	6.9 (2.5)
	Refer to the setting	6.5 (2.6)

Table 1 (continued)

Introduction (6.9)	Study questions and hypotheses	8.7 (1.8)
	Motivation for the study	8.1 (2.1)
	What is already known about the type of system	7.4 (2.0)
	A description of the system (e.g. function)	7.0 (2.4)
	Position of this study in a larger study/project	6.5 (2.4)
	Which stakeholders viewpoint(s) is/are used	6.3 (2.4)
	Potential influence of the study	6.1 (2.3)
	Formal permissions and ethical concern (e.g. ethical board)	5.0 (3.0)
Methods – study context (7.1)	Kind of facility (e.g. outpatient clinic, hospital)	8.2 (1.4)
	Aim of the system	8.0 (1.9)
	Type of system	7.8 (1.9)
	Type of information managed	7.6 (1.7)
	Clinical or other tasks of the system	7.4 (1.9)
	How long the system is used	7.4 (1.9)
	How wide spread the system is used	7.4 (2.0)
	Description of how the system works	7.3 (2.2)
	Which facilities/department(s)	7.1 (2.1)
	Professions and number of users	7.0 (2.3)
	Reference to a full technical description of the system	6.7 (2.4)
	Geographical location of the health organization	6.4 (2.6)
	Name of the health organization	4.3 (2.9)
Methods-study design (7.9)	Whether it is a laboratory, simulation or field study	9.1 (1.1)
	Description of the outcome measure/evaluation criteria	9.1 (1.5)
	Study type (e.g. case study, (quasi) experimental etc)	9.0 (1.5)
	Methods to select participants	8.5 (1.6)
	Allocation strategy in controlled trials	8.3 (1.8)
	Definition of the key concepts e.g. Medical error, Adverse Drug Event	8.2 (2.1)
	Focus of the researchers in case of qualitative concepts	8.0 (1.8)
	Entry criteria	8.0 (1.9)
	Description of the study flow	7.7 (2.0)
	Sample size calculation in controlled trials	7.6 (2.3)
	Start and end dates of the study	7.6 (2.2)
	Date of intervention(s)	7.3 (2.5)
	Theory on which the study is based (e.g. the user acceptance model that guided a quantitative survey)	6.9 (2.5)
	Biases following from the chosen study design	6.8 (2.6)
	Motivation for the study design	6.3 (3.0)
Methods-data collection (7.8)	Methods used per outcome measure	8.8 (1.4)
	Retrospective or prospective data collection	8.6 (1.6)
	Validity of the measurement (e.g. use of a validated questionnaire)	8.3 (1.5)
	Blinding of observer and participants	8.1 (1.9)
	Number and type of interviews	8.0 (1.8)
	Type and duration of observations	8.0 (1.8)
	Details about new measurement tools	7.7 (2.2)
	Location and setting where data is collected	7.7 (2.3)
	Full disclosure of new measurement tools in appendix	6.8 (2.8)
	Professional background of the interviewer	6.2 (2.7)
Methods-data analyses (7.7)	Analysis methods for qualitative data	8.7 (1.3)
	Statistical techniques for quantitative data	8.7 (1.5)
	Kind of triangulation used	7.4 (2.0)
	Awareness of any analysis bias	7.2 (2.6)
	Analysis software used	6.5 (2.7)

Table 1 (continued)

Results (8.1)	Basic numbers of the study (e.g. no. of observations, response rate etc)	8.9 (1.5)
	Quantitative data in tables and figures	8.6 (1.2)
	Most important results in the text	8.6 (1.6)
	Sufficient data for all outcome measures	8.6 (1.6)
	Baseline demographic data / characteristics of participants	8.3 (1.7)
	Special notice to any unexpected striking result	8.3 (1.6)
	Any unintended side effect (positive or negative) of the system	8.1 (1.8)
	Absolute numbers and not just relative numbers	7.9 (2.1)
	Characteristics and qualities of the participants in qualitative studies	7.8 (2.0)
	Influence of unexpected events on the study findings	7.8 (2.0)
	Number and type of drop outs	7.7 (2.0)
	Quotes to illustrate any major qualitative points	7.6 (1.9)
Discussion (8.3)	Interpret the data and an answer to the study question	9.5 (0.9)
	Strong and weak points of the study	9.0 (1.2)
	Meaning/implications of the study	8.8 (1.4)
	New insight from this study	8.7 (1.3)
	Generalizability/ applicability of the study results	8.5 (1.7)
	Discuss any biases	8.4 (1.7)
	What is novel compared to other studies	8.3 (1.6)
	Reasons for disagreement with other studies	8.0 (1.8)
	Critically discuss the methods used	8.0 (2.1)
	Agreement of findings with other studies	7.8 (1.9)
	Comparability of the setting of other studies	7.3 (2.2)
	New future research questions	7.3 (2.3)
Conclusion (7.7)	Impact of the findings	8.4 (2.1)
	Summarize the findings	8.3 (2.6)
	Relation of the findings to the big picture	7.7 (2.1)
	Recommendations of the authors	7.4 (2.4)
	Future research to be done	6.8 (2.6)
References should be included according to the conference guidelines		8.9 (1.5)
Acknowledge any financial or other support		8.0 (2.2)
Financial or other interests which may influence the design or interpretation of the results		7.6 (2.3)
An appendix can be used to describe any supporting material		6.6 (2.7)
Authors' contributions		5.1 (3.1)

Discussion

In this study we used opinions from key stakeholders to develop a ranked list of reporting items for health informatics evaluation studies. Rather than presenting a rigid list of items to report in a conference paper, the prioritization framework of "Mini STARE-HI" assists authors in meeting the principles of the STARE-HI guideline within the constraints of a conference paper, and related to their study topic.

We were somewhat surprised by the low mean score (5.0) for "Formal permission and ethical concern" in the introduction section of a paper. In medical research formal approval of a study by an ethics committee or Internal Review Board is mandatory. Based on the premise that evaluation of health informatics interventions is ethically imperative (as stated in [1]), we should be careful that all participants in such studies are properly protected. This is clearly an issue that requires a wider discussion in the health informatics community, in particular since about an equal number of our respondents found this item either unnecessary (6 scored 0) or essential (8 scored 10).

We asked the respondents to score the items with the common limitation of a 5-6 pages conference paper such as MIE, Medinfo and AMIA in mind. Conference papers and abstracts for medical conferences are often even more restrictive in space (250 to 300 words). As the basic principle of Mini-STARE-HI is to prioritize items to report instead of urging what should be or should not be reported we believe these guidelines are also applicable to health informatics evaluation studies presented as the more restrictive short medical conference abstracts. Similar methods as applied in our study were used to develop comparable guidelines for RCT abstracts based on CONSORT [7]

and for observational study conference abstracts [8]. Our response rate of 63% was comparable to [7].

A weakness of our study is that we only sent out the questionnaire once. We did not give feedback to the participants and did not ask for a potential revision of their position as is commonly done in Delphi studies.

For our ranking purpose, we computed the mean of the scores of the respondents. In principle our measurement scale is of ordinal type and medians and percentiles are the most appropriate way to represent the characteristics of the underlying distribution. Ranking on medians, however is more problematic, since the median can only take the integer values assigned to the response categories. Since we have 11 response categories, the response categories approach an interval scale. Hence we considered taking means as a good alternative for ranking purposes.

We plan to measure the quality of health informatics evaluation conference papers published in the past. Authors, reviewers and editors of health informatics evaluation papers are encouraged to use the results of this study to improve the quality of conference papers. In the future, we will monitor the effect of (Mini) STARE-HI on the publications as some studies (i.e. [9]) show an increase of publication quality after the publication of similar reporting guidelines.

Conclusion

It has been possible to produce a ranking of reporting items from STARE-HI according to their prioritized relevance for inclusion in space-limited conference papers. Only a few items were considered to be (nearly) essential for inclusion in a conference paper, some of the items from STARE-HI that add credibility to full paper publications were considered of less relevance to be included in a conference paper on a health informatics evaluation study and can be left out. Which of the other items to select to be included in a report is the responsibility of the authors, but the ranking that resulted from our study will help them to make an informed decision.

We believe that by guiding authors in prioritizing what information is important to report within the given constraints of a conference paper, quality and utility of such publications can be improved.

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Formatively evaluating the importance of different aspects of an electronic blood transfusion system from the end users' point of view: a questionnaire study

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Abstract

Blood transfusion is a process in which potential errors may result in serious adverse events to patients. To help improve the safety and efficiency of the blood transfusion process an electronic clinical transfusion management system is being piloted by NHS Connecting for Health. Evaluation of the implementation is being carried out in parallel. One component of the evaluation project aims to assess the importance placed in the various potential benefits of this new system by patients and healthcare workers. A questionnaire was generated and completed by healthcare workers and patients. Results indicate respondents viewing all factors as at least "important". "System" factors were deemed most important. Overall, clinical workers expressed the lowest importance to new process factors. Ultimately these results will be measured against final satisfaction with the system to assess 'fit' between perceived importance and satisfaction to guide areas for attention and resource allocation.

Keywords:

Blood transfusion, Value theory, Evaluation.

Introduction

Blood transfusion is the transference of blood or any blood products from one person to another. In many instances such as major trauma of post surgical operations this process can be life saving. It is also essential in treating certain chronic diseases which cause anemia.

A fundamental factor in safe blood transfusions is the compatibility between the transfused blood and that of the recipient. This compatibility is based on blood groupings. There are 30 major blood groups, among which the ABO and Rh systems are most significant. If incompatible blood is transfused to a patient the reactions may vary from a simple allergic reaction to severe hemolysis.

Cross match testing is used to ensure the compatibility of blood products to the recipient. In this test red blood cells of the donated blood are tested against the plasma of the recipient; if no agglutination occurs, it means that the product and the patient are compatible. Although rigorous regulations exist and cross match testing is performed prior to each transfusion, any mistakes during the transfer of the blood unit from the blood bank to bedside and then transfusion may result in fatal errors. Although this process appears deceptively simple it is composed of 11 stages and 66 steps. To tackle this potential problem a detailed procedure utilizing electronic technology – the Electronic Clinical Transfusion Management System (ECTMS) - has been defined by the National Patient Safety Agency (NPSA) in conjunction with the National Blood Transfusion Committee (NBTC) and the Serious Hazards of Transfusion (SHOT) to ensure the transfusion of right blood to right patient at bedside.

Traditionally this process was performed manually by two nurses. As blood transfusion is mostly required for more critical patients in high traffic wards, a new system would prove highly beneficial by reducing the number of staff required for this process, increasing the accuracy of this procedure and reducing the overall time spent carrying out the steps.

The ECTMS has been designed to improve this process by tracking the blood product through from arrival to blood lab to transfusion of the right blood to the right patient. After the pioneering implementation of this system at the Oxford Radcliffe Hospital, the Mayday Healthcare NHS Trust, South London, is the second site of implementation of this system and is the first site to integrate Radio Frequency Identification (RFID) technology into this process. One of the biggest problems in health care is the failure of uptake of new technologies which have been successfully implemented in other industries. To help document and prevent such problems in the Mayday project, the Centre for Health Informatics at City University, London, has been commissioned to perform a formative and summative evaluation of the implementation.

As the evaluation commenced before the "go live" of this system, the evaluation team had the opportunity to measure the perceived importance of factors in the new process before undertaking evaluation of opinions influenced by the bias of experience with the live system.

Based on definitions from Rokeach, Feather and Brown [1-3], values can be described as enduring principles with which people use to guide object evaluation and attitude formation.

Values are the main independent variables in the study of human attitude and behavior. User attitude and behavior are key factors in the acceptability of a new system which will lead to increased uptake and effectiveness. Rokeach classifies values into two groups, terminal and instrumental. Terminal values are those which are the end-state that one can strive for and in most cases are inaccessible to achieve. Instrumental values are single preferable modes of conduct, or means of achieving terminal values. The Johonson definition [4] includes a usability factor. According to this definition we attempted to include only instrumental values in this survey as both achievability and usability were the key factors for this evaluation.

As this evaluation was carried out within a formative framework, the goal of researchers in this phase of study was to ensure that the future users of system had the most realistic view of it. Pre-existing low expectations will result in unacceptability of the system. On the other hand extreme high expectations for the system will result in risk of future dissatisfaction.

Methods

Initially a literature review was performed to identify various values of electronic blood transfusion system or similar electronic management systems in health care [5].

In a brain storming session the obtained list of variables was discussed and related terminologies were merged. Finally, agreed variables were classified into four main categories: System, implementation, technical support and outcome. Detailed list of questions are presented in Table 1. Questions were adapted from the expected benefits outlined by the Mayday Project Initiation Document (PID), the updated DeLone and McLean model of Information System success [6].

A list of job roles related to blood transfusion was prepared. This list consisted of clinical staff (doctors and nurses), paraclinical staff (laboratory technicians and phlebotomists), IT technicians, porters and patients. A matrix of relativity between the values for blood transfusion management systems and the above roles was generated. The respondents were gathered via pseudo-proportionate opportunistic sampling.

According to King and Epstein a rating scale can be as reliable as a ranking scale [7]; to measure perceived importance of generated values a questionnaire was created using Likert-type scaling.

Table 1 – List of questions in value measurement questionnaire

Question Group	Question
System Specifications	The ability to track products across the hospital in real time
	Improving product information due to electronic storage and delivery of information
	The system is easy to use
	The system is fast
	The system is responsive
	The equipment is durable and hard wearing
	The system is flexible and is able to absorb any changes in processes
	The system is secure from unauthorized access
	Compliance with standards and legislation
	Data recovery from error e.g. if there is a problem with the power supply
Implementation	Involving patients in the ordering process
	Involving patients in the checking process
	The requirement for adequate training
	Terminals and equipment are readily available to use
Technical Support	The implementation of a formalized change management plan including training on the new system
	Improved system auditing and control
	If there's a problem with the system, there is immediate support
	Availability of online help
	Availability of back up devices in case of device failure
Outcome	Reducing the number of blood samples rejected by the lab
	Time savings for staff involved in blood transfusions via the automation of processes
	Decreasing the number of manual labor intensive systems

Table 1 (continued)

Question Group	Question
Outcome (Continued)	Having guided steps in any given process involved with blood transfusion
	Improving access to patient transfusion history and any special requirements
	Patient information is accurate and complete at the time of enquiry due to quick and easy information updating
	Providing early alerts to blood labs for product requests and special product requirements
	The system is reliable and does not experience substantial "down time"
	Removing paper-based processes and providing information electronically
	Improving the wristband technology to assist the checking process

Based on the recommendation from Kahle and Kennedy [8], a zero to positive rating model was chosen for this value survey. To prevent the middle point effect being interpreted as a neutral point, we chose a six item scale according to recommendation from Fowler as shown in Table 2.

Table 2 – Classification of Likert-type response used in this questionnaire

Importance level	Description
1	Not important
2	Not so important
3	Slightly important
4	Important
5	Very important
6	Extremely important

Demographic questions concerning and age and gender were included for further classification of responders.

Regarding the internal validity of this questionnaire, a review of the literature was performed to ensure that all proposed elements about importance of such a system were covered. A semi-structured questionnaire was also carried out to give the responders the opportunity to express other values which were not included in the questionnaire. To verify external validity the same study should be performed in other sites to check if similar results will be obtained.

A paper-based questionnaire was designed and completed during individual interview sessions with respondents.

For checking the reliability of information obtained, a random sample of 10% of responses was checked by another member of team before data analysis.

All recruitment was carried out at the Mayday Healthcare NHS Trust.

Results

SPSS 16 was used to analyze data obtained in this study. A pre-analysis data preparation process was performed for further validation of data.

Outlier Control

This study included 29 variables. Two methods of multivariate outlier control were used; if any response failed in both methods it was excluded from final analysis. The first method used was Mahalanobis Distance which evaluates the distance of each case from centroid of the remaining cases. Mahalanobis Distance Test was performed on the 29 questionnaire items. The maximum residual statistic was 35.673. The related value in table of Chi Square (degrees of freedom = 28) and P value of 0.05 is 41.34. The second method used was Cook's Distance. In this test one of the records had the value of 3.7 and as this value was more than 1 it was considered to be an outlier and excluded from final analysis (see Figure 1).

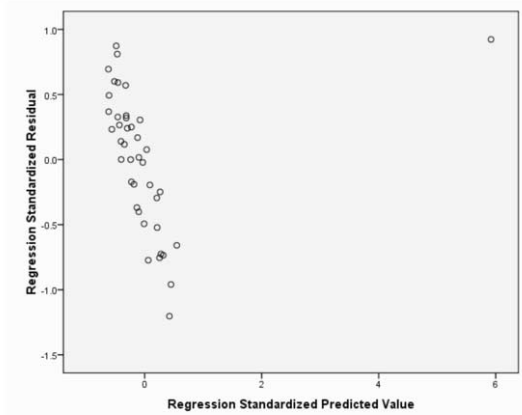

Figure 1– Distribution of responses based on residual and predicted values

After deleting the single outlier record, the distribution of respondents based on their role was presented in Table 3.

Table 3 – Frequency of participants according t role-based classification

Respondent Group	Frequency of respondents
Clinical Staff	45 (54.22%)
Para-clinical Staff	9 (10.84%)
Porters	9 (10.84%)
Patients	20 (24.10%)

Reliability

This is the first time that a value questionnaire has been implemented in this field. To validate this questionnaire the reliability of the items were evaluated using Cronbach's alpha test shown in Table 4.

In the next step, the mean value of responses for each category of questions was calculated. A Kolmogorov-Smirnov test showed normal distribution of these calculated mean values. Also there was a high internal consistency between these grouped variables, with Cronbach's alpha equal to 0.864.

Table 4 – Reliability test results for value questionnaire

Values	Cronbach's alpha
System	0.906
Implementation	0.714
Support	0.846
Outcome	0.816

The overall results obtained for level of importance in each aspect of the system is presented in Table 5.

Table 5 – Descriptive analysis of mean of value in each aspect of system

Mean of Values	Minimum	Maximum	Mean	Std. Dev
System	2.90	6.00	4.95	0.91
Implementation	2.50	6.00	4.73	0.84
Support	1.20	6.00	4.56	1.03
Outcome	3.00	6.00	4.55	0.72

Comparing the results between the respondent role groupings by using ANOVA analysis showed significant difference among the mentioned groups as presented in Table 6.

Table 6 – Comparison of results between the respondent groups

Values	F	P Value	Eta Squared
System	13.18	0.000	0.34
Implementation	2.54	0.062	0.09
Support	3.61	0.033	0.11
Outcome	3.28	0.044	0.10

Post hoc tests showed significant difference in clinical staff responses compared to answers from porters and patients in importance of the system. Clinical staff gave overall lower scores for importance in the survey items. The effect size test showed this was a large effect for "system" values and medium effect for the rest of the items according to the Cohen classification.

Most of the people involved in blood transfusion process at the Mayday Hospital were female. In our survey 8 of participants did not respond to the question about gender but a similar pattern was found in the respondents presented in Figure 2 which demonstrates proportionate sampling based on gender.

There was a significant difference between the responses from two gender groups on "system" values with t (73) = 3.702 and P = 0.000, with lower average by females.

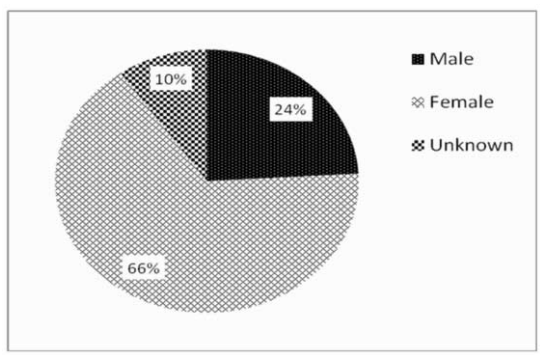

Figure 2– Distribution of responses based on gender

The other demographic factor that was used to classify the participants was age. We discretized the participants by age based on quartiles in four buckets as shown in Figure 3.

A one way ANOVA test showed a significant difference among the mentioned groups in the "outcome" category as presented in Table 7.

Post hoc analysis was not possible because of limitations in sample size.

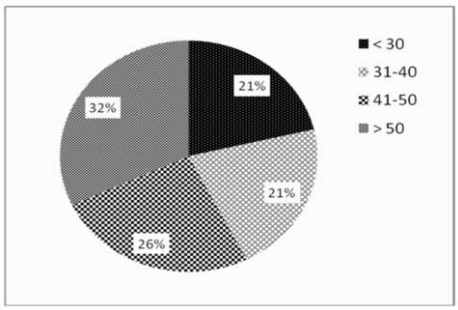

Figure 3– Distribution of responses based on age groups

The effect size test showed a large effect in "support" and "outcome" values and a medium effect in the rest of the items according to the Cohen classification.

Table 7 – Comparison of results between the age groups

Values	F	P Value	Eta Squared
System	2.13	0.110	0.13
Implementation	2.15	0.107	0.13
Support	1.81	0.170	0.17
Outcome	2.98	0.049	0.26

Discussion

The results presented appear to express a relatively high level of importance placed in all aspects of a potential blood transfusion management system by end users. The highest importance was given to "system" values and the lowest to "outcome". This implies that the end users it is important for this system to be more of a process facilitating tool rather than something to produce effective final outcomes in blood transfusion.

There was a significant difference in importance placed in different factors between the clinical staff compared to porters and patients. Clinical staff expressed lower importance in all aspects of the system. Some of these differences might be explained by the type and amount of involvement in the process of blood transfusion. For example, clinical staff are more directly involved at the point of transfusion and may rate their own self-efficacy in the process comparatively highly, thus additional technology as superfluous. It may be a factor that clinical staff see additional technology as an unnecessary complication in a job they consider as fairly routine.

For most factors, males and females have similar views, but males placed higher importance in the system itself. Different age groups have generally no significantly different views but outcomes were considered more important in respondents over 50 years of age.

Conclusion

Although this was the first time that value-based model was applied to a blood transfusion management system, the designed questionnaire appears valid and provided statistically reliable results. All four categories relating to the new system were rated as at least "important" on average, with "system" variables rated most important overall.

According to value theory, the outcomes of this importance survey are related to perceived effectiveness of the system. Disproportionately high expectations may result in dissatisfaction with the system. This is a subject for the next phase of evaluation, to be investigated at the end of the project.

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Towards a National Health Information System Evaluation

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Abstract

Most EU Member States have a documented policy on eHealth. Documented follow-up and evaluation strategies for assessing whether national level systems have reached their set aims and outcomes are, however, rare. Methodologies for large scale information system assessment and evaluation are poorly established. This article describes the approach used to generate the Finnish National Health Information System (NHIS) evaluation plan. The core elements of the plan are illustrated, discussing also challenges and solutions in implementation. The article is based on NHIS evaluation planning project [15] and its presentation in the MIE workshop in Sarajevo in 2009 [16], where core issues and challenges of large-scale evaluations were discussed using the Finnish NHIS evaluation plan as a frame of reference.The Finnish plan offers other countries tools with which to assess their own plans and generate national methodologies for NHIS evaluation.

Keywords:

Medical informatics, eHealth policy, Program evaluation, Evaluation methodology

Introduction

By the end of 2006, 25 out of 27 EU member states and the four other countries active in the i2010 initiative of the EC, were identified as having a documented government level policy on eHealth [1]. In Finland, a decade of implementation activities of the eHealth strategy culminated in the publication of the Finnish eHealth Roadmap in 2007 [3]. Permanent legislations introduced in 2007 on electronic processing of health and social care client data and on ePrescribing, were a major step in the implementation of the Roadmap.

The most common aims for EU eHealth policies are reforming the health care system, improving its performance for more efficiency and quality of care, promoting quality of life and citizen centeredness in care, better data for management of the system and better communication among stakeholders. [1].

In contrast to the vigorous development of national health-IT programs, surprisingly few national level plans and actions were found in a rapid literature review that documented the steps taken for follow up and evaluation of these programs. [2]. Among EU Member States, only the UK was found to have launched national level evaluation [2].

In Finland, the legislation of 2007 stipulated that a National electronic Health Information System (KanTa) [20] is to be built in Finland. The Social Affairs and Health Committee of the Parliament required an action to *monitor and assess the implementation of national eHealth services with a view to providing timely support to the different actors involved.* The project described in this paper is premised on the given requirement. An evaluation planning project (KaTRI) was launched in November 2008 as a joint venture between the Ministry of Social Affairs and Health (MoH) and the National Institute for Health and Welfare (THL). The KaTRI-project set out to draft a plan on how to monitor and assess the implementation of the NHIS (KanTa) taking into account the Committee's requirement. Rather than producing a detailed evaluation plan, the idea was to lay the groundwork for research collaboration to generate knowledge that is mutually beneficial to the government and all parties and that could support success of the construction work of the NHIS.

Evaluation Materials and Methods

In order to define the objects, objectives, questions and methodologies for the NHIS evaluation, three preparatory strands of work were undertaken by the core KaTRI-project team consisting of the authors:

1. A selective literature review of international experiences on evaluation of large scale systems
2. Content analysis of documents describing the NHIS to be implemented in Finland.
3. Content analysis of the bills of ePrescription and eArchiving legislation, which set official objectives, intended outcomes and requirements for the system.

Results of the eHealth ERA project (Towards the Establishement of an eHealth European Research Area) [1] together with a more globally oriented review of the adoption of health in-

formation technology [21] confirmed the leading role of a handful of countries. Due to this fact and our limited project resources, the literature review focused on the experiences of the UK [4], Canada and Australia [5-7] using materials available through official web sites. The analysis focused on objects and objectives of evaluation, methodologies and organisation of evaluation.

Content analysis of documents describing the NHIS and its elements focused on questions depicted in Table 1. Content analysis of the documents stating objectives and intended outcomes of the NHIS was conducted using a qualitative data analysis programme AtlasTI. Open coding of the data was grounded on the data, axial coding was done by using elements from the ICT-enhanced service change model [10] and elements of the IS success model [13] as a conceptual framework to group the codes. This approach provided 10 dimensions for evaluation. These are depicted in Table 2.

The results were fed to eight working groups (WGs), formed by extending an open invitation to end user organizations, research and industry, as well as organizations representing patients and lay people. Leading scientists on Health IT from Universities of Oulu, Tampere and Turku were appointed to lead each group: Prof. Pirkko Nykänen from University of Tampere led the NHIS development and requirements assessment teams, Dr. Eija Karsten from Åbo Akademi led the implementation team, Prof. Reima Suomi from Turku School of Economics led the process change and cost-benefits -teams, Dr. Persephone Doupi from the National Institute for Health and Welfare led the quality evaluation team, and Dr. Ilkka Winblad from University of Oulu led the health benefits assessment team. Dr Hannele Hyppönen from the National Institute for Health and Welfare coordinated and collated the work.

The task of each WG was to refine the evaluation outlines, the core evaluation questions and methodologies identified in the three preliminary studies listed above, taking into account the Committee requirement. The reports of the WGs were then collated into the NHIS evaluation methodology. The Steering Group for the work was led by the Ministry of Social Affairs and Health, and consisted of representatives of all key stakeholders.

Results

Review of evaluation methodologies for large-scale health information systems

The elements included in NHIS systems vary, but all are build around an Electronic Health Record. Evaluations have focussed on benefits to healthcare access, quality and productivity; patient safety; user satisfaction, usability and acceptability and organisational aspects. The use of multiple methods is emphasised, focusing on combining formative and summative evaluation, and covering the whole roll-out life-cycle (pre-implementation, implementation and post-implementation phase). A useful tool (Delone and McLeans model [13]) for structuring the required pre-post-implementation data was identified through the Canadian documentation. Organizational, cultural and business process elements are out of the tool's scope, and needed to be added. The model also does not cover the planning and implementation phases of an IS. A suitable conceptual model and evaluation methodology was, thus, not found, and had to be generated. National level evaluation also raises challenges for and demands development of large scale methods for data collection [2, 10].

Analysis of the object of evaluation - the NHIS and its functionalities

The National Health Information System in Finland consists of a national EHR (Electronic Health Record) archive and ePrescription centre, with ePrescribing, eArchiving and citizens' eViewing as the main functionalities. The architecture (planned to be functional by 2011) is depicted in Figure 1.

The national EHR archive and ePrescription centre will be maintained by Kela (Social Insurance Institute) and used via different legacy systems in public and private health care organisations and pharmacies over public networks. In order to be operational, the core services require interoperable EHR-systems, various national terminologies and classifications, consent management, certification and registering as well as security services.

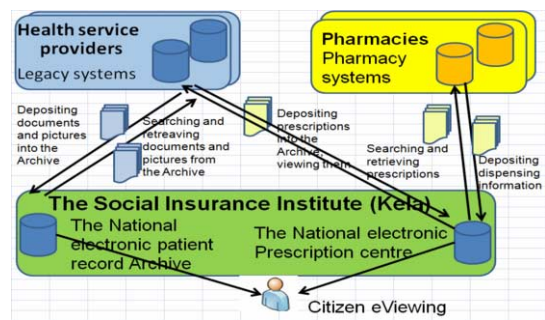

Figure 1- The Finnish NHIS architecture with key actors and their roles

For the purposes of evaluation, a more detailed description of the NHIS system and services was needed. To generate a structured overview of the NHIS and its characteristics, a classification of questions generated in the field of Health Technology Assessment (HTA) [11] was found useful.

The key questions for NHIS are depicted in Table 1. Most elements of the NHIS are "manufactured" by different actors for specific purposes. Together they form the NHIS. Some elements (e.g. legacy systems, variously structured records) exist, but need updates in order to be operational with NHIS. Other elements (e.g. ePrescription centre, national archive, citizens' access) are new, replacing existing ways of transferring and dispensing prescriptions, archiving patient records and accessing the EHR data NHIS evaluation is not a question of comparing a paper-based system to a fully electronic NHIS. The setting is much more complicated, consisting of comparison of combination of local and regional IS systems and services in different phases of transition towards the NHIS.

Table 1- HTA-drawn questions [11] for defining the NHIS as an object of evaluation

Nr	Question (EUnetHTA question ID nr in brackets)
1	Who manufactures technology (A0019)?
2	What are the technical and functional characteristics of technology (B0001)?
3	Are there any special features relevant to this technology (B0006)?
4	For what purpose (Why) is technology used (B0002)?
5	What are the current "tools" used for this purpose (A0011)?
6	Do other evidence-based alternatives exist? If so, what (A0014)?
7	Who are the users of the technology and where is it utilized (context of use) (B0004-5)?
8	How much is the technology being used, are there any restrictions on the use of technology (A0009, C0004-5)?
9	Are there variations in use across countries/ regions /settings (A0010)?
10	How many people belong to the specific target group (A0007)?
11	What is the phase of technology (design, testing, pilot/experimental, diffusion, routine use), is it a new use for an existing technology (B0003, A0015, C0003?
12	What material investments, equipment and special premises are needed to use the technology (B0007-9)?
13	What kind of records/registers are needed to monitor the use of technology? (B0010-11)?
14	What kind of training is needed for the personnel using or maintaining the technology (B0012-13)?
15	What kind of training is needed for the patients, their families and for the general public (B0014-15)?
16	Are there published guidelines how the condition should be managed (A0012)?
17	Has the technology been included/ excluded in the benefit basket of any country? Are there differences in coverage across countries (A0017-18)?
18	Does the technology need a license or certification (C0001)?

Analysis of the objectives of the NHIS/ domains of evaluation based on the text of the Finnish bills

The bills on eArchive and ePrescription stated the official objectives and anticipated impacts of the NHIS architecture and related services. The relative importance of the generated dimensions was estimated by calculating frequencies of dimension-specific key words in the bills. Several important observations can be made from Table 2. The relative importance of meeting of the requirements set for the eArchive, followed by improvements of the service processes due to ePrescribing became evident. There was a strikingly low frequency of statements related to health impacts of ePrescribing and eArchive. This may be due to health impacts being quite far in the impacts-hierarchy (many of category 1-5 impacts need to be realised before health impacts become visible). Health impacts also need time to mature and are dependent on a multitude of other factors. The seemingly low expectations of cost-benefits of ePrescribing may be due to overlapping with category 4 objectives.

Table 2 - Dimensions of evaluation and frequency of dimension specific statements in the Finnish ePrescribing and eArchive bills

NHIS Objectives => dimensions of evaluation (keywords in brackets)	ePresc.	eArchive
1. Quality of development process (process requirements, actor roles)	14	35
2. Meeting the set requirements (requirement, interoperability, secuirty, usability, reliability etc.)	42	124
3. Successful implementation (training, procurement, change management, implementation, support system)	12	11
4. Improvements in service processes (activity, processes, practices etc.)	57	31
5. Quality improvements (information quality, service quality)	24	25
6. Positive health impacts (health, welfare)	3	3
7. Cost-benefits (economy, costs, savings, productivity, efficiency)	8	31
8. Secondary impacts (secondary beneficiaries e.g. state authorities, supervisors, researchers)	18	11
9. NSIS-development boost (National Social Information System development, Social services)	0	48
10. Future service models (future)	4	3

The analysis showed the importance of constructive or formative data from the key stakeholders' viewpoints to be used to inform the development of the systems (dimension 1), especially for eArchiving, where development started later than that of the ePrescribing system. However, the relative importance of objectives related to implementation and diffusion for both the eArchive and ePrescription was strikingly low. This is in contrast to the requirement of the Social Affairs and Health Committee of the Parliament to monitor and assess the implementation of national eHealth services with a view to providing timely support to the different actors involved.

Generating a comprehensive evaluation plan

Figure 2 illustrates the proposed evaluation activities versus the evaluation studies that have actually been launched thus far. The evaluation planning project KaTRI suggested the evaluation to be organised into three main projects, targeting different phases of the NHIS system life cycle: The development support project (Project 1) should focus on providing information through formative assessment of NHIS project activities during the NHIS construction phase, and through assessing the system against set requirements in the testing phase. The implementation support project (Project 2) would use formative assessment methods and focus on support for the service provides' during implementation. The diffusion and impacts follow-up project (Project 3) would focus on providing information

mainly for the national decision makers on diffusion of the system and meeting of its objectives using primarily questionnaires and register data. For each phase a list of key evaluation questions and suggestions for data collection methods were drafted.

A coordinated programme funding to cover the key projects was seen as an ideal way of organizing the evaluation. However, this type of funding mechanism was not available in Finland. Three consortia (for formative assessment, assessment of implementation and impact assessment) have been collaborating and seeking separate funding. Projects 1 and 2 have not received funding so far in spite of the rhetoric and evidence [10; 14] on importance of this work. Two studies in project 3 have started (study 1 and study 2).

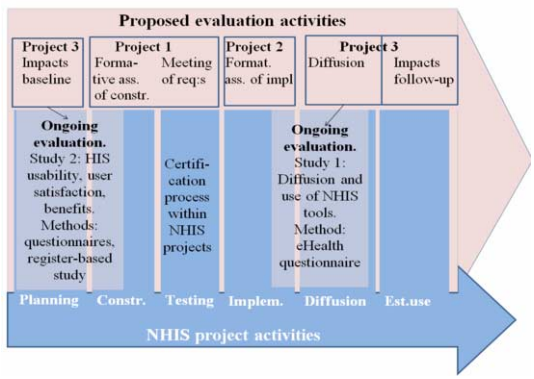

Figure 2- Evaluation framework and ongoing projects in different phases of NHIS implementation.

The diffusion study (Study 1 in Figure 2) focuses on questions in Table 1 (specific focus on questions 4, 5, 7, 8, 9, 11, 12, 13, 14) and is funded by the Ministry of Health and Social Affairs. It is a questionnaire-based study; aiming to map the state of the art of Information Systems used in health care at regular intervals to see a change from old IS tools and services to the new. The questionnaire is targeted at the health care information officers, and results are targeted for the national decision makers [18].

Study 2 in Figure 2 focuses on collecting baseline information on questions 4-7 in Table 2. Two sub-studies have started as stakeholder collaboration without external funding. The first is a questionnaire-based study for doctors (sample = 12 000), collecting baseline information on usability of current HIS and their impacts on service processes, quality, efficiency and health. The Canadian NHIS evaluation tool based on the Delone and McLean's IS success model [13] together with conceptual tools from a co-construction framework [10] was used to construct an information model for the study. The results are targeted to benefit NHIS project participants and decision makers. The ex-ante study offers concrete information on state-of-the art and user needs related to IS usability, user satisfaction and experienced benefits on service processes, quality, productivity and health. The ex-post study will inform on changes in these. For decision makers the results can be used to clarify short and long term objectives and steer the activities of the NHIS project.

The second sub-study aims at defining register-based indicators for process, quality, productivity and health related change, which can be used to indicate NHIS impacts. The sub-study has performed a small-scale pilot structuring EHR data manually with selected national EHR classifications, which will be implemented in Finland by 2011. The pilot aimed to test the utility of the selected classifications for evaluation purposes. Classifications are part of NHIS semantic interoperability development, and exploited as part of a national register reform which aims to implement an on-line nation-wide register on primary care patient visits directly from EHR data with unified data structures [19].

Discussion and conclusion

The planning project KaTRI was set out to draft a preliminary plan on how to evaluate construction and impacts of NHIS. Work done by other national evaluation efforts was elaborated by combining elements of HTA [11], IS success model [13] and ICT-enhanced change model [10]. The work to operationalize the elements and to develop an information model of the individual measures has been started in the diffusion and indicator -studies. The work generates a solid basis for implementing the recent EU Council conclusions (to follow-up and evaluate the health benefits and cost-effectiveness of different eHealth services, building on accumulated knowledge at EU and national levels) [17]. With the results of this work Finland joins the still small number of EU countries with a documented follow-up and evaluation plan of their national level eHealth programs. The plan offers also other EU countries tools with which to develop their plans and methodologies for NHIS evaluation. The work done offers basic building blocks for a solid conceptual framework and methodology, which covers the entire life cycle of a NHIS development from planning to implementation and impacts evaluation.

There are several risks for realizing the plan produced by the planning project KaTRI, which need to be tackled, starting from the availability of resources for committing the evaluation studies. Currently the Finnish NHIS is under construction and the first ePrescriptions are to be launched soon. Delay of evaluation in relation to NHIS development and implementation increases the risk of being too late for effective feedback. Availability of the required data especially for financial and register-based evaluation, limited possibility for controlled studies and challenges inherent in multidisciplinary work required form yet other challenges. The will to invest in this work can determine the future of the NHIS. In the end, the NHIS will not be defined by its current problems and challenges, but by the way they will be solved.

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Mapping stakeholders for system evaluation - the case of the Electronic Prescription Service in England

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Abstract

This paper discusses the process of identifying stakeholders for the evaluation of health information systems through a map. Defining the multiplicity of stakeholders associated with a new system as well as the nature of their relationships is an important aspect of evaluating any intervention. We report a study of the Electronic Prescription Service (EPS) in primary care in England. We describe the complexity associated with the process of identifying stakeholders and illustrating their dynamic relationships. Reflecting upon our experience of map-making *and* map-using*, we discuss the role of a stakeholder map to generate and communicate knowledge. The EPS stakeholder map – in its variety of possible alternative representations – reveals the complexity of the electronic prescribing scenario and the challenge of its evaluation. Recognising the drawbacks of a static two dimensional representation, we argue that a dynamic use of a stakeholder map and a reflective map-making practice is useful and important for the evaluation of IT programmes in healthcare.*

Keywords:

Information systems, Electronic prescribing, Community pharmacy services, Method, Evaluation studies as topic

Introduction

Health information systems are expected to improve the delivery of healthcare, raise patient satisfaction and support excellent work practices by healthcare professionals. The adoption of any health information system will be dependent upon a number of different stakeholders including the people who are directly or indirectly associated with and affected by it (patients, nurses, doctors, software developers, IT managers, product specialists) and a number of organisations and institutions that frame its adoption and functionality (government departments, regulators, health care institutions, professional bodies, technical service providers) [1-3]. Identifying the multiplicity of stakeholders associated with a new system as well as the nature of their interests and relationships one to another, constitutes an important prerequisite for evaluating any intervention. A powerful means to do this is through the drawing of a map, a visual representation of entities and relationships.

This paper discusses drawing a stakeholder map as part of an evaluation study of the Electronic Prescription Service (EPS) in primary care in England. EPS is the National Health Services (NHS) new system for the electronic transmission of prescriptions. EPS is part of the UK National Programme for IT (NPfIT), which is delivered by the Department of Health agency, Connecting for Health (CfH). One of the main objectives of the EPS is to provide a more efficient and accurate NHS prescription service, able to cope with the issuing, dispensing and reimbursement of "around 1.5 million paper prescriptions" per working day [4]. This service is being delivered over two main releases of software and functionality, and our paper draws upon work investigating the introduction of the Electronic Prescription Service Release 2 (EPS2).

Stakeholders are often identified in accordance with their position relative to a focal system and/or an organisational position. In that way stakeholders may be distinguished, for example, as being either 'internal' or 'external' stakeholders relative to the owner organization [5]. Stakeholder importance may be identified by their power to influence, their legitimacy to make decisions, or their right to make claims (perhaps urgent or arbitrary) that have an immediate impact on the focal system or on other stakeholders [6]. In conventional maps, stakeholders are often depicted as revolving around an organization or system, and to have unidirectional and simple relations with it [5] but not with each other. Pouloudi and Whitley [3], however, argue that identification of stakeholders is a complex and dynamic procedure that requires taking into consideration that stakeholder inter-relationships are important, temporally and spatially bound, interdependent, dynamic and often conflicting. We contribute to this critical approach by discussing the complex nature of stakeholder mapping during the identification of stakeholders in EPS2.

The paper has two aims. First, we explore the complexity associated with the process of identifying different stakeholders and illustrating their dynamic relationships - *map making.* To do so we reflect upon our experience in drawing a stakeholder map as a methodological question. Second, we aim to discuss the benefits and drawbacks that emanate from using the map as an analytical tool - *map using*.

An Introduction to EPS2

At the core of EPS is the electronic transmission of prescription messages from prescribing systems, to a secure server - the 'Spine' - from which the prescription message can be sent to, or called by a dispensing contractor of the patient's choice. The service is being introduced into England over two releases. EPS Release 1 (EPS1) introduced and tested the technical infrastructure, with electronic messages holding copies of prescription content supplementing the traditional paper prescriptions. In EPS2, launched in 2009, the prescription switches to a digitally signed electronic message, offering a potentially paperless prescribing and transmission process. The prescription is transmitted from the prescriber through the Spine enabling the unique identification of patients, and service providers (prescriber and dispenser in this case). Access to the Spine for digital signing of prescriptions is allowed by use of a person specific smartcard, with chip and pin code. Software suppliers for prescribers and dispensers are expected to independently implement EPS2 compliant functionalities. Their systems are then subject to a CfH certification process before they can connect to the Spine. Prior to deployment of EPS2 prescriber systems in different Primary Care Trusts (the purchasers of healthcare for a geographic area), the Secretary of State must authorise the issuing of electronic (paperless) prescriptions and electronic signatures. This is done area by area, making electronic prescriptions legal in England for the first time.

A detailed description of the functioning of EPS compliant systems is outside of the scope of this paper. Information can be found on the CfH website[1].

Methodology

The stakeholder mapping for EPS2 was part of a wider project aimed at the evaluation of the Electronic Prescription Service. The evaluation began while software testing for EPS2 compliant systems was still in progress and EPS1 compliant systems were in use. The technology for EPS2 was not available for use at the start, but key stakeholders were preparing for initial pilots and successive deployments across PCTs in England. The data reported here was therefore based on stakeholders' initial experiences with EPS1 (e.g. feedback from pharmacists) and *expectations* for EPS2, *plans*, *prospected* problems and solutions. The study is based on interviews with a number of different groups and organisations including software suppliers for dispensing and prescribing systems, PCTs, community pharmacies and the Department of Health. Interviews were recorded when possible with participants' consent, and transcripts were used for the analysis. Written field notes were used when recording was not possible.

The map – in its successive cyclical revisions - was used during these interviews as a starting point for discussing roles and relationships of different parties and organisations in the pre-EPS business model, and in the development, adoption and use of EPS. The stakeholder map was (and at the time of writing still is) constantly modified and further refined in order to reflect participants' viewpoints.

Results – Map-Making

Connecting for Health presents the expected benefits of EPS2 in terms of benefits for prescribing staff, dispensing staff, patients and their representatives[2]. Initially these appear as the three primary stakeholders of EPS2 as direct users of the system functionality (Fig 1). Prescribers (Pr) (typically General Practitioners - GPs) use EPS2 compliant systems for issuing prescriptions; patients (or their representatives) (P) use EPS2 systems to nominate the pharmacies where they wish to collect the prescribed medications; dispensers (D) (typically Community Pharmacists) use EPS2 compliant systems to receive the e-prescriptions, and then dispense and label products, record the dispensed medication and transmit the e-prescriptions onward to the reimbursement agency (NHS Prescription Services).

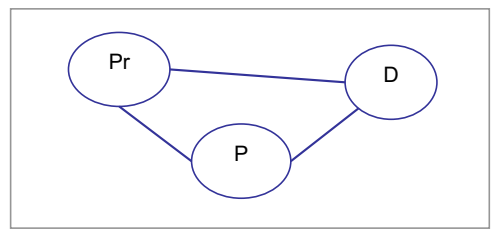

Figure 1- Three stakeholders - direct users of EPS systems

Reading the official documentation of EPS2 [eg. 4], the reimbursement agency could be interpreted as (at least) a secondary stakeholder. Yet, some interviewees thought of the reimbursement agency as one of the main beneficiary of a paperless system on the grounds that EPS2 would reduce manual paper handling and eliminate data entry duplication. Our initial map with the three main users would need to expand and include another perhaps less visible beneficiary in the Prescription Services (PS).

Further analysis of prescribers and dispensers revealed a multiplicity of different parties under these broad headings. For example, among the receivers of prescriptions, are Care Homes, requesting and collecting prescriptions on behalf of their residents. Among the dispensers, together with local small community pharmacies are larger organisations of pharmacy chains under the control of a multinational company, supermarket pharmacies, internet pharmacies, and dispensing appliance contractors. There are also the interesting hybrids – dispensing doctors and prescribing pharmacists. All these stakeholders may adopt EPS2 compliant systems, but differently - depending on their prospects, hopes and fears - and with more or less choice in terms of software or autonomy in organising their work practices around EPS2.

[1] http://www.connectingforhealth.nhs.uk/systemsandservices/eps

[2] http://www.connectingforhealth.nhs.uk/systemsandservices/eps/staff/benefits

Moving from a perspective of system users to the stakeholders involved in the implementation of EPS2, the map extends to the software suppliers (SW) that develop and provide prescribing and dispensing solutions to prescribers (SWpr) and dispensers (SWd) respectively (Fig 2). Developers offer system compliant solutions responding to requirements presented by users, Connecting for Health, professional bodies and Royal Colleges. Prescribing and dispensing software solutions are different markets (and, usually, companies) in England and therefore we chose to present them in the map separately. The relatively simple map in figure 2 is rapidly revealed too restricted to illustrate the number of stakeholders associated with EPS2 and who might be incorporated in an evaluation.

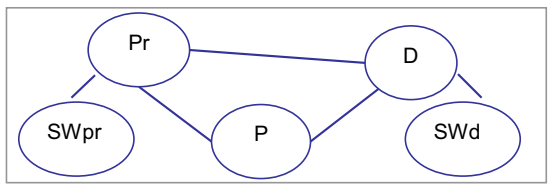

Figure 2- Five stakeholders - implementers and users of EPS systems

The delivery of EPS is a complex partnership between the Department of Health (DH), its agency Connecting for Health (CfH), the regional Strategic Health Authorities, the PCTs and dispensing and prescribing system suppliers. The role of CfH is to define standards, ensure these are adhered to, and to provide the infrastructure in order to support this service. The DH provides funding for community pharmacy to purchase EPS compliant systems (via PCTs) and also an ongoing allowance to pay for the maintenance of the required secure broadband connection. General practices also gain support for purchasing CfH accredited prescribing systems as part of their IT systems. Pharmacies and GP practices as independent contractors, however still make, at least in theory, the ultimate choice of which software to purchase and use.

If we follow financial exchanges, more stakeholders enter the map. Financial exchanges in connection with EPS relate not only to the payment and reimbursement of prescribed medications and appliances, but also to payment and reimbursement for software and services, connection to secure network, possible financial incentives to use the service, potential sale and purchase of prescribing/dispensing data and marketing opportunities for pharmaceutical products/medical services. This indicates the potential of EPS2 to condition important changes in the business of community pharmacies. For instance, the rise of internet pharmacies, or the capture and use of prescribing and dispensing data for research purposes. Indeed, patient data and information governance is a sensitive aspect of EPS2. The design of this system will potentially allow a comprehensive database of drug use (prescribing and dispensing) linkable to patient medical history. This could be incredibly valuable for research purposes and for medicine management, but also potentially subject to abuses and infringement of patient confidentiality. An important stakeholder here may be the Information Commissioner.

Table 1- List of stakeholders (not comprehensive, in alphabetical order)

AG	Aggregators
CP	Community Pharmacies (independent and chain headquarters)
CPst	Community Pharmacy stores (dependent from chain management/headquarters)
CP.pr	Prescribing community pharmacists
DAC	Dispensing Appliances Contractors
D	Dispensers (including CP, DAC, IP, etc.)
DH	Department of Health
DW	Drug and Medication Wholesalers
GP	General practitioners (family doctors)
GPd	Dispensing GP
IMS	IMS Health Pharmaceutical
IP	Internet Pharmacies
IC	Information Commissioner
NPA	The National Pharmacy Association
NPSA	National Patient Safety Agency
NP	Nurse prescribers
P	Patients (and carers)
PCT	Primary Care Trusts
Pr	Prescribers (including GP, NP, etc.)
PSNC	Pharmaceutical Services Negotiating Committee
PS	NHS Prescription Services
RS	Royal Societies
SHA	Strategic Health Authorities
SUS	Secondary Use Service
SW.gp	Software supplier for GP
SW.cp	Software supplier for CP

The above brief description of our attempt in map-making indicates the complexity found in the unfolding of interests that occur in the process of identifying stakeholders and representing their inter-relationships. Table 1 lists some (but not all, given space restrictions) of the stakeholders found to have a role or interest in EPS2 and Figure 3 illustrates examples of their interdependent relationships. The map can support further investigation of transactional, financial, regulatory, or professional relationships. Of course the map is never complete and never an exact illustration of all stakeholders and all their relationships. The drawbacks and the benefits of a map as a tool for analysis in evaluations are discussed below.

Discussion – Map-Using

The stakeholder map is intended to serve multiple purposes. It serves as an effective *communication tool*, used to elicit views and insights from interviewees by visualising presences and relationships. Over time and as it developed the map became a

means to *generate knowledge*. By developing an object which could be shared and discussed between the various stakeholders (and which each would recognise and be able to contribute to), we were making use of the map as 'a boundary object' [7]. Boundary objects are objects which allow the tacit difficult to express knowledge of one community to be expressed and shared by another community [8]. Through readers' different interpretation of the map and through constant discussions, the map's perceived gaps and 'errors' came to the fore, leading to further refinements and expansions, and allowing the interests and perspectives of stakeholders to be captured. This iterative process broadened our understanding of the meaning of EPS to different people and organisations. But to the extent that people differed on who was a stakeholder and how they fitted into the map, the challenge remained as to how to capture these multiple versions of reality.

The strength of a map as a means to *produce* knowledge derives from its three main features: *mobility*, *stability* and *combinability* [9]. The map is a mobile tool in the sense that it can be transferred between different people and organisations crossing boundaries. Using the map's mobility we could communicate our understanding of stakeholders and their relationships among researchers as well as between researchers and participants/stakeholders. The map also embeds information that is perceived as stable (relatively) when the map is transferred between people. In this way, information the map holds can resist distortions and misunderstandings that may emerge in any one place. Finally, the map is combinable because it enables further refinements and developments, inclusion of new stakeholders and new relationships, or a drilling down into stakeholders in more detail, for example into the complex structure of a PCT. Mobility, stability and combinability is what has allowed the map to develop from a simple three-stakeholder version (Figure 1) to the complex 28 stakeholder version (Figure 3).

The map reveals the complexity that surrounds EPS2 and the ways in which different stakeholders interrelate and contribute to it. However, the process of map-making is inevitably a process of selection and omission of stakeholders or relationships. For instance, figure 1 represents the typical flow of a prescription going from prescriber to patient and then to dispenser; however, some pharmacies provide a collection service which means that prescriptions go direct from prescriber to pharmacy, bypassing the patient. This could be considered an exception to the usual scenario – whether (and how) exceptions are represented in the map is an open question. Exceptions, being on the one hand by definition unusual, but on the other, as boundary conditions, are key areas of interest to any analysis. Map making is in other words both an intended and unintended mode of simplification as complexity is synthesised into a comprehensible and sharable picture [10].

A stakeholder map can only illustrate part of the 'whole' picture or one possible picture among many potentially to be drawn. This implies that a map is fundamentally *political* as it prioritises, accentuates and excludes stakeholders and their relationships, and embodies the worldviews of those who take part in its construction. As illustrated, our map started with three basic stakeholders who constituted our initial understanding of the 'pragmatic' view of EPS2. Through research we expanded the map in such a way so as to include additional stakeholders, who remained in the earlier version hidden. And there are many other potential stakeholders and relationships still to be discovered and presented. For that reason we would rather accept, in the spirit of Heisenberg and Schrödinger, that "*Every new attempt to represent the world in a scientific formulation, no matter how detailed and cumulative, will be swallowed up by the world expanding to contain it*" [11]. In that way, a map is not only a means to generate knowledge but it is also a means to hinder and hide it. Furthermore, a static 2 dimensional map in itself does not provide a rich account of

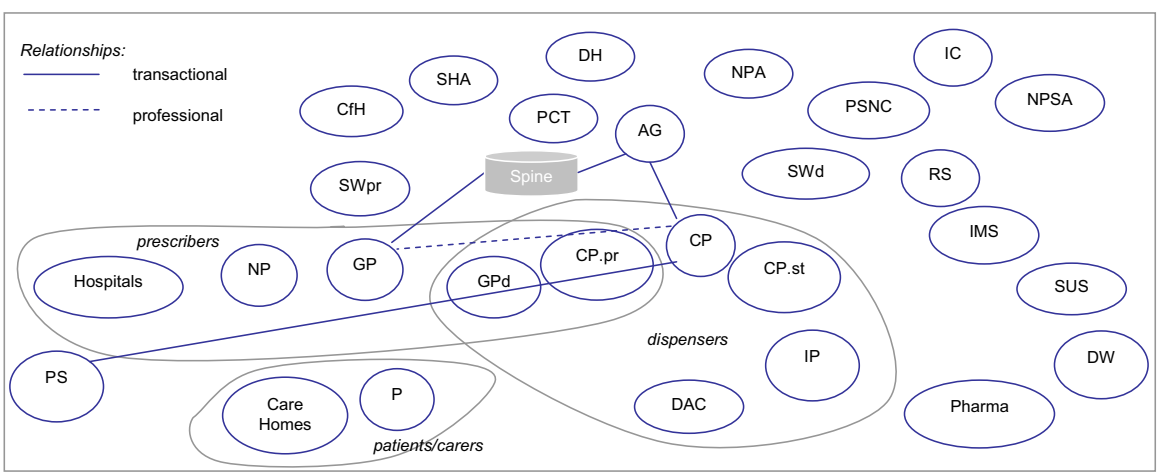

Figure 3- A more complex stakeholder map of EPS2 (a transaction flow of a patient's e-prescription and a professional relationship between general practitioner/prescriber and community pharmacist/dispenser shown as examples.)

the dynamic changing of relationships between stakeholders. Though, through layering of versions or digital animation a map may present or account for the historical development of stakeholder relationships, even if it cannot predict their future dynamics.

Conclusion

This paper discusses the strengths of map-making as a tool as well as the complexities and challenges surrounding a stakeholder map in terms of *map-making* and *map-using*. We present the iterative process of identifying stakeholders in the Electronic Prescription Service and some of the benefits and drawbacks of using a map as a methodological tool for data collection and analysis.

The map shows strongly how implementation and adoption of systems in healthcare takes place in a distributed landscape. In relation to our research topic this implies that electronic transmission of prescriptions does not start with a prescribing authority and end with a dispensing authority. Rather the EPS draws in a great number of stakeholders who mediate between prescribing and dispensing, each of whom has distinctive interests and a role in making this initiative work (or not). Understanding stakeholders and their interests as part of evaluating the adoption of EPS2, ultimately means capturing this distributed network of interests and relations.

Our research has also illustrated the limitations of a map in analysing stakeholders. The map is not an exact representation of the prescribing and the dispensing scenario in all its detail (although when it is taken out of the context of the identification process - it may be interpreted and judged as such). Our map, as a tool to identify stakeholders and their interests, constitutes one among many possible representations of the world of prescribing and dispensing. Cartographers are well aware that maps are an outcome of a reductionist activity that abstracts complexity from reality: "*...mapping allows for an understanding of terrain as only the surface expression of a complex and dynamic imbroglio of social and natural processes*" [12].

As our map-making and map-using research processes continue, we will investigate different variations of the stakeholder map; we will depict, explore, compare and superimpose: stakeholders, boundaries, transactions, flows, movements, and transformations of business models, connected with the introduction of electronic prescribing in primary care in England. We argue that a dynamic use of a stakeholder map, and a reflective map-making practice, has great potential to inform the analysis and evaluation of IT programmes in healthcare and beyond.

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Development and Testing of a Work Measurement Tool to Assess Caregivers' Activities In Residential Aged Care Facilities

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Abstract

The introduction of computerized information systems into health care practices may cause changes to the way health-care workers conduct their routine work activities, such as work flow and the time spend on each activity. To date the available work measurement tools are confined to activities in hospitals and do not cover residential aged care facilities (RACFs). There is little evidence about the effects of technology on caregivers' work practices, including the distribution of time on activities in a RACF. This requires the measurement of caregivers' activities using a valid and reliable measurement tool. The contribution of this research is to develop and test such a tool. The tool was developed based on literature research and validation in two RACFs. The final instrument contains 48 activities that are grouped into seven categories. They include direct care, indirect care, communication, documentation, personal activities, in-transit and others. This measurement tool can be used to measure the changes in caregivers' work activities associated with the introduction of computerized information systems in RACFs, including the efficiency gains of such systems.

Keywords:

Caregiver, Computerized information system, Residential aged care, Work measurement, Work sampling, Work activity.

Introduction

Computerized information systems are increasingly being introduced in Residential Aged Care Facilities (RACFs) with the expectation of improving the efficiency, quality and safety of care to the elderly. These systems range from stand-alone, hand-held technologies to Web-based applications, with some RACFs using a combination of several systems. However, there is limited evidence about the effects of these systems on caregivers' work performance, because the majority of research in this area has been confined to hospital settings [1, 2, 3, 4]. A clear understanding about the effects of health information systems on caregivers' work is necessary in justifying the need for technology in nursing practice [5]. This requires the availability of a measurement tool that can provide valid and reliable assessment results. Such instruments have been developed for assessing health care workers' activities in hospitals [1, 2, 6, 7]. However, many caregivers' activities in RACFs are significantly different from those in hospitals [8] and appropriate measurement tools are not available. The aim of this project is to develop and test a work measurement tool for use in RACFs.

Methods

The work measurement instrument was developed through a three-stage research process;

1. Literature review to understand the research methods of previous authors with similar aims and to identify activities that may be relevant to a RACF.
2. Development of specific categories of activities in a RACF.
3. Validation of the measurement instrument. The following sections describe the research processes.

Developing the categories of caregivers' activities

The first step of this investigation was to identify and classify caregivers' activities in a RACF. Potential activities were identified from the previously published instruments [1, 2, 9]. Nursing activities can be grouped into six categories. They include direct care, documentation, unit related, personal, personal education and faculty/research time. The following definitions of these categories were suggested by Bosman et al.[1].

- 'Direct care' includes all nursing activities directed at the patient and in the vicinity of the patient, such as administration of drugs, endotracheal suctioning, admission/assessment, hygiene, medication, patient mobility, patient/family interaction and transporting a patient.
- 'Documentation' includes all activities that are related to paper-based or electronic documentation, such as registration of fluids and writing hand over reports.
- 'Unit related activities' are those activities related to general maintenance of the unit such as cleaning the room and ordering supplies.

- 'Personal activities' include those activities that are not related to patient care or unit activities, such as meals breaks and personal phone calls.
- 'Personal education' includes activities that are designed to increase the knowledge and skills in nursing practice.
- 'Faculty/research time' is time spent on activities of research and/or the preparation for and supervision of students.

We believe that the first four categories of work activities reflect caregivers' routine tasks in Australian RACFs based on our research experience in these settings. Existing work measurement tools [1, 2, 9] have three main gaps hindering their immediate application in RACFs. These are:

- The naming of the categories of activities does not conform to the convention used in Australia.
- Some terms in the instrument are not relevant to the activities in RACFs.
- Incomplete coverage of caregivers' activities in a RACF. In our experience, oral communication between caregivers, with allied health workers and with the elderly and their relatives, is a common activity undertaken to meet care requirements of the elderly in a RACF. It is also evidently caregivers' preferred means of communication in aged care facilities [10].

Development of specific categories of work activities in a RACF

Two steps were undertaken in the development of specific categories of work activities in a RACF.

Step 1. The categories of work activities in the previous measurement instruments were screened and those considered relevant to a RACF were adapted into our measurement tool.

Step 2. Amendments were made to the adapted categories of nursing activities: some were re-named to comply with the common vocabulary in RACFs in Australia. For example the term 'unit–related activities' was re-named 'non-nursing activities' and 'patient' was re-placed by 'resident'. The resulting work measurement tool contained 25 activities that were grouped in five categories. Nine activities were grouped under the category of direct care, seven activities under oral communication, five under documentation, three under non-nursing and one activity under the category of personal (See Table 1).

Table 1- Caregivers' categories of activities

Category	Work activities
Direct care	Admission/assessment, hygiene/oral care/toileting/shaving, medication preparation/administration, nutrition/feeding
Oral communication	Information about a resident, staff orientation, resident/family interaction
Documentation	Taking records from the storage place, flipping through to identify the correct page
Non-nursing activities/miscellaneous	Supplies check/re-stock, room cleaning/bed-making
Personal	Personal errands/off unit chores/meal breaks

Validating the content of the measurement instrument in a RACF

A three-step approach was undertaken to test the preliminary five classifications of work activities with the aim to determine their validity and accuracy for measuring work activities in RACFs.

Step 1. The face value of the measurement instrument was validated with the Residential Service Manager (RSM) of a RACF. The RSM agreed with the classification of activities. She suggested minor changes in the nursing activities, for example, the addition of 'entero-feeding system' under the activity of 'nutrition' in the category of direct care activities.

Step 2. A further refinement of the tool was carried out with two Registered Nurses (RNs), one Endorsed Enrolled Nurse (EEN) and five Personal Carers (PCs).

Step 3. The measurement tool was further validated in a pilot study at a RACF through a work sampling study using the tool to record caregivers' activities. The observation lasted 3.5 hours per day for three days in a week. A tabular data collection tool was used to collect caregivers' observed activities for three weeks (See Table 2).

Table 2 - Data collection tool for the observed activities

Date_____Day_____Time_____Section of the house_____

Observed work activities					
Participants / **Round of observation**					
1					
2					
Comments					

The instrument contained information about the day and date of observation, the time period and the section of the house under observation. A section for comments allowed the observer to record any significant events that could assist during interpretation of data, for example staff shortages.

Procedures for data collection using the work measurement instrument

Using the developed data collection tool, an observer started each round of observation from a specific point in the facility. Following the same route within the facility, the observer recorded all the observed tasks for each caregiver on every round of observation using a code number allocated to each task. A unique code number was also used to identify each caregiver on the data collection tool. This was necessary for ensuring anonymity of participants and to facilitate longitudinal comparison of caregivers' task time and pattern of work. Caregivers were observed at an interval of 20 minutes. This gave the observer time to rest before starting the next round of observation, thus avoiding errors introduced due to observer fatigue. A caregiver who was missing at the time of observation was denoted by a dash (-). This pilot study led to the clarification and validation of caregivers' activities in a RACF.

Validation of the measurement tool in a second RACF

Validation of the work measurement tool was conducted in another RACF with the aim of further testing the generalisability of the instrument. A focus group discussion was conducted with the RSM, four senior RNs and two EENs. This was followed by a direct observational work sampling study using the modified instrument. Besides agreeing with the five categories of activities in the original work measurement tool, the group recommended the addition of two new categories of activities, 'in-transit' and 'others'. 'In-transit' includes the time caregivers spend between tasks, for example time spent walking to access medication in the store. 'Others' covers all activities that are not included in the identified categories of activities, for example, faxing medication orders.

Inter-rater reliability of observations was tested by two observers who independently observed the same activities. A training session was given by the first author (EM) to an RN with residential aged care work experience. Following the same procedures for work sampling, EM and the RN independently recorded activities of four caregivers for a period of two hours. Comparison of recordings suggest that a minimum agreement of more than 90% was achieved, which was adequate according to Pelletier et al. [9].

Results

Work categories and activities

Inter-rater reliability achieved 93% agreement. The remaining 7% was for the activities initially grouped together, which include 'recreational' and 'active' exercises. Observers agreed that these activities should be recorded separately to achieve accurate recordings.

The structure and content of the work measurement instrument

The initial testing of classifications and activities in the first RACF resulted in the development of a work measurement tool that includes 30 activities that were grouped into five categories. There were eight activities in the category of direct care, seven activities in communication, nine in documentation, five in indirect care and one in personal activities.

The following are the amendments to activities specified in the previous work measurement instruments [1, 2, 9]. The activity of 'palliative care/care for the deceased' was added to the category of direct care activities. 'Family interaction' and 'resident interaction' were recorded as separate activities in the category of communication, as the RSM was interested in the separate time spent on these activities. Four computer related activities were added to the category of documentation. They include; locating the correct window/resident's name, inputting a username and password, typing progress notes/care plans and closing the system. 'Room cleaning' was omitted from indirect care as the activity was not undertaken by caregivers in a RACF.

The results of further validation in the second RACF

Validation of the tool in the second RACF resulted in a measurement instrument with 48 directly observable activities that can be grouped in seven main categories (nine in direct care, 13 in communication, 12 in documentation, 11 in indirect care and the remaining three activities in separate categories of personal, in-transit and others) (See Table 3).

The following amendments were made to the work measurement tool developed in the first RACF. The activity of 'transporting a resident' under the category of direct care was replaced by 'preparing a resident for transfer'. Several activities were added to the category of oral communication, including 'discussion with allied health workers', class training and 'receiving a phone call'. Medication-related documentation was recorded under documentation. Additional activities under indirect care included 'answering to buzzers', 'personal hygiene set-up', 'cleaning up spills' and 'transporting waste/clinical waste'.

Discussion

The purpose of this project was to develop a work measurement tool that can be used in work measurement studies in RACFs. To our knowledge, this work measurement tool is the first of its kind in the setting of a RACF. Our research achieved a higher score of inter-rater reliability (93%) than the recommended level of 90% [9]. This implies that the work measurement tool is implementable in measuring caregivers' activities in a RACF.

Inadequate coverage of caregivers' activities appears to be one of the factors hindering the application of work measurement tools designed for hospitals into RACFs. Through developing and validating the work measurement tool in RACFs, our approach has potential to alleviate this problem and provide a more comprehensive instrument that is applicable in different aged care settings such as nursing homes and aged care facilities in hospitals. The major challenge is getting caregivers to participate in this process of developing a work measurement tool as their time is often limited because of staff shortages in these settings [11].

Table 3 – Caregivers' activities included in the validated instrument

Categories	Work activities
Direct care	All nursing care activities performed in the presence of the resident and/or relative, for example assessments/ sub-sequent assessments, hygiene/oral care/toileting, resident mobility, medication preparation/ administration, assisting with procedures/wound care, specimen collection/urine collection, nutrition/entero-feeding system, preparing a resident for transfer and palliative care/care for the deceased.
Communication	All activities related to oral communication such as sharing information about a resident/de-briefing, discussing with allied health workers, receiving a phone call/making a phone call, staff orientation, on-job training/induction, class training, co-ordination of care/care planning, staff meeting, resident interaction, family interaction.
Documentation	All activities related to paper-based or electronic documentation including taking records from the storage place, flipping through to identify the correct page, reviewing resident information, writing progress notes/charts/forms/care plans, putting records back to filing area, medication documentation, admission documentation, locating the correct window/resident's name , inputting a user name and password.
Indirect care	All activities that are not resident specific for example identifying correct supplies, packing supplies to a trolley, restocking supplies in a residents cupboard, equipment set up, bed making and de-bulking.
Personal	All personal activities unrelated to residents' care such as meal breaks, making telephone calls.
In-transit	Time between tasks
Others	Tasks not included above

In our development of the instrument from those previously formulated for use in hospitals, the categories of work activities increased from five to seven and directly observable work activities increased from 25 to 30 and then to 48. These increases in the classifications and activities are partly due to the differences in caregiver activities in different health care settings including hospitals and RACFs, as described earlier. The increases may also have been caused by the increased attention by caregivers in the second validation group to the rigor of the instrument, motivated by their strong interest in having accurate results about time on their activities. A further reason may be that care practices in different aged care facilities are different. The second RACF that participated in this project is vast in its layout and caregivers found it necessary to measure their time in-transit between tasks, in contrast to their counterparts in the first RACF.

These points suggest the need for the current work measurement instrument to undergo revision before its application in any other long term care facility. Based on our experience with this process, the following suggestions may be useful in modifying the tool.

- Have a clear research objective. The objective is important in determining the activities and classifications to be included in the measurement tool, for the purpose of answering the research questions.
- Understand caregivers' work flow. Aged care facilities may have different work flows including those that are run by the same management group, as was the case in our project. The work flow may have significant implications on activities to be included in the measurement tool. An understanding of the work flow may be achieved through discussion with the facility' managers and the caregivers in different job roles. Their views are necessary in obtaining a deeper understanding of work practices, including the layout of the facility and what may be termed as 'normal' activities in a shift, including their definitions. To confirm the completeness of these activities, it may be necessary to conduct a pilot study using the modified instrument.

Conclusion

To date, there is a lack of reliable and valid work measurement tool that can be used to measure caregivers' activities in a RACF. This project has led to the development of such an instrument. It can be used by researchers to measure how care staff members work and their proportion of time spent on each task in the settings of aged care facilities. This measurement is important in contributing to our understanding about the effects of electronic information systems on nursing practice. As demonstrated in our research, work activities in different RACFs may vary by layout of the facility and also the terms used for various activities in different countries or regions. Therefore, further validation of the work measurement tool is required in any future application of our measurement instrument.

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A Multi-method Approach to Evaluate Health Information Systems

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Abstract

Systematic evaluation of the introduction and impact of health information systems (HIS) is a challenging task. As the implementation is a dynamic process, with diverse issues emerge at various stages of system introduction, it is challenge to weigh the contribution of various factors and differentiate the critical ones. A conceptual framework will be helpful in guiding the evaluation effort; otherwise data collection may not be comprehensive and accurate. This may again lead to inadequate interpretation of the phenomena under study. Based on comprehensive literature research and own practice of evaluating health information systems, the author proposes a multi-method approach that incorporates both quantitative and qualitative measurement and centered around DeLone and McLean Information System Success Model. This approach aims to quantify the performance of HIS and its impact, and provide comprehensive and accurate explanations about the casual relationships of the different factors. This approach will provide decision makers with accurate and actionable information for improving the performance of the introduced HIS.

Keywords:

Evaluation, Health information system, Implementation, DeLone and McLean IS success model, Multiple methods

Introduction

Many healthcare organizations around the world are introducing health information systems (HIS) to improve health care quality and efficiency. To ensure that their HIS will be accepted and used by the intended users and bring in the expected outcomes, the decision makers would wish to fully understand the extent to which the HIS fulfilling its objectives, the strategies, processes and final outcomes of introducing the system, particularly its impact on health care quality and efficiency. Therefore, an important area of health informatics research is to evaluate the processes and outcomes of introducing HIS in health care organizations. Evaluating HIS is a complex issue that has long plagued HIS researchers [1-5]. As different stakeholders have different interest in the evaluation study; the nature and types of questions to be asked can be quite different; health care organizations vary in size, organizational culture, power structure and management; there is no one-size-fits-all solution. Also different issues may emerge at different stages of system introduction; therefore, the evaluation methods and approaches vary significantly. The previous researchers have discussed the challenges in evaluating HIS and raised the problem of lacking a uniform conceptual framework to guide the evaluation research [1,2]. In an effort to conceptualize and conduct a comprehensive investigation to produce thorough and accurate answers about the best strategies, practices and outcomes of HIS introduction, this paper discusses a multi-method approach to evaluating HIS. This is followed by a case study to illustrate how various evaluation methods are integrated in a comprehensive evaluation project that has been undertaking in long-term care facilities in Australia.

End user HIS perspectives

In 1992, the DeLone and McLean Information System Success Model (abbreviated as the D&M IS success model) was developed [6]. This model consists of six interrelated dimensions of success: system quality, information quality, system use, user satisfaction, individual impact and organizational impact. In response to the increasing importance of information services, DeLone and McLone added another dimension - service quality to the quality constructs [7]. To increase the genealizability of the model, they collapsed the two constructs about individual impact and organizational impact into one construct: net benefits. Therefore, the reformulated D&M IS success model is composed of six constructs: (1) system quality, (2) information quality, (3) service quality, (4) user satisfaction, (5) use and (6) net benefits. They believe that use and user satisfaction are determined by information quality, system quality and service quality, besides their mutual influences. Use and user satisfaction determine the final outcome of system introduction – net benefits (see Figure 1).

The D&M IS success model has been widely adopted by many researchers in measuring success of introducing various information systems into organizations. It was used by van der Meijden *et al.* [8] as a conceptual framework to summarize the critical factors that contribute to the success of inpatient clinical information system introductions from 31 empirical studies during the period of 1991 to 2001. This study shows that the majority of variables or attributes the previous researchers used to measure the success of HIS introduction can be successfully assigned to the six dimensions in the D&M IS suc-

cess model. Lehmann et al. adapted the model to qualitatively interpret the critical success factors of a mobile bed management system in a regional hospital in New Zealand [9]. Jen et al. used it to measure a mobile patient safety information system success in Taiwan quantitatively [10].

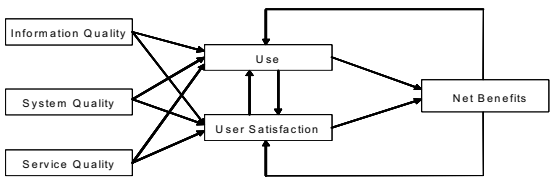

Figure 1- The reformulated DeLone and McLean Information System Success Model

Qualitative requirements

It is recognized that the introduction of HIS involves not only technological systems but also a significant change in culture, politics and power that tie professional groups together in organizations [11]. Organizational change and the implementation of information and communication technology are closely intertwined. It is an innovation and learning process. Therefore, Seddon [11] and DeLone and McLean [7] all recognize that the application of the D&M IS success model to empirical research requires a contextual variance specification of the model. Friedman and Wyatt [12] also emphasize the importance of context for the empirical investigation of the practice of introducing HIS into health care settings. However, the context issue is not addressed in the D&M IS success model. This leads to an inability of the D&M model to interpret the failure cases in the systematic review of the published literature about inpatient clinical information system implementation by van der Meijden *et al.* [8]. To remedy this deficiency, Yusof et al. [5] proposed a new model of human, organization and technology-fit evaluation framework (HOT-fit), which is a combination of D&M IS success model and the IT-Organization Fit Model adapted from Morton [13].

The D&M IS success model describes the relationships between different inputs, process variables and outputs. According to Lee and Lings [14], a model by itself can only describe what happens, but not explain how phenomena relate to each other and why this may be so. Although the proposed HOT-fit model was used successfully to explain what happened, how and why in the implementation of a Fundus Imaging System in a health care setting through qualitative case study approach [5], this mixed model appears to have lost significant potential of each of the original ones as psychometric measurement models. In order to understand this perspective, it is essential for us to understand the basics of psychometric measurement theory.

Psychometric measurement theory

"Measurement is the process of mapping the magnitude of an attribute to a numerical value – to transferring the amount of a quality to a quantity" [14]. As the science of psychological measurement [15], psychometrics is based on the assumption that latent constructs actually exist, although unobservable, they influence some things that we can actually observe [14]. Structural equation modeling is the conventional statistical method used to conduct psychometric analysis to test the causal relationships between the constructs. There are two models in a structural equation model: a structural model and a measurement model [16]. A structural model consists of the unobservable, latent constructs and the theoretical relationships among them, such as the six latent constructs in the D&M IS success model (see Figure 1). For each construct in a structural model, there is a related measurement model, which links the latent construct with a set of observed items. The measurement model consists of the relationships between the observed variables (questionnaire items) and the latent constructs which they measure [16]. For example, questionnaire items can be built to measure each construct, such as 'system quality' in the D&M IS success model. The relationships between the questionnaire items and the latent construct 'system quality' are the interests of the measurement model. Together, the structural and measurement models form a network of constructs and measures.

Psychometrics is widely used to measure knowledge, abilities, attitudes and personality traits. The D&M IS success model is derived from empirical data analysis and has been proved to be a validated psychometric measurement model. Petter and McLean [17] included 52 empirical studies that examined relationships within the IS success model at the individual level of analysis in their meta-analytic assessment of the D&M IS success model. The recent empirical psychometric examination of the D&M IS success model includes Wu and Wang [18], Wang and Liao [19].

The limitation of the HOT-fit model

Come back to the limitations of the HOT-fit model. This model was proposed as a conceptual framework for researchers to incorporate comprehensive dimensions and measures of HIS [5]. The case study of the Fundus Imaging System provides a good example on how to use the HOT-fit model to interpret the complex, interweaved relationships amongst people, organization, processes and technology. However, by this extension of the original D&M IS success model, the causal relationships among the constructs in the D&M model is mixed with the concept of 'fit', which is not a term in psychometrics.

Quantifying the weight of each construct is important, because without rigorous quantification, the magnitude of the impact of each contributing factor to the success of HIS can not be decided. As most healthcare organizations are resource stressed, without adequate information about the weight of each construct, the decision makers would find it challenge to make informed decisions on how to effectively allocate

resources to the much needed area to support HIS implementation.

Lee and Lings [14] suggest that the function of model is to describe, whereas the function of theory is to explain. Ortigueira believes that it is a utopia to think that it is possible to build models with all attributes, properties and characteristics of a specific system [cited by 20]. Roldå and Leal [20] also suggest that it is impossible to obtain a total correspondence between the attributes of the real-world system and the model. Thus the ambitious HOT-fit model is yet to prove its capacity to accurately and thoroughly explain the complex phenomena associated with the introduction of HIS and be validated quantitatively.

Having discussed various evaluation frameworks, their contributions and limitations in guiding HIS evaluation effort, we propose a multi-method approach combining the strength of quantitative evaluation guided by D&M IS success model and supported by other quantitative and qualitative methods.

A multi-method evaluation of HIS

To accurately identify and classify the issues that are critical for the introduction of HIS and explain the observed phenomena thoroughly and accurately, both quantitative and qualitative research methods need to be adopted in HIS evaluation research.

In order to implement the evaluation framework of the D&M IS success model, appropriate measurement items need to be adopted in a self-administered questionnaire to measure each construct. This questionnaire survey can then be implemented to gather end users' responses to each measurement statement.

This strategy of evaluating IS through structured questionnaire survey has a long established tradition in IS research. It is supported by Goodhue, who believes that users are capable of performing the evaluation of the task-technology fit of a particular technology that they have been using [21]. The modified technology acceptance model developed by Venkatesh and Davis [22] has been applied in more than 1000 empirical investigations through questionnaire survey to predict end user acceptance of information technology. In addition, questionnaire surveys also have a number of distinct advantages, including the ease of distributing questionnaires to a large number of users and the automated analysis of the results with statistical packages [23].

Therefore, the approach and rational for the undertaking of each type of research is summarized below:

Approach 1. Both cross sectional and longitudinal questionnaire survey of HIS end users to ascertain their changing perceptions about the HIS to be evaluated. The questionnaire is structured to measure the six theoretical constructs of the D&M IS success model (see Figure 1).

Rational. Self-administered questionnaire is the proven best method for measuring personal belief, perception and attitude. It has been employed broadly in information system and health research. Cross sectional questionnaire survey can quantify the performance of each construct in different sites; longitudinal survey can quantify the change of end users' perceptions about each measurement items.

Approach 2. Conduct Interview or focus group discussion with a convenient sample of HIS end users at different levels of participating organizations. This activity should be conducted at the same period of time when questionnaire data was collected.

Rational. In-depth interview and focus group discussion is effective for understanding how and why things have happened and would happen, and end users' perceptions on what can be done better. This will provide relevant explanations to the results of the questionnaire survey.

Approach 3. Work sampling with direct observational study to objectively measure any changes in work activities undertaking by each member of the care team and validate whether there is any objective evidence that the introduction of the HIS has improved the efficiency of work tasks that the system supports or vise versa.

Rational. End users' perceptions and opinions can be biased; therefore, objective measurement is required to validate the changes in work practices associated with the introduction of the HIS under evaluation. Work sampling is also effective in providing objective, relatively accurate measurement of the proportions of time end users spend on different work activities.

Approach 4. Auditing records that have been recorded both before and after the introduction of the HIS if the system is a health record system. Both quantitative and qualitative auditing needs to be conducted.

Rational. Direct auditing of health records can provide objective evidence about the changes in quality of records associated with the introduction of the HIS, if the HIS is a health record system. The results of cross-sectional auditing will be sound evidence for benchmarking across sites. Regular, longitudinal auditing will provide valid evidence about the longitudinal changes in quality of records.

The information collected from the above four sources, once triangulated, will provide a comprehensive and accurate picture of what has happened, why and how and what is the direction for the further evolution of the HIS. It is useful for the decision makers to implement effective interventions to ensure adequate return on investment from the HIS at different stages of system introduction and infusion.

A case study

The health information systems evaluated in this case are commercial electronic nursing documentation systems introduced by two aged care management groups in two states in Australia. Our research settings are residential aged care facilities belonging to these two aged care management groups. The project started in June 2008 and the planned completion date is May 2011.

For elderly people living in residential aged care facilities in Australia, nursing documentation includes functional assessment, care planning and daily progress reporting. Such documentation is essential for providing care that reflects the needs of the elderly [24, 25]. The functions of the two electronic nursing documentation systems were similar; both include resident details, assessment forms, progress notes, care plans, charts and printing out reports. The system was used by all levels of care staff members and management to record and review nursing records.

This particular evaluation study aimed to develop and validate the D&M IS success model and instruments to measure the model and identify factors that affect IT implementation in residential aged care using the above mentioned multi-method evaluation framework.

Approach

A multiple case study with both cross sectional and longitudinal research design has been undertaken. The above mentioned research methods were adopted. The implementation of each research component is described below:

Questionnaire survey. The questionnaire survey instrument was further developed from that used by Yu et al. [26]. Face validity of the instrument was validated through a consultation process with 16 personnel, including three focus group discussions with nursing managers (11 people in total), interviewing managers in aged care organisations (3 people), two vendors of HIS and health IT managers (6 people). The questionnaire survey was conduct 1-3 months before the introduction of an electronic documentation system, repeated 3 months, 6 months and 12 months after the electronic documentation system was introduced.

Interview. Interview guide was designed to elicit care staff members' perceptions about 'why' and 'how' things have happened and what can be done better. After acquiring consent, each interview was audio-recorded and transcribed. The interview transcripts are analysed in NVivo software.

Work sampling study. After a systematic literature review and detailed observation of care staff members' work practices in residential aged care facilities, a staff work activity classification system was developed. It included six major categories of care staff activities in a residential aged care facility: direct care, indirect care, nursing documentation, communication, personal and transit (such as walking between residents' rooms). There are many sub-categories of activities under each of the above six categories of the activities. The work sampling instrument was validated through two focus group consultations with care staff members in two aged care facilities.

Pilot study was conducted before the start of the formal measurement. The data quantified how different categories of care staff members spend time and how many proportions of their time is spent on each activity.

Auditing nursing records. A registered nurse was recruited to undertake this research component. The person developed nursing documentation audit tool based on extensive literature review and residential aged care accreditation standards in Australia. As most of the previous studies in this field were conducted in Europe in hospital setting, whereas Australian residential aged care setting has specific documentation requirements and protocols, significant development has been conducted to reflect Australian aged care documentation standards and practice.

Results

Currently 351 questionnaire responses were collected from eleven residential aged care facilities. Preliminary data analysis suggests that the instrument is adequate in detecting the performance difference of each measurement item between facilities; as well as different measurement points in one facility. This allows the research team to confidently inform the management group about the performance of the HIS as perceived by the participating care staff members in each aged care facility, between different facilities, and the longitudinal changes of their perceptions over time. Through triangulating questionnaire survey data with interview and work sampling data, a comprehensive picture about what happened, why and how were drawn.

For example, longitudinal questionnaire survey results in one facility suggest that the care staff members' perceptions about HIS quality and information quality were less positive than those measured in the previous survey. The interview data suggested that new staff members were not trained properly, also the support services could be more accessible. Based on the feedback, the facility management implemented more effective training and support strategies, such as peer-support, HIS training for any new member joining the team. After the enhancement of education and training programs, the survey conducted one year later found that the care staff members' perceptions about the performance of the system was improved in all aspects. The cross-sectional survey results also suggested that the electronic documentation out-weighed the paper-based documentation system in another facility. This re-enforced the management that investment in electronic documentation was correct.

Future work

The author is in the process of building structural equation model to validate the HIS success model in residential aged care settings in Australia. The members of the research team are in the process of analysing data collected from interview and work sampling study.

The nursing documentation audit instrument has been developed. It has been validated through two focus group discussions with RNs in two aged care management groups and consultation with nursing experts. The next step is to recruit two RNs to conduct nursing documentation audit, together with our RN researcher to test inter-radar reliability, then start nursing documentation audit in each participating site.

Conclusion

After explaining the importance of HIS evaluation, this paper introduced the D&M IS success model for evaluating HIS.

The limitations of the D&M IS success model are discussed. This led to the introduction of a recently developed HIS evaluation framework HOT-IT fit model. The weakness of this model is addressed through the introduction of the basic concept of psychometric measurement theory and the importance of quantitative measurement for both cross sectional and longitudinal benchmarking of HIS performance and impacts. Then a new model of HIS evaluation was introduced. This model is based on a multi-method approach that incorporates both quantitative and qualitative methods and centered on the D&M IS success model. A case study was presented to show an approach to implement the multiple methods to a large scope, both cross sectional and longitudinal HIS evolution project.

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Why GPs do not follow computerized guidelines: an attempt of explanation involving usability with ASTI guiding mode

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Abstract

Clinical decision support systems (CDSSs) have the potential to increase guideline adherence, but factors of success are not well understood. ASTI-GM is an on demand guideline-based CDSS where the user interactively characterizes her patient by browsing the system knowledge base to obtain the recommended treatment. We conducted a web-based evaluation of ASTI-GM as a before-after study to assess whether the system improves general practitioners' (GPs) performance and how they would use it. Five clinical cases had to be solved, as usual in the before phase, and using ASTI-GM in the after phase. On a 2-month period, 266 GPs participated and 1,981 prescription orders were collected. The overall guideline adherence rate increased from 27.2% to 64.3%. Only 56.4% *of ASTI-GM uses corresponded to a "good use" of the system. Adherence increased from 28.5% to 86.1% in the sub-group of "good uses", whereas it only increased from 28.1% to 36.6% in the complementary sub-group. Reasons for non "good uses" of CDSSs should be investigated since they impede their potential impact.*

Keywords:

Clinical decision support system, Intervention study, Guideline adherence, Primary health care.

Introduction

Clinical practice guidelines (CPGs) are commonly being developed to provide up-to-date knowledge of evidence-based best clinical practices. They are intended to improve the quality of clinical care by promoting effective care procedures and avoiding ineffective interventions. However, despite the development and the wide dissemination of CPGs, there is still a considerable variation in the effectiveness of guidelines to change the behavior of clinicians. Clinical decisions support systems (CDSSs) are defined as any software in which characteristics of individual patients are matched to a knowledge base (KB), built from the computerized version of original textual guidelines, to generate patient-specific assessments or recommendations. Numerous studies have established that CDSSs have the potential to increase physician compliance with recommendations. However, delivering patient-specific recommendations appears to be *"neither necessary nor sufficient"* to ensure adherence [1]. Failure to improve adherence using computer-based strategies has been often reported [2, 3] addressing the issue of identifying factors responsible for the success or failure of CDSS intervention strategies. Researches have been carried out to elicit successful design factors although many reports failed to describe the systems in sufficient details to precisely ascertain users interfaces or operating modalities. "Unintended consequences" [4] and the potential for CDSSs to harm patients have also generated much debate.

ASTI [5] is a guideline-based CDSS applied to therapeutic prescribing in primary care. ASTI can be used according to two modalities: *(i)* the "critiquing mode" which operates as a background process and automatically provides critics in the format of alerts when the physician's order does not follow guideline recommendations; *(ii)* the "guiding mode" which operates on demand when the general practitioner (GP) needs support to assess the best drug prescription of a complex case. Both operating modules have been integrated in the workflow of the GP and implemented using the commercial "éO"[1] electronic medical record (EMR). While the critiquing mode exclusively relies on coded patient data to operate, the guiding mode can be used as a stand alone tool. In this case, the infomation necessary to characterize a patient's clinical condition has to be documented by the user while browsing the KB.

[1] The "éO" software is a product of Silk Informatique, Angers, France.

Prior to a large scale appraisal of ASTI on physician adherence with CPG recommendations and the organization of a cluster randomized clinical trial, we have conducted a web-based preliminary evaluation of ASTI guiding mode (ASTI-GM), carried out as a before-after study. The aim was to check that using ASTI-GM does improve adherence for a series of clinical cases, apart from any connection with an EMR. Another objective was to analyze the situations where ASTI-GM propositions were not followed by GPs, to identify the explaining factors of such situations, and assess GPs' acceptance to using such a system.

Background

Reviews of computer-based guideline intervention strategies have reported mixed conclusions about the effectiveness of CDSSs to improve physician compliance with CPGs [1, 3]. The type of medical support provided by guidelines seem to influence the success or failure of guideline implementation systems. For instance, CDSSs have often demonstrated to improve preventive practice for vaccination, cancer screening, and cardiovascular risk reduction [6] whereas numerous studies evaluating CDSSs in the management of chronic diseases have found that the intervention had little or no effect. In addition, CDSSs vary greatly in design and modalities of output presentation, ranging from brief prompts and calculation services through complex decision-support systems providing explanations and the rationale that supported specific recommendations. Four features have been identified as independent predictors of improved clinical practice by Kawamoto *et al* [7]: *(i)* automatic provision of decision support as part of clinician workflow, *(ii)* provision of recommendations rather than just assessments, *(iii)* provision of decision support at the time and location of decision making, and *(iv)* computer-based decision support.

However, this is only a statistical statement based on the identification of a significant correlation, no causality or logic implication has been established, and there are CDSSs with no impact on physician behavior that possess the four features. In fact, no design factor is consistently associated with significant improvement. Even the success of reminder-based approaches is subject to variability: Garg *et al* [3] reported that CDSSs that automatically prompt users improve practitioner performance, whereas other authors were unable to influence guideline adherence with concurrent reminders. More recently Shojania *et al* [8] showed that computer reminders achieve small to modest improvements in physician decisions, even when they make the difference between point of care computer reminders, e-mail alerts, computer-generated paper reminders and any other way of delivering "computer reminders". Thus the question of understanding why and when a given guideline-based CDSS could improve physician compliance with CPGs is still open. ASTI-GM is a CDSS that holds the four features of success identified by Kawamoto *et al*. The web-based evaluation has been handled to check whether using ASTI-GM would improve physician compliance with CPGs and to help understand why and when physicians don't follow the system propositions.

Material

ASTI guiding mode

ASTI-GM is a guideline-based CDSS elaborated with a knowledge-modeling approach in the document-based paradigm first developed with OncoDoc [9], keeping the advantages of CDSSs that deliver optimized patient-centered information and the advantages of text reading that allows for contextual interpretation. Decision knowledge is encoded as a tree where nodes represent the patient parameters that drive the decision process. As a consequence, a path in the tree represents a patient-specific situation as a list, or conjunction, of statements *parameter* = *value*, *e.g.* coronary disease = no.

Borrowing from Shiffman's multi-step process to translate textual CPGs into the KBs of CDSSs [10], the verification of completeness ensures that all medically relevant combinations of state parameters are anticipated. Thus, the total expansion of the tree is the exhaustive nosological catalog of all the possible clinical situations that can be encountered in practice, and the search through the tree can be considered as a discrimination process to select the path that best fits a given patient clinical condition. The discrimination process can be driven either automatically from patient data or under the control of the user while dynamically browsing the KB. At each depth level of the tree, a patient parameter is displayed as a closed-ended question along with its definition, and the user has to answer by a simple mouse click. When this hypertextual navigation is completed, *i.e.*, when the leaf level of the tree is reached, a page is displayed with the summary of the selected "scenario" along with recommended therapeutic propositions. All leaf pages are numbered to characterize the corresponding paths of the tree (Figure 1).

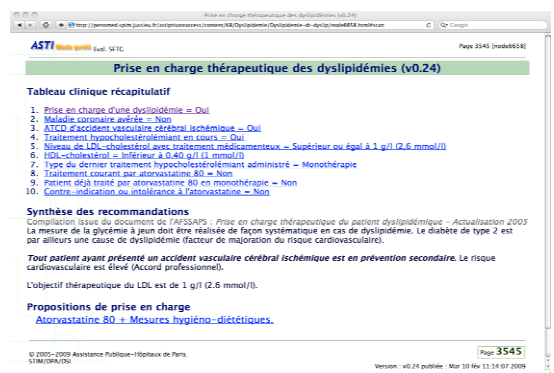

Figure 1- Recommendations issued by ASTI-GM for a patient profile with the page number (bottom right)

ASTI-GM propositions are guideline-based recommendations except for clinical situations, or profiles, that result from the verification of completeness, which are by construction not explicitly covered by CPGs. In these "gaps" of CPGs, therapeutic options proposed by ASTI-GM are expert-based.

ASTI-GM is currently applied to the management of hypertension (HT), lipid disorders, smoking cessation, and auricular fibrillation (AF). Knowledge bases have been built from national French CPGs published by HAS and AFSSAPS. ASTI is not yet used in routine care.

Patient case set

The web-based study consisted in the resolution of 5 clinical cases. The 5 clinical cases are not hypothetical simplified cases but *actual* clinical cases extracted from the EMR database of a general practice (Paris, France). All cases are presented as a textual description of the patient clinical situation, including disease history, comorbidities, and relevant biological data. Cases have been selected to cover different levels of patient complexity. Three cases are moderately difficult and describe patients under monotherapy: case 1 concerns a patient with cholesterol disorder, the current treatment is tolerated and active, but suboptimal because of the patient's personal history of stroke; case 2 concerns an hypertensive patient who coughs under ACE inhibitors, the current treatment is thus non tolerated although active; case 5 concerns a patient with familial hypercholesterolemia, the current treatment is neither tolerated nor active. Case 4 is more complicated and concerns a diabetic hypertensive patient (two comorbidities) under a non-active bitherapy. Finally, case 3 is really complex and concerns a patient with a documented history of auricular fibrillation. The difficulty here comes from the double management of rhythm troubles and thromboembolic risk.

Method

Protocol and data collection

This study has been handled as a web-based questionnaire following a before-after design. The questionnaire has been implemented using the dedicated "It's Quizz" platform[2]. GPs in relation with the SFTG (Société de Formation à la Thérapeutique du Généraliste, the French national association of GPs involved in the ASTI project) were invited to participate by email. Participation was on a voluntary basis. There was no financial incentive although CME credits were offered to GPs that completed the questionnaire. No training on how to use ASTI-GM was provided. Only a one-page textual user's guide was attached to the call for participation.

In the "before" phase, GPs had to solve the 5 clinical cases. Each case was displayed on a page. The textual description of the case was followed by 10 input fields for the GP to enter her order in plain text, one drug by input field. In this first phase, the user had no access to ASTI-GM so that case resolution was performed without the support of ASTI. As long as the before phase was not completed, it was possible to switch from one case to another and modify previous prescriptions. Once orders were validated, they were definitely recorded and the before phase was completed.

In the "after" phase, the GP had to solve the same clinical cases and enter her prescriptions but after having used ASTI-GM. A link to the CDSS had been inserted after the case description so that it was easy to access ASTI-GM once the case reviewed. For each case, GPs could use at their convenience, one, two, or the three KBs (HT, lipid disorders, or AF) to get the therapeutic propositions related to each disease. They had to report in the questionnaire the page number that characterized their navigation in ASTI-GM (see Fig. 1). Similarly to the before phase, the user could get back to any of the 5 cases resolved with ASTI-GM. Once orders of the after phase were validated, the questionnaire was completed.

Gold standards

Each case was reviewed with a domain expert to establish the gold standards to which collected data should be compared.

The gold standard order considered as the "solution" of the case, was determined according to CPGs completed by the state of the art[3]. As it is the case in CPGs, this order has been expressed at the abstraction level of therapeutic classes. For instance, for the first dyslipemia case (#1), the specific correct order was "atorvastatin 80", but the gold standard has been set as "atorvastatin". As a result, any order of atorvastatin, whatever the dosage or the commercial name used, was considered as compliant with CPGs.

Then, we determined the gold standard navigation as the navigation that best matched the case description, characterized by its page number. For instance, for the first case, the "good" page is 3545 (see Fig 1). Any user that reported this page number was considered to have performed a good use of ASTI-GM[4]. Any other situation was considered as a "non-good use". This category includes *(i)* a missing page number (although the user might have used the system or not, used it correctly or not), and *(ii)* the report of a page number that doesn't correspond to the gold standard navigation.

Data analysis

The analysis unit is the prescription order. Each line of prescription was first abstracted to its therapeutic class to reach the level of abstraction of CPG recommendations. Then the abstracted order was compared to the gold standard order of the case to assess the adherence of the prescription with CPGs. This comparison is independent of the use of ASTI-GM.

Overall adherence rates were computed for all prescriptions in the before and after phases. To eliminate orders only done in the before phase, with no corresponding order in the after phase, we selected matched pairs of orders proposed for the same case by the same GP in the two phases. In this subpopulation, adherence rate of the before phase is considered as the baseline rate to which the adherence rate of the after phase can be adequately compared. Then we have identified two subpopulations according to the "good use", or not, of ASTI-GM in the after phase. Intra- and inter-group comparisons of adherence rates have been performed (Fisher's exact test or χ^2, and McNemars's test in the case of paired data).

[2] "It's Quizz" is a product of "It's Sauquet.com", Paris, France.

[3] In some cases, several order patterns were possibly used.

[4] Interpretation of some clinical cases could lead to more than one good navigation.

Results

The study started on February 11th, 2009 when the mailing was performed. It was closed and data collected on April 1st. A total of 2,040 GPs were solicited, among which 266 registered on the web site, 143 completed the questionnaire and solved the 2×5 cases. A total of 1,981 orders have been collected, 1,193 in the before phase and 788 in the after phase.

Overall adherence rates

For each of the 1,981 orders, adherence to the gold standard has been computed. Table 1 reports this data by case and by phase. The baseline adherence rate, measured in the before phase, increased from 27.2% to 64.3% in the after phase. It should be noticed that the number of reported prescriptions decreased as the number of solved cases increased, showing a progressive loss of user commitment.

Table 1 - Adherence rates by case in both before and after phases.

	Before phase		*After phase*	
Case (theme)	*n*	*Adherence*	*n*	*Adherence*
1 (lipids)	256	25.8%	177	66.7%
2 (AHT)	252	68.7%	160	78.8%
3 (AF)	233	1.7%	155	63.9%
4 (AHT)	237	5.9%	153	50.3%
5 (lipids)	215	31.1%	143	60.8%
Total	1,193	27.2%	788	64.3%

Adherence rates in paired orders

Matched pairs of orders are the orders proposed in both before and after phases for the same case by the same GP. There are 752 pairs of matching orders, 441 orders of the before phase has no correspondent in the after phase, and 36 orders of the after phase has no correspondent in the before phase. Table 2 gives the distribution by pair patterns, with the number of occurrences and corresponding adherence rates in both phases.

Table 2 - Paired orders according to pattern and adherence rates in both phases.

Pair pattern	*n*	*Adherence before*	*Adherence after*
$(O_1,\varnothing)$	441	25.17%	—
(O_1,O_2)	752	28.32%	64.49%
$(\varnothing,O_2)$	36	—	61.11%

The difference of adherence rates between before and after phases in matched pairs of orders (28.32% vs 64.49%, n = 752) is highly significant ($p < 10^{-15}$, McNemar's test). This suggests that the intervention might have an impact.

However, the difference of adherence rates in the before phase between orders with a matching order in the after phase (28.32%) and those without (25.17%) is not significant (Fisher's exact test). This suggests that the GPs that gave up after the before phase (n = 441) would not be different in performance level than those who carried on in the after phase.

Good vs non-good system uses

For each of the 752 matched pairs of orders, we considered whether the second order was prescribed after a "good" use of ASTI-GM. This splits our sample into 2 subgroups. Table 3 reports the overall proportion of good and non-good uses of ASTI-GM and the adherence rates in the two phases.

Table 3 - Good and non-good uses of ASTI-MG and corresponding adherence rates in both phases.

Category	*n*	*%*	*Adh. before*	*Adh. after*
Non-good	328	43.6%	28.05%	36.59%
Good	424	56.4%	28.54%	86.08%
Total	752	100.0 %	28.32%	64.49%

Orders associated with good system uses represent about one half of the GPs (56.4%). In the after phase, the comparison between adherence rates of the two sub-groups, i.e. when ASTI is correctly used (86.08%) and when it is not (36.59%), is highly significant ($p < 10^{-15}$, χ^2), illustrating that a "good" use of the system does considerably increase adherence.

However, the adherence rate in the "non-good use" sub-group significantly increased between the 2 phases (28.05% vs 36.59%, p = 0.0015, McNemar's test). This suggests that, despite a "non-good use", something in the intervention might have impacted GPs' prescriptions.

As the difference of the baseline adherence rate (before phase) in both groups is not significant (Fisher's exact test), it can be assumed there is no difference of initial performance level in GPs who used the system correctly (or at least reported it) and the others.

Discussion and conclusion

ASTI-GM has been designed to be a computer-based *thinking support* on how to decide. Indeed the interactive characterization of a patient clinical condition is intended to play the role of a check list of guideline-based relevant parameters to structure the understanding of the patient by the GP and thus help her improve her therapeutic decision.

In this study, 5 clinical cases were proposed to GPs for which they had to give their prescription as usual, without using ASTI-GM, and after using ASTI-GM. Guideline adherence of GPs' orders was computed with respect to a gold standard, established for each clinical case by a domain expert on the basis of the currently used French national CPGs improved by last results from the state of the art, but not to ASTI-GM propositions while included in the gold standard. ASTI-GM was only (part of) the intervention, but not the reference.

In this experiment, as reported by many studies of CDSS-based interventions, the adherence rate of GPs to CPGs was significantly increased from 27.2% to 64.3% after using ASTI-

GM. When analyzing the results by clinical case, we observed in the before phase a variability of adherence rates, which seems to depend on the a priori difficulty of the case, with higher rates on cases 1, 2, and 5 that describe less complex patients, and lower rates on cases 3 (atrial fibrillation involving 2 types of therapeutic management) and 4 (patient under bitherapy). It must also be noticed that even simple cases on high blood cholesterol management (lipids) are not well handled by GPs in the before phase suggesting the weak penetration of cholesterol management CPGs and illustrating their poor quality (that we experimented when formalizing the textual document to built ASTI-GM's KB). However, after using ASTI-GM, variability of adherence rate by case is decreased which suggests a normative effect of the intervention and the resulting harmonization of practices that could be expected after using the system.

The good use of ASTI-GM seems to be a determinant factor of the system impact. Indeed, considering the sub-population of good users, the increase of the adherence rate is considerable from 28.54% to 86.08%, suggesting that GPs are more disposed to follow therapeutic propositions when they correctly interpret a clinical case. They probably found the system advices consistent with their case perception. On the contrary for non-good users, adherence rates before and after remain low although there is a significant increase. This may be attributable to the help-to-think effect of using the system, or simply because of thinking twice about the case. For those who reported a "wrong" page number, the question is thus why did they do a "wrong" navigation? We have little information to answer. We can only assume hypotheses such as *(i)* misinterpretation of clinical cases explained by the fact that there is no actual patient and that it is difficult to reason on textual description (some GPs for instance interpreted the appearance of side effects with simvastatin as a contraindication to all statins), *(ii)* careless mistakes in the navigation explained by the fact that GPs are busy people, the study took them at least one hour and they wanted to go fast (error on the categorization of the age, HDL-cholesterol, personal vs familial history of a pathology, etc.), *(iii)* incoherent navigations beyond ASTI-GM misuse (technical difficulties related to the poor computerized environment of some GPs, old versions of browsers, wrong report of the page in the questionnaire...).

The limitations of this study concern the potential recruitment bias of GPs since there was no randomization and participation was on a voluntary basis. In addition, because of variable computerization of medical practice, some GPs experimented technical difficulties even without knowing it (they could not navigate through the KB, they did not find the page number, etc.) leading them to withdraw. Moreover, results have been obtained for only 5 cases (2 with AHT, 2 with dyslipemia, and 1 with AF) and could be generalized neither to this 3 domains nor to other domains. We have evaluated ASTI-GM apart from its actual use in general practice.

However, it seems that usability features of CDSSs and how CDDSs are used could impact adherence rates of GPs with CPGs. Therefore, a better understanding of the reason why CDDSs are not used or misused is required. This has to be further investigated.

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A qualitative analysis of Emergency Department physicians' practices and perceptions in relation to test result follow-up

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Abstract

Follow- up of abnormal test results for discharged Emergency Department (ED) patients is a critical safety issue. This study aimed to explore ED physicians' perceptions, practices, and suggestions for improvements of test result follow-up when using an electronic provider order entry system to order all laboratory and radiology tests and view results. Interviews were conducted with seven ED physicians and one clinical information system support person. Interviews were analyzed to elicit key concepts relating to physicians' perceptions of test result follow-up and how the process could be improved. Results described the current electronic test result follow-up system with two paper-based manual back-up systems for microbiology and radiology results. The key issues for physicians were: responsibility for test follow-up; the unique ED environment and time pressures, and the role of the family physician in test result follow-up. The key suggestion for improvement was a complete integrated electronic information system with on-line result endorsement. The study highlighted the complexity of the test result follow-up process and the importance of engaging clinicians in devising solutions for improvements.

Keywords:

Test result follow-up, Computerised provider order entry systems, Electronic medical records, Patient safety, Laboratory test results, Emergency department, Family physician.

Introduction

Problems with follow-up of test results have been identified in a number of studies [1, 2]. Physicians acknowledge that they need safe and efficient processes to manage test result follow-up [1, 3]. Emergency Departments (EDs) have been shown to be complex, interrupt driven environments with rapid throughput of patients and team-based care delivery [4]. It is understandable that in this environment, particularly for discharged ED patients, follow-up of results presents challenges for physicians and safety concerns for patients. The test follow-up process, therefore, needs to be systematic to ensure diagnoses are not delayed or missed and patients receive appropriate treatment in a timely fashion [5-7].

A number of studies have explored the extent of failure to follow-up test results in the ED [5, 7-12]. The extent of the problem varies depending on the study methods used and test type examined. However rates of failure to follow-up laboratory tests for ED patients have been found to range from 3% for microbiology tests [9] to 75% for pregnancy tests [7]. Radiology lost to follow-up is also an area of concern with one study finding that for 6% of ED patients who had a missed diagnosis of cervical spine injury, the error was due to the treating surgeon not seeing the radiographs [10].

The systems used to manage test results in EDs vary with studies reporting physicians using completely manual systems [7], completely electronic systems [11] or more commonly a mix of electronic and manual systems [8, 9]. Suggestions for improvements to the test result management process have suggested further utilization of electronic test management systems [13, 14]. However, studies have shown that electronic systems can create their own problems and hinder rather than assist clinical processes [15, 16]. Given that lack of follow-up of test results is a critical problem for ED clinicians, there needs to be an exploration of physicians' perceptions of the test management process and how technology might assist. We could find no published studies which investigated the practices of result follow-up and opinions of ED physicians already using an electronic test management system. This study aims to fill that gap by exploring in-depth, physicians' perceptions, practices and suggestions for improvements of follow-up of test results in an ED which used a computerised provider order entry system to order and view all laboratory and radiology test results.

Methods

Design and setting

A qualitative study design using interviews to explore ED physicians' current test management work practices was undertaken. The ED was situated in a 400 bed metropolitan teaching hospital which had 25,000 attendances per annum of which 17,000 were discharged (68%). Physicians in the ED used a commercial computerised provider order entry (CPOE) system, which had been in place since 1992, to order laboratory and

radiology tests and view test results for all in-patients and ED patients.

Sample

Five consultant physicians, one ED resident physician and the ED clinical director (n=7) were interviewed. An Information Systems Department clinical support person (n=1) was also interviewed to describe features of the CPOE system.

Data collection

Semi-structured interviews were conducted with the eight participants over a one week period in August 2007. The lead questions included: How do you manage your test results currently? What factors impact on your current management of viewing test results, for example, handover, team-based care etc? Can you suggest ways in which the follow-up of test results might be improved? Which features of the current system hinder you in tracking test results? How could the computerised test management system be used to improve tracking of test results? Each interview took approximately 25 minutes and was undertaken during work hours in an administrative area of the ED. The study was approved by the Human Research Ethics Committee of the study site.

Data analysis

Interviews were taped and transcribed to allow for qualitative analysis using a thematic grounded theory approach. Two researchers (JC & MP) independently analysed the interview text to elicit key concepts. These two researchers then discussed their independently derived concepts and agreed on a final set to accurately reflect perceptions and practices of the respondents in relation to test-result follow-up.

Results

The results are presented in four sections: demographics of study participants; description and perceptions of current test result follow-up processes; key concepts in relation to what impacts on the result follow-up process, and physicians' perceptions of how follow-up could be improved using the electronic test management system.

Demographics of participants

Six of the physicians interviewed were emergency specialist physicians and this represents the population of specialist physicians for the ED. One physician interviewed was a registrar. Five of the staff specialists, including the ED Director, were male with ages ranging from 30 to 52 years with one female 30-35 years of age. The registrar was a 25-29 year old male.

How do ED clinicians follow-up test results?

Description of current process

ED physicians use a computerised provider order test management system (*Cerner Powerchart*) to order and view all diagnostic laboratory and radiology tests. Clinicians almost always accessed test result electronically, except sometimes for urgent results they would phone the laboratory.

"I would wait for results to come up on Powerchart unless it was a particularly urgent result, for example, raised potassium which I would let the lab know the urgency of the result and get them to either ring it back down or ring them up directly" (Doctor 5)

Some physicians built their own personal *patient list* in the *Powerchart* test management system (by ward or specialty) to assist them manage their results, however only two of the seven clinicians described doing this. At the time of the study there was no operational function to allow physicians to endorse test results on-line. There was a *bookmarking* function which enabled the user to indicate they have seen all the results of one patient on the screen; however this was used intermittently by only one ED clinician.

In the ED there is an additional manual back-up practice specifically for radiology and microbiology test results as these may arrive after the patient is discharged home.

"So particularly with micro results and things like that by the time you actually grow something…by the time a result's back it's maybe four days so the patients gone home" (Doctor 7)

Radiology and microbiology results for discharged ED patients were reported electronically and also sent to a dedicated printer in the ED. Staff specialists in the ED department are rostered to administrative duty for one shift per week and it is their responsibility during this shift to check all manual radiology and microbiology results to ensure they have been seen and acted upon, that is, appropriately followed up. To do this the ED staff specialist on administrative duty checks all printed radiology and microbiology results and any abnormal results are checked against the electronic discharge summary or the manual medical record to ensure the patient's family physician or general practitioner (GP) has been alerted to the outstanding result. In some cases the ED specialist will contact the patient or the family physician to ensure follow-up of the abnormal result has occurred. To further ensure that there is no duplication of follow-up for microbiology results which may have a number of interim reports printed with the final report coming through days after the initial interim report, the physician who sees the abnormal result and follows-up with appropriate action, will document this in an 'Abnormal result log book'.

ED physicians' perceptions of the current process

All clinicians liked the electronic process of ordering and viewing test results using the current computerised system. Two clinicians mentioned that they were not very good at typing with one stating, *"Well I'm just slow at typing" (Doctor 2)* and one admitting that he *"still liked pen and paper"* and typing was *"like a two finger job, very slow" (Doctor 1).* One of these clinicians (Doctor 1) suggested that a voice recognition system would be useful to improve the tracking of test results.

"If you had a little mike system and you could talk into it and it automatically typed for you.." (Doctor 1)

Key concepts in relation to what impacts on ED clinicians' follow-up of test results

The three key concepts derived from the data were: responsibility for test result follow-up; busy ED environment and time pressures, and the role of the family physician in test result follow-up.

Concept 1: Responsibility for test result follow-up

There were mixed opinions regarding the extent of the physicians' responsibilities in following up discharged ED patient's test results. Most ED staff specialists agreed that they had final responsibility for following up their patients results.

"If you order a test you should be checking the results." (Doctor 2)

In response to how a result is followed-up if it is abnormal and the patient has been discharged, most physicians said they would contact the patient or the GP.

"So generally we will contact the patient. …I see it as our job to try and organize what's going to happen and not just fob it off on the general practitioner." (Doctor 3)

Some however thought that if the result was written as 'outstanding – GP to follow-up' in the discharge summary, then it was the patients and GPs responsibility to follow-up the result.

"… the letter says for the GP to follow that up. Now I don't go and ring the GP because I think patients should have some responsibility for their own health." (Doctor 1)

"..it's clearly impractical for us to verify that they have gone and seen their general practitioner. And on the other side you know people do have to assume some responsibility for their health" (Doctor 3)

"So with us the delineation of who is going to follow-up the result is much clearer – it's not us because we are an isolated emergency visit. So for patients it's very clear. That's it, you're out. We won't be seeing you again. Whereas they have an ongoing relationship with the GP…" (Doctor 7)

The complexity of the decision of whether to contact the patient or not post-discharge regarding an abnormal result was highlighted by one clinician who reported in relation to an elbow x-ray which might state 'cannot exclude fracture':

"…if it's reasonable that the thing does exist rather than it's just 'it might be' because obviously you don't want to create unnecessary distress or panic amongst people when it's not a conclusive finding….These judgments are not easy…myself and other clinicians do them slightly differently…" (Doctor 3)

"…this is why we have senior clinical people doing this job [in reference to the administrative staff specialist checking all hard copy microbiology and radiology results of discharged ED patients]*...because there's a lot of subjectivity around well which ones do you follow- up and which ones don't you follow-up and what advice do you give and do you always ring the GP, you know there are a lot of 'ifs' in there and that's why ..it does need a senior clinician to make those sort of judgement decisions and assume the responsibility." (Doctor 3)*

Concept 2: ED environment and time pressures in test result follow-up

The clinicians highlighted their time pressures, unique ED work environment and the large number of test results which come through.

"…it takes a lot of time going through all the results and then checking the letter [discharge summary] to see if they've [the GP] been asked to follow-up." (Doctor 1)

"…you know it's well known that no matter what the error rate is the more volume you've got the higher your absolute number of errors are going to be….you're never going to be able to eradicate errors even putting in whatever sense of follow-up you want to do there's still so many subjective steps in there that it's never going to be possible to have an error rate of zero" (Doctor 3)

Two clinicians raised the issue of the absence of an on-going relationship between ED physicians and ED patients:

"..as an inpatient consultant you have accepted responsibility for an inpatient admission … there is absolutely no doubt that everything that happens to that person is your responsibility. The situation in emergency is much less clear and different departments do it in different ways. I mean here everything is done under the name of the director…that's just the way we do it here." (Doctor 3)

"… it's very clear that we have no ongoing relationship with the patient when they leave us." (Doctor 7)

Concept 3: The role of the family physician in test result follow-up

A key issue raised by most respondents was the problem of the electronically created discharge summary at the study site which was not transmitted to the patient's family physician either electronically by email or by facsimile. The hospital had a system whereby an electronic discharge summary was created on-line and then printed and the hard-copy was given to the patient to give to their family doctor or GP. Most ED specialists thought that the family physician should play a key role in following up test results which were outstanding at the time of the patient's discharge from the ED.

"We have looked at the issue of faxing or emailing to GPs. There's still a lot of security issues around that….I mean the system has the capability…it's a security issue." (Doctor 3)

"The main difficulty as an ED specialist in following up results is actually tracking down the local doctor." (Doctor 5)

Another issue raised in relation to the discharge summary was the difficulty of completing summaries for all ED patients due to time constraints.

"I must admit that I don't do them all…It takes time." (Doctor 2)

How could test result follow-up be improved using the electronic test management system?

When asked how the current test result follow-up system could be improved most clinicians responded that they would like "all the information in one place." They acknowledged that

there were currently electronic and manual test management information systems and this created problems.

"I think a lot of the way it could be improved is actually just to have all the information in one place…I think that we've done a pretty good job of centralizing the information, although obviously the reliance on it still being a piece of paper that can be lost, destroyed not printed…" (Doctor 3)

Verifying on-line that a test result was seen and what action was taken was also seen as a positive advance with a reduction in reliance on the manual medical record.

"I think that if you could arrange for it to be transmitted electronically, reviewed electronically…that would be ideal" (Doctor 3)

Refining on-line endorsement for just critical results and only for senior clinicians to verify was suggested by one clinician.

"If it has a functionality that anything that you order comes to your in-box and then you have to sign off…now that could be made to work, that would make sense but only at a senior level. There's no point having RMOs and interns having every single electrolyte coming back to their in box, that's just useless….I mean for the bulk of tests there's no point and there'd be hundreds of them and you'd just get overwhelmed. You could have criticals coming back to the staff specialist that was on." (Doctor 7)

One staff specialist also emphasised that if the electronic system was used to assist with verifying results on-line it would have to be reliable and fast.

"..it would have to work all the time because if it doesn't work reliably we just stop doing it and go back to old ways that we know work all the time down here …if it works sometimes or it's too slow or when you've got downtime then that's a big problem." (Doctor 7)

Discussion

This study showed that the ED physicians at the study site, who work in an environment which uses a computerised provider order entry system to order and view all test results, would generally be comfortable moving to some form of integrated clinical information system with a complete electronic test result follow-up system. On-line electronic endorsement of test results presents as the logical next step to these ED physicians in assisting them track the large volume of test results they receive and particularly to assist them in tracking late arriving results of discharged ED patients. Some specific functionality requirements were requested, such as on-line endorsement of critical results only and endorsement by senior clinicians only, which reinforce the importance of involving physicians in any plans for developing and implementing such a system. A number of other studies support the importance of engaging clinicians to ensure an appropriate fit between the technology, the clinical environment and clinicians' work practices [17-21].

A combination of manual and electronic information systems presents challenges in terms of safety, with some items possibly being missed, and duplication of information, with wasting of resources and time [22, 23]. The printing of manual microbiology and radiology results for all discharged ED patients at the study site was seen to be an essential back-up system to the CPOE system as these results, particularly for microbiology, were likely to arrive several days post-discharge. The ED physicians however, acknowledged that the combination of manual and electronic test management systems was not ideal. When asked for suggestions for improvements to the current system a number stated that a completely centralized electronic medical record with on-line endorsement of results was preferred. The problem of a mix of electronic and manual information systems is shown in another study by Casalino et al. [24] who quantified the extent of failure to inform patients of abnormal results in 23 medical centres in the United Sates. They found that where there was a partial electronic medical record (electronic progress notes or test results but not both) it was associated with higher rates of failure to inform patients of clinically significant outpatient test results compared to not having an electronic medical record (OR 1.92, p=0.03) or with having an electronic medical record that included both progress notes and test results (OR 2.37, p=0.007) [24].

The results from our study show that the test result follow-up procedure is a complex and often subjective process for ED physicians. Decisions are made about whether to contact discharged ED patients or family physicians when results are abnormal depending on the context and level of abnormality of the result. There are subtle differences between clinicians' practices in relation to follow-up of test results for discharged ED patients. Differences between clinicians in the integration of information systems into their work practices have previously been reported [25]. Other studies have also reported that the test result follow up process is complex and multifaceted [26, 27]. It is important to recognize this complexity when designing and implementing clinical information systems.

Limitations:

This study was qualitative and undertaken in one Emergency Department so results may not be generalisable to other settings. The study did not explore physicians' perceptions of direct reporting of test results to patients through secure web-based portals however this has been reported in other studies as an option [26, 27] and future studies should investigate physicians' attitudes towards this.

Conclusion

Our study has highlighted the complexity of the test management process and the importance of engaging the users in any design and implementation of new systems. On-line test endorsement is perceived by ED physicians as a way to improve the efficiency of the test result follow-up process for clinicians.

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Evaluation Methodology for Automatic Radiology Reporting Transcription Systems

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Abstract

This article describes a usability evaluation methodology for automatic transcription system used for radiology reporting. In order to assess this class of system's limitations and strengths, a review of the concepts involved in this kind of system is done in a critical way. Specific requirements, for this category of application, that are forgotten when a product is launched in the market, are listed and a methodology for their evaluation is presented.

Keywords:

Voice user interface, Usability evaluation, Automatic transcription system for reports

Introduction

Voice User Interface (VUI) uses technology of recognition and voice synthesis to provide access to information to its users, allowing them to perform transactions and offering communication support. Even though dialogue speech systems have appeared in the 1950's, during the onset of Artificial Intelligence research [1, 2, 3], a significant growth in the production of systems with users interface based on voice took place in the past decade, especially for commercial use, via telephone, such as airplane ticket reservations, hotel reservations, flight schedule queries, accessing bank accounts and others. The state of the art in voice technology (recognition and synthesis) allows for the development of automatic systems that work in real conditions, even though the systems are quite simple, meaning they have a limited vocabulary and therefore a high rate of recognition – close to 95%. Companies such as Philips [4], IBM [5] and Nuance [6] have invested in the development of voice recognition technologies for restricted domain [7-10].

According to [8], this uncontrolled growth is due to a series of factors: clients dissatisfaction when using touch tones systems, information access through mobile devices growth, the company's need to provide clients with a more efficient way and with lower costs for their clients demands. Although the authors state that this growth is due to the development of voice recognition and synthesis technology that have become stronger and more capable of sustaining effective interactions, one must realize that the present systems have a restricted capacity for voice recognition, a limited vocabulary and grammar coverage, and a limited ability of tolerating and correcting mistakes. Voice recognition systems, based on tasks that have a high level of variability, with a large vocabulary and that have to work with an open grammar, similar to man-to-man communication, make real voice recognition more difficult.

In Health Care, the use of voice recognition in general-purpose systems, in emergencies for instance, does not work efficiently because of the large domain's vocabulary (it is known that a Health Worker uses more than 100 thousand vocabulary words in their daily routine) In addition, there are over 60 million diagnostic possibilities in SNOMED [11]. The information available in Health Care is quite diverse.

Nevertheless, VUI has been used in voice recognition systems for more specific purposes, such as the Automatic Transcription of Reports in Radiology. That means the vocabulary is considerably smaller and gives a higher precision of recognition of specific denominations.

Regarding the usability of Voice Recognition Systems as a whole, there is yet much to determine as an evaluation methodology. In his research, Nielsen [12] proposed rules and determined heuristics to allow the interfaces to be analyzed in regard of usability. The authors got his inspiration from the user's graphic interfaces that were (and still are) in widespread use. But VUIs system evaluation is different from GUIs, mainly when it comes to voice transience that affects major usability factors such as transparency, learning, cognitive overload, error handling and user's control.

The research for usability evaluation of voice recognition systems is still quite new. The Methodology and suggested methods to evaluate VUIs come from the present knowledge of UI evaluation, related to the work of some researchers that developed methods to investigate their specific projects, and that tried to generalize and proposed reference models for such applications. That is the case of PARADISE [13], EAGLES [14] and DISC [15].

An even more incipient case is the usability evaluation of automatic transcription system. There are many specific usability issues that have not being analyzed as part of more concrete evaluation methodologies. There are two main reasons for that. First of all, owing to the fact that the classic usability evaluation methodologies cannot cope with voice systems, significant changes must be done for these methodologies to become efficient for that purpose. Secondly, the evaluators of such systems are still focused on evaluating only the accuracy or detecting mistakes in these systems [16-19]. In other words, there

are many other usability issues that are being neglected. The evaluation of automatic report transcription systems is a relatively different task because:

- Health Care vocabularies are more extensive than commercial vocabularies, and also contain specific terms, increasing the likelihood of a lower rate of recognition.
- The dialogue between the user and the system is much simpler, since the system must only generate a text from the user's speech, with no questions to be made (through speech) to the user.
- The handling and prevention of mistakes are quite different. The system must be able to show, somehow, the words in the text that are misunderstood, but must not interrupt the user or ask for confirmation. The radiologist does not wish to be interrupted by an error message while they are dictating a report.
- The quality of the messages and the adequacy of the outcoming speech should be replaced by the text's accuracy.

There are some other important considerations applicable to the automatic report transcription system.

- Flaws in the report that were caused by a wrong recognition of words can be catastrophic to the patient, for it can lead to an inaccurate diagnosis.
- It is necessary to think of how to create a methodology that takes into consideration the main requirements for this kind of system.

The challenges found when assessing automatic report transcription systems are:

- Define the VUI requirements that have to be considered to evaluate this system;
- Determine which, among the many requirements presented, are said to be essential and viable of evaluation;
- Determine how to measure each requirement pointed out as essential for these systems;
- Define how to evaluate these systems in a viable way, with acceptable costs and time for the Health Care organizations and/or systems supplier;

Thus, any suitable evaluation methodology for these systems must take into account the issues mentioned above in order to decide if a product is appropriate in matters of use efficiency, user's satisfaction and functionality, or if the product has only a good rate of voice recognition.

The objective of this article is, therefore, to organize concepts of voice recognition, voice recognition systems evaluation aiming at proposing a useful set of methods that are feasible, practical and suitable. So, a specific methodology to evaluate this category of applications will be suggested.

This article is organized as follows: The following part points out the material and methods used in the research. After that, a critical review of the concepts involved in this work will be made: Voice recognition and synthesis, technology evaluation, automatic transcription system for report and its specific demands. Then, a methodology for the evaluation of these systems is described. In the end, the limitations and advantages of the proposed methodology are discussed.

Materials and Methods

This article is enclosed in a wider context of a doctorate's research for the evaluation of user interface based on voice with the purpose of accomplishment of the following activities:

- Bibliographic review of the themes in use in the Project, including: VUI, radiology information systems with VUI and traditional methods of usability evaluation;
- Identification of generic demands for the users interfaces based on voice and the users interface requirements for voice-based system in Health Care, especially for radiological information systems.
- Proposition of a methodology that is able to provide usability evaluation focused on automatic transcription system for radiology reports.

Conceptual Foundations

Voice Recognition

The main characteristic of the VUI applications is the interaction, through voice, of a user with a system. This kind of interface includes elements such as: *prompts* or system messages, grammar and logical dialogue or call flow. Prompts are all the pre-recorded or synthesized voice messages that must be executed during the dialogue with the user. Grammar defines all the words, sentences or phrases that can be said by the user in answer to a prompt. The logical dialogue defines all the actions that should be taken by the sys-tem in a specific moment of the interaction, such as the access to the database [8, 20, 21].

According to [22], when an application with a users interface based on voice is developed, there are some issues that shouldn't be neglected for the application to be successful.

- The vocabulary affects the voice recognition through its size and subject field coverage. So, an extensive vocabulary with good subject field coverage is appealing, for it is capable of recognizing more words. Nevertheless, smaller vocabularies provide an enlargement in recognition accuracy.
- The users influence the voice recognition through clarity and consistency in the pronunciation of words. User- dependent systems have a higher rate of voice recognition than the systems that are user independent, but the formers need training sessions and can be more sensitive to noise, microphone and voice variations.
- A noisy environment affects the voice recognition in two ways: a) voice signal distortions cause difficulty to distinguish the pronounced words; b) when in a noisy environment, users tend to alter their voices and doing so, cause distortion in or alter the voice signal.
- All voice recognition systems are based on the statistical standards principles. However, in spite of its similarities, systems differ in their voice signal parameterization, the acoustic model of each phoneme and the language pat-

tern used in the choice of words accord with the words spoken and stored previously. Thus, many systems bring about differences in relation to the recognition errors, even when they have similar rates of recognition.

Voice Synthesis

Voice synthesis is the process that converts text into voice. The synthesizer receives a piece of text in digital form and vocalizes it. A Voice Synthesis program is useful to vocalize information that comes from data base queries and when the user cannot divert his attention to read something or does not have access to the written text; a system with the users interface based on voice can use a module for voice synthesis or use pre-recorded messages when there is no variation in the information given to the user [8].

It is worth noting that until now, the voice synthesizers cannot represent intonation and are still quite poor when compared to voice dialogue among humans.

Usability in Voice Recognition Systems

Usability is a system quality requirement that contains aspects related to the efficiency when using the system, ease of learning, subjective satisfaction from the user and adequacy to specific patterns; it is the process of assuring interface usability and guarantee that the user's demands be met [12, 23- 25]. Although the aspects for usability mentioned above are conceptually clear, it is difficult to use these definitions in practice. When the evaluation is made through empirical studies, the researchers need to decide about metrics for each factor [26].

If the companies in general have not been preoccupied about following usability patterns in its websites, established many years ago, these issues are even more serious in VUIs, for it is an even newer and less settled form of interaction with the user.

General Usability Requirements for Voice Recognition Systems

One way of evaluating voice recognition systems usability is through general heuristics proposed by Nielsen [12] such as: simple and natural dialogue, use of feedbacks and handling and preventing errors. Nevertheless, more specific criteria are necessary to evaluate VUI specific issues, such as the ones proposed by [27- 31]. Those criteria include:

- Output phrasing adequacy: The output content of the system must be correct, relevant and informative enough, without providing information overload to the user. The system's way of communicating with the users must be clear and unambiguous and the language must provide an appropriate and familiar terminology to the user.
- Output voice quality: this quality is connected to issues of clearness and intelligibility (right intonation, emotion, appropriate speech pace and pleasure when heard).
- Input recognition adequacy: appropriate voice recognition means that the system rarely misunderstands the user's entry. But this is associated to many factors in the environment (as level of noise) and also to user's factors: gender, age, accent, depth or shrillness of voice and the voice quality as received by the system.
- Adequacy of dialogue initiative: it is necessary for the system to choose, in a reasonable way, the dialogue initiative established between it and the user. This is related to the user's level of knowledge of the system.

Voice Recognition Systems in Radiology

One of the main problems shown in the literature [16, 17, 32-35, 37] is the delay in radiology reports due to the time spent from the moment of entry of a recorded reports to its return in textual form for the radiologist to assess.

The automatic report transcription systems (that use VUI) have been thought of as a solution to decrease this time (Turn Around Time) and also to decrease the running costs of the radiology department. To verify the efficiency of the use of automatic report systems, not only the VUI general requirements must be evaluated but also the specific demands in the area, to see if the available commercial products have been used correctly by the users.

Specific Usability Requirements for the Automatic Transcription System for Radiology Reports

In addition to the general requirements for interfaces and to the general requirements found in voice recognition systems, there are specific requirements for automatic transcription system for radiology reports. We propose that the following set of requirement should be formally assessed when evaluating VUI-based report transcription systems

1. Accuracy: It is one of the most important requirements, because the wrong information can compromise report quality, alter a diagnosis and compromise a treatment.

2. Vocabulary Extent: It is a very important requirement, as the vocabulary can neither be too big in order to lower the rate of word recognition nor too small for it not to consider the words in the application's dominion.

3. Specific Dictionary for RIS: The system must consider the words used daily in radiology reporting

4. Hospital environment: depending on the area, hospitals can be very noisy, but that should not interfere with the efficiency of recognition.

5. Continuous Recognition: the user must be able to dictate the report naturally, without having to worry about pauses between words, i.e., the user must be able to speak in a natural and continuous way.

6. Desirable separation between the keyboard and the dictation system: The user should be able to dictate through a specific voice capture device, through a cellular or regular phone, allowing the application to be ubiquitous;

7. Use of client-server or browser-server architectures: For the radiologists to be free to move from one station to another in a hospital or clinic, or even across hospital units in a network of health care providers:

8. Integration with exiting systems: PACS, HIS e RIS;

9. Time for the report to be ready: must be at least shorter than the human transcription systems;

10. User's naturalness of speech: The user must be able to speak in a natural and continuous way, as if the user were recording an audio tape;

11. Resolution of ambiguity for homonyms: Words that have the same pronunciation but different spelling should not affect the application.

Proposed Methodology

The proposed evaluation methodology should be able to:

- Use additional usability and inspection tests to provide a lower cost and shorter assessment time.
- Be applied to previously implemented systems;
- Function as a guide to evaluating the usability in this class of systems;
- Investigate the difficulties in evaluating specific requirements;
- Group the proposed requirements according to their characteristics;
- Propose metrics for evaluating each of those requirements.

This methodology proposes that the interface evaluation should be done by inspection[1] whenever possible, without involving the user in order to decrease the usability tests session prices. Use the usability tests when it is verified that the inspection is not enough.

To assess automatic report systems, the following classes were here defined in a modified way from what Möller [31] proposed in his work about general purpose voice recognition system evaluation:

- Class 1 – Achievement Requirements associated to the correct operation of the application without degrading its achievement. Accuracy, vocabulary size, specific dictionary for RIS, noisy environment, user's naturalness of speech (continuous recognition)
- Class 2 - Usability Efficiency and efficient requirements, decreasing the user's cognitive load: Minimization of memory overloads, adequate modality, time for the report to be ready;
- Class 3 – Hardware and Integration: Requirements connected to physical achievement: Separateness between keyboard and dictation, use of proper architecture (client-server or browser-server), integration with existing systems, quality of audio system, and quality of database entries.
- Class 4 – Human Factors Requirements connected to the user's pleasure in using the system and the will to continue to use it;
- Class 5 – Feedback: System's feedback time, system's visibility, feedback's adequacy, message exit quality;
- Class 6 – Handling Error and Help: Requirements that are related to the capacity of the system in correcting not only errors found but also correcting a dictation, may it be in real or posterior time.

[1] Usability inspection is a set of methods where an evaluator inspects a user interface. It can generally be used early in the development process by evaluating prototypes or specifications for the system that can't be tested on users. It generally considered to be cheaper to implement than testing on users [35].

The requirements were classified according to the level of assessment difficulty (Level 1 – low complexity, Level 2 – medium complexity and Level 3 - high complexity) as an example: accuracy; vocabulary size; noisy environment; continuous recognition fall in complexity Level 1.

A method for analyzing each requirement was developed. A template was created for each requirement in order to facilitate the assessment, as illustrated in Table 1, for Client's Satisfaction.

Table 1 – Template of Client's Satisfaction

CLIENT'S SATISFACTION	
Kind of Evaluation	Subjective
Evaluation Methods	Questionnaire
Importance	High
Difficulty in Evaluation	Level 3
Evidence to look for / Metrics to use	Ease of use, aggregated value, success of the task

The corresponding questionnaire was based on SUMI (Software Usability Measurement) of University College Cork.

Conclusion

This article focuses on the evaluation of automatic transcription system for radiology reports. Various specific requirements in this class of systems that are not taken into consideration either by the classic evaluation methodologies of usability or by the new VUI evaluation methods were identified. These requirements have been neglected when these applications are evaluated.

A methodology to provide these peculiar requirements based on usability inspection and usability tests was proposed, in order to assure a lower cost and a higher efficiency.

As future work, this methodology should be applied to several case studies in order to be perfected and validated for real cases.

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A New Approach for Goal-oriented Analysis of Healthcare Processes

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Abstract

The development of efficient e-services for patient-centered healthcare requires insight into concrete problems in administrative and clinical work processes as well as an understanding of the strategic goals that should guide these healthcare processes. However, considering both concrete process-related problems and high-level strategic goals during process analysis and solution design can be problematic. To address this, we propose a structured approach for analyzing both high- and low-level goals in a healthcare process and relating these to identified problems. Thereby proposed solutions for each problem in form of, e.g. e-services can be connected to strategic goals. The approach consists of five steps; process modeling; process-based problem identification and classification; process goal identification; mapping to strategic goals; and solution proposal. The approach is illustrated by examples from a case study of Swedish stroke care. In conclusion, the approach enables analysis of high- and low-level goals in a healthcare process by relating these to identified problems. The results thereof form a basis for redefinition of current care processes, as well as for design of supporting e-health solutions.

Keywords:

Medical informatics, Systems analysis, Process assessment (Health Care)

Introduction

Healthcare is facing a number of challenges, due to demographic, economic and societal developments. This has brought a movement away from episodic treatment of acute health issues to provision of coordinated services that will provide continuity of care for those with chronic conditions and enhance the health status of defined populations [1-3]. Yet, current care provision processes remain to a large extent organisation focused, which leads to fragmented care and a lack of continuity. This is particularly problematic in the care of patients with chronic, sometimes multiple, conditions who require care from many care provider organisations.

One example of increased focus on a holistic, high-level view, of healthcare processes is the recent interest in *patient-centered* care. The concept is used to describe a shift from organization- to patient-centric provision of healthcare, in order to strengthen the role of patients and family carers [2]. This change poses new challenges for existing healthcare processes; new solutions that create concrete value for patients while meeting general high-level goals set by the healthcare community need to be provided. In order to be able to redesign healthcare to meet the described challenges, new instruments to represent and visualise the complexities of healthcare are required.

The objective of this paper is to describe an approach for analyzing high- and low-level goals in a healthcare process by relating these to identified problems in the process, and to apply this approach in form of a case study.

Related work

The approach presented in this paper combines the use of processes and goals. Generally a process describes a set of linked activities that produce a certain output [4]. In the health care sector the use of processes is crucial to understand problems and improve performance [5]. While we in this paper use processes as a mean to identify process related problems in a health care organization, more detailed process models can also be used for verification purposes [6]. Together with processes we employ the notion of goals to relate high-level strategic goals with the low-level goals needed to be attained in order to solve the identified problems. The way we use goals in this paper is similar to the well-known approach of goal decomposition [7]. However, rather than performing a top-down decomposition, such as in [8] and [9] we relate identified low-level process problems to a fixed set of high-level goals.

Material and Methods

Data for this study is collected: (1) from documents, (2) through focus groups with different stakeholders, (3) through interviews with single experts, and (4) by using the Business Process Modeling Notation (BPMN) [10] for process model-

ing. These methods are iteratively applied during the approach described below, using document analysis, focus groups and BPMN for initial process modeling and applying focus groups and expert interviews in each successive step of the approach for further modeling and verification. The entire approach is then applied in form of a case study using stroke care.

Overview of the proposed approach

The purpose of the approach presented in this paper is to improve healthcare processes by aligning them with well-accepted, high-level goals, starting from concrete problems that exist in the processes and continuing to propose solutions to those problems. The suggested approach consists of five steps:

Step 1 - Process modeling: the healthcare process at hand is modeled (if such a model is not already available). This is done in collaboration between all the stakeholders relevant for the given healthcare process and process modeling experts.

Step 2 - Process-based problem identification and classification: concrete problems in the process are identified by using a *problem classification* based on process aspects. Here, we address four process aspects (functional, behavioral, organizational and informational [11, 12]), but other aspects can be taken into account. For each process activity, every process aspect is considered and related problems are identified.

Step 3 - Process goal identification: all identified process problems are transformed into low-level goals, by rewriting the problem as a desired state that alleviates the problem.

Step 4 - Mapping to strategic goals: after defining a process goal, this low-level goal is mapped against one (or more) strategic, high-level goals. The high-level goals can either be set-up on a process basis, or more likely, a well-established set of goals such as the organization's strategy can be used. In this paper, we apply the major aims for healthcare improvement set up by the Institute of Medicine (http://www.iom.edu/); safety, effectiveness, efficiency, patient-centeredness, timeliness, and equity [13].

Step 5 - Solution proposal: the final step is to propose possible solutions in order to solve the problems and achieve the goals. In this step the problem classification and each problem's related goal can aide in the design of the solution.

In contrary to previous work, we chose these steps because a bottom-up analysis was considered best to relate existing problems to strategic goals. This way we aim to both find suitable solutions for the problems and to elucidate the entire process between the operational and the strategic level.

Application of the approach to Swedish stroke care

In the following sections details of our approach will be further explored by describing how each of the five steps in the proposed approach was performed in the VIPPA (the Swedish acronym stands for visualization of patient-centered process models in healthcare) research project.

Step 1: Process modeling

In the VIPPA project a combination of process-modeling, interviews, and structured problem analysis was used to gather information about the stroke care process and its inherent problems. Modeling of the stroke care process was based on documentation of previous work done in Sweden [14] as well as interviews with key stakeholders. Swedish national guidelines and national performance measures [15] for stroke care was also a valuable source of information. The modeling was done according to the Business Process Modeling Notation (BPMN) [10]. Both process modeling and analysis were done in collaboration between experts on process modeling, stakeholders from healthcare and health informatics researchers. The results were also presented to different stakeholders who had not been actively involved in the modeling process to receive feedback and validation.

An extract from the process model, showing discharge of a patient from hospital care to homecare, including examples of identified problems, is presented in Figure 1.

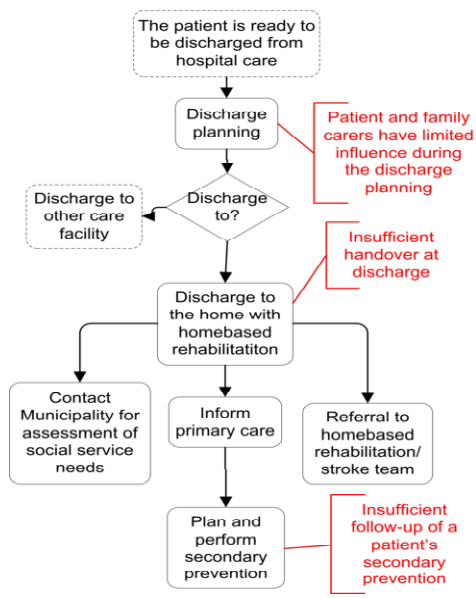

Figure 1 – Extract from the Stroke care process model indicating identified problems

Step 2: Process-based problem identification and classification

The process modeling revealed a number of problems in the stroke process. To structure, document and analyze the problems they were classified into four problem classes. Each problem class conforms to a specific process aspect, as presented by Jablonski [11] and Raush-Scott [12]:

Information: problems related to availability of process information. It is for instance problematic if the hospital doing the

acute treatment does not pass on information to the primary care and the patient's municipality.

Functions/Activity: Problems related to the outcome and execution of process activities; for instance limited follow-up activities regarding secondary prevention is considered a functional problem.

Behavior/Time: These problems refer to the timing, ordering and selection of activities; for instance, in the stroke process it is important that the time between the first symptoms (the first activity) and diagnosis is less than three hours in order for certain effective treatments, such as thrombolysis ("clot busting"), to be possible.

Organization: Problems referring to the actors that participate in the process and their available resources, such as skilled nurses and physicians, and equipment. It is for example considered as an organizational problem that patients and family carers have limited influence on discharge planning.

Each elicited problem in the process was assigned to one of the above described problem classes. When an initial problem was difficult to classify it was further decomposed into more concrete problems by the use of the four problem classes.

Figure 2 illustrates how the problem "Insufficient handover at discharge" is broken down into three more concrete problems in this manner.

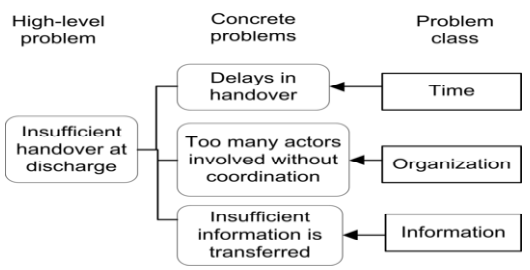

Figure 2 – Problem break-down and classification

Step 3: Process goal identification

Once the problems identified in step two are addressed the health care process under study can be improved. However, in addition to addressing classified process problems it is of interest to examine how a solution of the problems contributes to high-level goals, such as increased patient safety.

In order to relate the problems to high-level goals we transform each problem into a low-level goal by rewriting the problem as a desired state that alleviates the problem. Since each problem is related to a problem class (information, behavior/time, functions/activity, organization) we can express the desired state in terms of the desired condition for that class. For example the information related problem "Delays in handover from hospital care to other care providers" (figure 1), can be expressed as a desired state of the *behavior/timing* of the process, "Reduce delays in handover from hospital care to other care providers".

In Table 1, we provide a number of low-level goals defined based on the problems illustrated in Figures 1 and 2.

Table 1 – Classified problems related to lw-level and high-level goals

Problem class	Problem (concrete)	Low-level goal	High-level goal
Behavior/Time	Delays in handover from hospital care to other care providers	Reduce delays in handover from hospital care to other care providers	Timely care (continuity of care)
Organization	Too many actors involved in the care of a patient without coordination	Appoint a coordinator that is responsible for the overall care process	Patient-centered care
Information	Insufficient information is transferred from hospital care to other care providers	Improve the quality of the information being transferred	Safe care
Functions/Activity	Insufficient follow-up of a patient's secondary prevention	Create routines for continuous follow-up of stroke patients	Effective care
Organization	Patients and family carers have limited influence during the discharge planning	Invite patients and family carers to take a more active part in the discharge planning	Patient-centered care

Step 4: Mapping of low-level goals to strategic, high-level goals

After defining a low-level goal, the goal needs to be mapped to one of the high-level goals. In doing so, the goals of the process become justified from a strategic perspective. The approach presented here can be applied when using any high-level goal framework; it is up to the healthcare management to set up overall high-level goals. In order to illustrate our approach, we apply a framework of six goals proposed by the Institute of Medicine [13]. These goals state that healthcare should be

1. *Safe* - avoiding injuries to patients from the care that is intended to help them,
2. *Effective* - providing services based on scientific knowledge to all who could benefit and refraining from providing services to those not likely to benefit (avoiding underuse and overuse, respectively),

3. *Patient-centered* - providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decision,
4. *Timely* - reducing waits and sometimes harmful delays for both those who receive and those who give care,
5. *Efficient* - avoiding waste, including waste of equipment, supplies, ideas, and energy, and
6. *Equitable* - providing care that does not vary in quality due to personal characteristics such as gender, ethnicity, geographic location, and socioeconomic status.

In order to map an elicited low-level goal to a high-level goal it is examined *why* a certain low-level goal should be fulfilled. For example, why is it important to "Improve the quality of information transferred"? Is it (primarily) because safety will be improved (the first high-level goal), or is it because of effectiveness reasons (the second high-level goal)? In this case we indicated that improved information quality is primarily motivated by the desire to improve patient safety (Table 1).

Step 5: Solution proposal

Proposing solutions is a creative process, involving initial brain storming techniques to propose alternative solutions to each problem. Often a few solutions appear obvious, such as directly fulfilling each individual low-level goal. However, it is important to take this process further by considering how different solutions could contribute to several high and low-level goals.

As an example, Figure 3 depicts how a solution in form of an e-service for discharge care planning is suggested as a potential solution to achieve the different low-level goals. The solution analysis can be detailed to different levels, either remaining on high level suggestions, or being further detailed into different models depending on the type of problem analyzed. Further analysis of an informational problem may e.g. result in e-service specifications including information models.

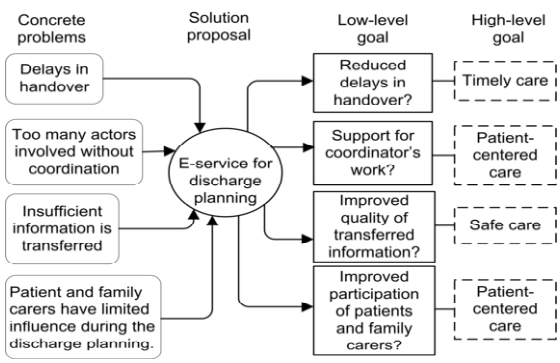

Figure 3 – Solution proposal

Results

We consider the application of this five step approach as useful for analyzing complex processes in multi-actor environments and specifically for elucidating the entire process between the operational, tactical and strategic level.

More specifically, we found the following advantages. Although some problems were previously known, others were first discovered and made explicit during the process modeling and analysis. Use of the process aspects was very useful to classify the problems and also when concretizing the problems further. As the low-level goals are defined based on the classified problems, they are process-related and concrete enough to be defined in a measurable form, In turn, high-level goals are difficult to measure but as they are connected to low-level goals, their impact on specific problems can be shown and it is possible to evaluate the impact on a strategic level. The mapping from low-level goals into high-level goals is not always a straight-forward process. However, the mapping is made simpler if the high-level goals are well defined, or even broken down into sub-goals. Likewise, the mapping is made easier if the low-level goals are not too wide; in the approach presented here this is ensured by using the four process aspect framework to break down the problems. In addition, the defined low-level goals will be further useful when evaluating the impact of the e-service. Considering several different concrete problems, low-level and high-level goals can improve the design of the e-service such that it gets the ability to tackle several problems in the complex care process. Moreover, during the detailed solution design, design decisions can be made and, sometimes more importantly, motivated based on the desire to reach the high-level goals associated with the solution.

Discussion and future work

Implementation of health information systems (HIS) will only be successful if decision-making processes at strategic, tactical and operational levels can be matched [16]. This is especially true for HIS that should support patient-centered care as they usually need to support both multiple actors and multiple organizations. The approach presented in this paper is a first step towards matching different levels by connecting problems in existing processes with high- and low-level goals as well as supporting e-services.

In the VIPPA-project, the entire stroke care process was modeled; from primary prevention, acute and continued hospital care, rehabilitation, discharge to primary care/homecare and finally secondary prevention activities. A holistic view of the process enabled us to identify problems relating to for example continuity of care and patient-centeredness that could otherwise have been overseen. The process involves a large number of different stakeholders, and we also aimed at analyzing the process from their different perspectives in order to capture all potential problems and their respective goals.

The goals described here need to be broken down further and be related to each other in order to evaluate potentially conflicting goals. Similarly, problems and possible solutions need

to be fine-grained and mapped to each other. In addition, their impact on the redesign of existing processes has to be analyzed. In order to be able to better understand all these relationships, we aim for visualizing selected scenarios out of the whole process. As a next step we will visualize a scenario as is in current care processes, then discuss possible sub-solutions for each identified problem, relate these to identified goals and visualize how implementation of these solutions would meet these goals and change current care processes.

Conclusion

In this paper, focus was on analyzing problems in existing healthcare processes, in order to solve them in alignment with strategic goals, as established in a certain healthcare community. Using a process modeling approach, we classified problems into four categories: behavioral/time, functional/activity, informational and organizational. This approach is used to aid domain experts when identifying problems in current processes. Once identified and classified problems are transformed to process-related goals, which aim to improve the functional, organizational aspects of processes. Those process goals are further examined for a relation with a set of well-established, high-level goals to justify requests for their realizations. A way to realize the goals implies the design of adequate solutions, for example in the form of e-services.

In conclusion, the approach presented in this paper enables analysis of high- and low-level goals in a healthcare process by relating these to identified problems in the process. The results thereof can be used as a basis for decision making and redefinition of current care processes, as well as for design of e-health solutions to support the re-designed processes.

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Implementation of a Patient Data Management System – An evaluation study of workflow alterations

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Abstract

This paper describes a combined evaluation approach for an information system on intensive care units. Staff self assessment of time needed for documentation activities during admission, daily treatment and discharge/transfer has been compared to a workflow analysis which demonstrated that the system eliminated process steps mainly in daily documentation activities. Interestingly, nursing staff reported major time savings rather during discharge/transfer than in daily documentation, whereas physicians noticed no time savings at all. We conclude that combining workflow analysis with either self assessment of time needed or alternatively appropriate time measurements or both increases insight into organizational changes and their implications after system implementation.

Keywords:

Evaluation, Workflow, Patient data management system.

Introduction

Implementation of a clinical information system does not only concern technical issues but is driven by operational, strategic, cultural or even political changes in the respective organization where the system is introduced. System failures can often be blamed on insufficient change management [1,2]. Berg even stated that implementation of a patient care information system can never be fully planned and controlled due to ongoing organizational changes in a process of mutual transformation [3].

Numerous evaluation studies found improvements after implementation of an information system but others couldn't confirm these findings (see e.g. [4,5,6,7,8] with focus on intensive care environments). Some studies demonstrated an impairment of communication and organization issues, with the potential of system failure or even endangering of patients [9,10].

With regard to Patient Data Management Systems (PDMS) for Intensive Care Units (ICU) there are few studies comparing modifications e.g. in organization and workflows before and after implementation of an information system. We found several studies [11,12,13] dealing with the development of new types of role- and activity-dependent respectively cognitive workflow models. Only Cheng et al [14] compare workflows before and after implementation of a CPOE system on ICU.

With the implementation of a PDMS in one ICU of Erlangen University Hospital we expected improvements in all areas where data could be reused, e.g. reuse of ADT data and automated data transfer from patient monitoring and respirators. We expected more work in all areas where previous paper documentation had now to be done tediously on computer.

The objective of this study was to analyze how our expectations would be met, which activities in the documentation workflow did change and how these workflow alterations correspond to time needed for clinical documentation.

Materials and Methods

The study took place between October 2006 and October 2007 in the Interdisciplinary Operative ICU (IOI) of Erlangen University Hospital, Germany. The IOI has 25 beds and cares for approximately 2000 patients respectively 6800 patient-days per year. In October and November 2006 a commercial PDMS (Dräger ICM) was stepwise introduced. It was fully operational for all 25 beds in December 2006.

A multifocus evaluation study consisting of time measurements, questionnaires and documentation workflow analysis was performed before and after system introduction. The questionnaire was distributed 3 times, namely before (t1), 3 months after (t2) and 12 months after implementation of the PDMS (t3). Among others it included a self assessment of time needed for different documentation activities. The questionnaire described decisively which activities should be assessed (e.g. all documentation activities around admission of a patient) giving explicit examples for physicians, nurses and clerks respectively. We asked to quote the total time needed to perform those activities for one single patient during one shift within the interval options less than 10 minutes, 10-19 minutes, 20 to 29 minutes, 30 to 39 minutes, 40 to 49 minutes and more (with the option to enter a precise number). From the returned questionnaires we calculated a mean value of time spent.

We analyzed documentation workflows before and after implementation of the PDMS and documented them using the software Aris® from ids Scheer. Workflow analysis was performed in two steps. In the first phase one person observed the activities and documented them over several weeks. The same person collected information on all kind of paperwork done on the ICU and the computer systems which were employed before PDMS implementation. This resulted in a first set of pre-PDMS workflow models. In the second phase those models have been reviewed and rectified together with staff members (physicians, nurses, medical clerks) of the ICU. A second similar analysis was performed 3 months after PDMS implementation.

For workflow analysis we used the method described by Pomberger/Gerken [15,16] which usually comprises seven steps:

1. *Analysis of structure.* Comprises organizational structures / hierarchies, number and qualification of staff and relationships to other divisions of the corporation.
2. *Analysis of forms and paperwork.* Systematic collection and analysis of all forms and paperwork with a formal description for each form and its workflow.
3. *Analysis of data items.* Systematic collection and analysis of all data items and information systems in which those data are applied or produced.
4. *Analysis of atomic actions.* Systematic collection and analysis of all process steps which are not further decomposed. For each process step responsible person, forms used and data required are recorded.
5. *Analysis of workflows.* Systematic collection of all complex action sequences based on the process steps analyzed in the previous stage.
6. *Analysis of communication structures.* Systematic definition of a communication matrix, illustrating all communication processes and information flows between different partners based on the first 5 analysis steps
7. *Analysis of weak points.* The identification of weak points aims at providing the basis for future optimization.

For the current project we restricted this analysis to Step 1 to 5 focusing on documentation workflows. Activities of nursing or medical care were omitted.

Workflow diagrams were arranged according to the Aris model [17] with a four level depth of hyperlinked workflows. We used value-added-chain models on level one and two, process-matrix models on level three and event-driven-process-chain models on level four. From these resources we synthesized parallel workflow diagrams in order to compare the status before and after PDMS implementation.

Results

Self assessment of documentation time

Nurses returned 42 of 92 (t1), 29 of 96 (t2) and 23 of 97 (t3) questionnaires. Physicians returned 11 of 15 (t1), 9 of 16 (t2) and 12 of 18 (t3) questionnaires. The average response rate was relatively low with 33% for nurses and 65% for physicians.

Figures 1 and 2 demonstrate the results of time estimations. While physicians did not estimate any relevant time savings for any of the activities such as admission, daily activities and patient transfer/discharge, nurses reported a continuously decreasing time spent for daily documentation activities (down from a mean of 41 at t1 to 31 minutes at t3) and a quickly decreasing time spent for documentation activities around patient discharge (down from 37 minutes to 11 respectively 13 minutes at t2 and t3).

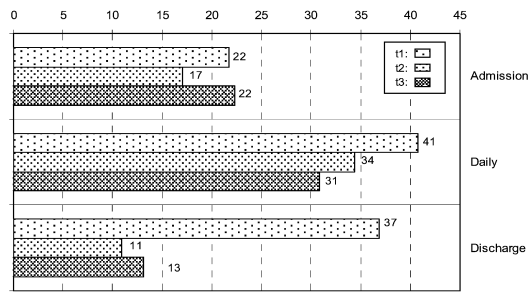

Figure 1- Nurses: estimated time needed in one shift for documenting one patient at t1, t2 and t3 (minutes)

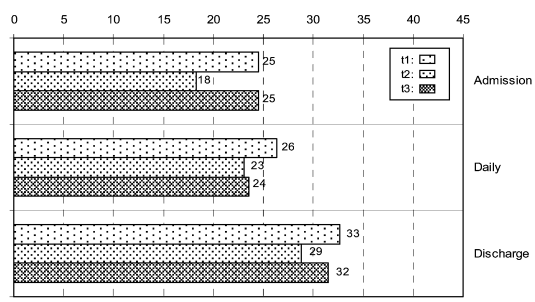

Figure 2-Physicians: estimated time needed in one shift for documenting one patient at t1, t2 and t3 (minutes)

Workflow analysis before and after PDMS implementation

We obtained a total of 29 workflow models for administrative activities of ICU staff before and 25 after PDMS implementation. We grouped them under the high level process-chain steps “admission”, “daily activities” and “discharge”. Together

with organizational view and data view models we ended up with a total of 61 diagrams before and after PDMS implementation. From these resources we synthesized 27 parallel workflow diagrams in order to compare the status before and after PDMS implementation. Figures 3 and 4 demonstrate two examples of such parallel workflow diagrams.

As shown in figure 3 nursing documentation activities for a blood gas analysis (a frequent process in an ICU) have been simplified with the implementation of the PDMS. Previous process steps such as printout of results from the BGA machine and sticking those paper results into the patient paper record have been eliminated after PDMS implementation due to automated data transfer, thus simplifying this workflow.

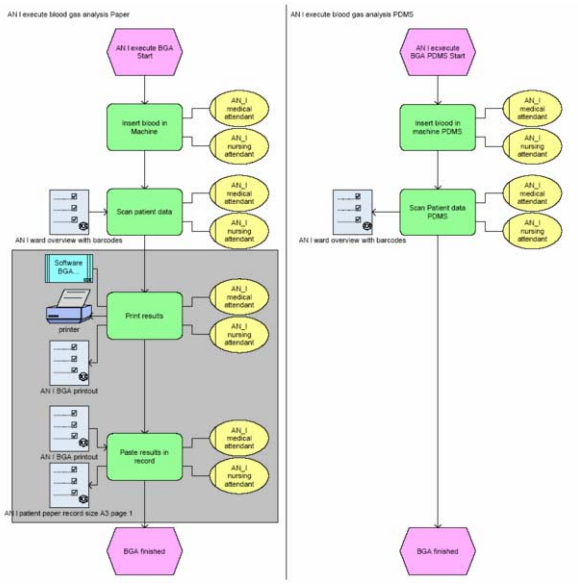

Figure 3- event-driven-process-chain "execute blood gas analysis" and related documentation steps. Left before, right after PDMS implementation

We also found workflows which have been extended. Figure 4 may serve as an example illustrating administrative process steps for admission of a new patient to the ICU.

In the former paper-based workflow the patient arrives on the ward with an empty paper record or the latest available paper record in case of previous admission. No further process steps were required. After PDMS implementation however a new electronic record had to be created for each patient upon arrival in order to start the clinical documentation. Creation of this electronic record comprises working in two software applications. In the generic hospital information system a short electronic admission procedure for the patient and the creation of a new follow-up case is necessary. In the PDMS the new patient case information must be imported and a bed must be assigned. In addition a third specialized ICU software application was used to collect essential reimbursement data. Later this last process step could be performed using new enhanced functionalities of the PDMS thus substituting this activity.

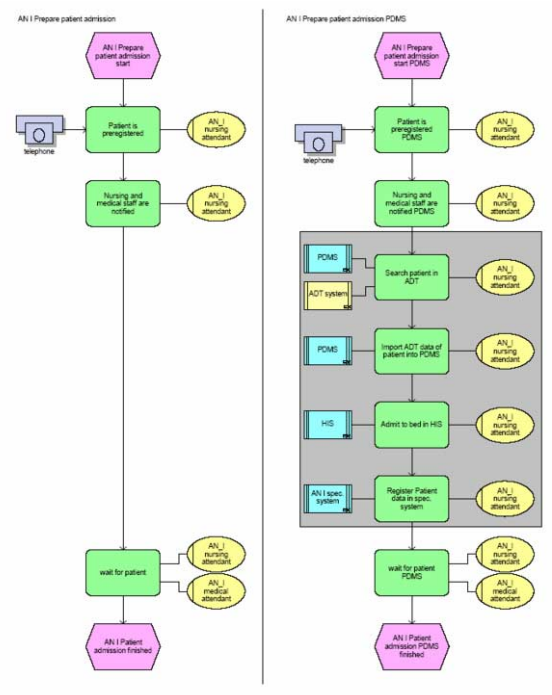

Figure 4 - event-driven-process-chain" prepare patient admission". Left before, right after PDMS implementation

The 27 parallel workflows can be divided into 5 workflows concerning "patient admission", 16 workflows for "daily activities" and 5 workflows concerning patient "discharge or transfer". A top level workflow links these three groups together. Summarizing we detected a multitude of workflow alterations within the 27 parallel workflows.

Eighteen workflows were found to be at least one process step shorter after PDMS implementation, six were of equal length and three workflows had grown considerably (table 1). We noticed shorter workflows in fields such as automated data import from medical equipment (see figure 3), but also in areas where documents could be composed semi-automatically with the help of the PDMS, e.g. during patient discharge and preparation of the discharge documentation. An increased number of process steps was found in the workflows "closing patient record" and "synchronizing PDMS data with HIS".

It is interesting to note that the largest reduction of process steps was found in the group "daily activities" (with three level 3 process steps eliminated). We saw a small respectively non existent reduction of process steps in the groups "admission" and "discharge/transfer".

Table 1 – rows 1-4: No. of workflows in the groups "patient admission"," daily activities" and "patient discharge / transfer" before and after PDMS implementation. Rows 5-6: Number of eliminated process steps in these workflows. Note that the total No. of workflows mentioned in the text (27) includes a top level linkage workflow which remained unaltered and is not considered here.

	Admission	Daily Activities	Discharge
1. Total No. of workflows	5	16	5
2. Workflows shorter with PDMS	2	13	3
3. No change in workflow length	2	2	1
4. Workflows longer with PDMS	1	1	1
5. Total No. of eliminated process steps	-1	16	0
6. No. of eliminated process steps level 3	1	3	0

This is in sharp contrast to the self estimation of nurses and physicians. Physicians reported no time savings at all whereas nurses reported considerable time savings during discharge activities which is not reflected in the actual workflows. Only the time savings in daily nursing documentation fit to a reduction of process steps in the respective workflows.

Discussion

Methods

Self assessment of time spent for documentation has been reported in other studies (see e.g. [18]). Compared to other available methods such as time motion studies, or workflow sampling its results are prone to subjective opinion, may reflect individual convenience and could be influenced by effects such as Hawthorne effect. In addition, predefined answering options may influence the results. Therefore we used intervals of equal length up to 50 minutes plus an option for precise numbers to minimize this effect.

Other time measurement methods require appropriate consent of the observed staff and enough observers to perform them. Another problem for exact time measurements is that we didn't know exactly what to measure before the second workflow analysis was finished. Thereafter a "before" measurement was no longer possible. Within the study we took some objective time measurements before and after system implementation, but the measured activities did not correspond well to the workflows. There are methodical limitations to measure e.g. the time spent for documenting for one patient one day or shift, because these are disruptive activities and clinical staff tends to combine documentation activities for several patients at a time.

We found only four studies dealing with workflow analysis in intensive care environment [11-14]. Just one study had a comparative approach [14]. Workflow analysis has gained impact in the area of hospital information systems and more specifically to improve workflows in radiology departments (see e.g. [18]). We are not aware of any study in ICU where workflow changes have been contrasted with time measurements or self assessment of time spent for activities. A potential problem of workflow modelling is the method used and the depth of process decomposition. We used a well described method for business workflow modelling [17] but nevertheless considerable degrees of freedom e.g. regarding depth of decomposition remain. Therefore it can be difficult to compare workflow models between institutions.

Results

Self estimations showed a reduction in nursing documentation time for daily activities and discharge whereas physicians did not report relevant time savings after PDMS implementation. This seems strange because the PDMS supports automated scoring of ICU patients and automated compiling of discharge summaries which otherwise consumes much time [20]. As a potential reason (apart from possible Hawthorne effect which should affect nurses and physicians likewise) we assume that fluctuation of medical staff, which was much higher than of nursing staff may have led to a situation where physicians at t2 and t3 had not been in contact with the previous paper based documentation. Altogether only 2 physicians completed all three questionnaires compared to 9 nurses. The majority of nurses had worked more than 4 years on this ICU, the majority of physicians less than 1 year. Both findings support this assumption. An objective time measurement should not be influenced by fluctuation, but self assessment of time spent for activities may well be dependent of the fact that the person noticed an improvement after PDMS implementation. Alternatively, the disjunct time intervals of self assessment (10 minutes) may have been longer than the potential time savings noticed by physicians.

We found a reduction of process steps in the "daily activities" workflows. Workflows during "admission" and "discharge" showed nearly the same total number of process steps before and after PDMS implementation. As mentioned previously, we expected improvements in those areas where data could be recorded once and then be reused. Typically, this would be the case e.g. in "daily" documentation of vital signs (automated data transfer from patient monitor), but also in activities around "discharge/transfer", where the PDMS helps to compile all previously recorded relevant information into one or several discharge documents. Obviously this is not reflected in a reduction of the total number of process steps. There, an analysis of time spent for "identical" process steps before and after system implementation would be conclusive. Again, the granularity of process steps (see methods discussion) may have influence not only on the total number of process steps but also on the differential count before and after PDMS implementation. Future work (the PDMS is in rollout to other ICUs as well) will concentrate on those findings and implement specific time measurements for such process steps.

Self assessment of time reduction reported by nurses did only partially correspond to a reduced number of process steps ("daily activities" group), but not in the "discharge" group. At this point a look into [14] is interesting. In this study dealing with a CPOE system the authors conclude that workflows in reality do not reflect workflow assumptions made during CPOE system design.

Methods such as direct time measurements or extensive work sampling studies to evaluate time savings after implementation of an information system have not always been conclusive [7,8]. In some cases time spent for indirect patient care tasks such as charting has been decreased, in others no change was found or even more time was required. Therefore we recommend to add the method of workflow analysis in order to pinpoint changes in workflow which can then be measured and validated much more specifically than before.

Conclusion

Considering our knowledge about change management and its influence upon success or failure of introduction of information systems it seems worthwhile to include pre/post workflow analysis into the toolbox for system evaluation in order to gain insight into the nature of inflicted changes. Results of this method can be used directly but will be even more valuable in conjunction with other evaluation methods such as time measurements, time estimates, subjectivist interview techniques, user satisfaction surveys etc. In addition, workflow analysis can play a formative role in system development and help to find weak spots in workflow. Its results may generate the base for an objectivist study which strives to deliver summative results. For comparison between different institutions it will be desirable to standardize the methods of workflow analysis and workflow modelling to achieve comparable workflow models.

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Chapter 18.

Imaging

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Evaluation of Methods for Bolus Arrival Time Determination using a Four-dimensional MRA Flow Phantom

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Abstract

In this paper an evaluation of methods determining the bolus arrival time (BAT) using a four-dimensional flow phantom to simulate 4D MR angiography is presented. Spatiotemporal 4D MRA images were acquired for analyzing the hemodynamic characteristics of cerebral vessel anomalies. Model-independent and model-dependent methods for BAT extraction are published. Generally, for the evaluation no gold standard exists and datasets with known BAT values are required. Here, a 4D flow phantom is generated based on a synthetic 3D MRA dataset with BAT values defining the time point of blood inflow for each voxel. Then, voxel-by-voxel concentration-time curves based on the gamma-variate function were computed leading to a simulated 4D MRA dataset. Additionally, partial volume effects and Gaussian noise were integrated. The simulated 4D MRA was visually inspected and regarded as similar to clinical data. Finally, phantom datasets with different vessel diameter and signal-to-noise ratio are computed. Three state-of-the-art methods were used to extract BAT values. Computed and known values were compared. The results suggest that model-dependent approaches perform better than the model-independent method.

Keywords:

Hemodynamics, Blood flow, Vascular desease, Phantoms, Imaging

Introduction

Cerebral vascular diseases like aneurysms or arteriovenous malformations are one of the major causes of death worldwide [1]. For an improved rating of the disease and therapy planning detailed knowledge about the individual vessel anatomy and hemodynamic situation is needed [2].

Generally, imaging techniques like 3D computer tomography (CT) or digital subtraction angiography (DSA) are clinical standard for the analysis of the hemodynamics. Unfortunately, those techniques are based on ionizing radiation. Furthermore Warnock et al. [3] reported that the DSA as an invasive procedure has a complication rate of approx. 3.8% and supplies only 2D projections of the vessel system. Recently, new parallel MR image acquisition techniques enables the time resolved 4D MRA imaging of the blood flow. In clinical practice these spatiotemporal 4D MRA images were acquired for the qualitative and quantitative analysis of hemodynamic characteristics of cerebral vessel anomalies like arteriovenous malformations (AVMs) or aneurism. Figure 1 shows an image sequence of a 4D TREAT MRA dataset from a patient with AVM.

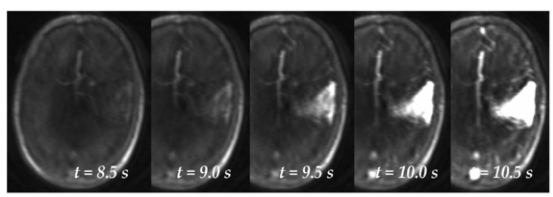

Figure 1- Temporal image sequence of a 4D TREAT MRA

Detailed evaluation of the arterial inflow and venous drainage of AVMs is important for clinical evaluation and management [4,16]. A lot of research has been done on simulation and determination of the cerebral blood flow. In 3D datasets often computational fluid dynamics (CFD) [5] were used to simulate the blood flow. Unfortunately, these approaches are computational expensive and due to acquisition time requirements the vascular system is often not completely covered by the resulting images [8].

In 4D image sequences BAT values can be determined by analyzing the concentration time curves after bolus-injection [6,7]. Here, the tracking of the signal changes provided by an injected bolus of contrast agent travelling through the vessels is used for further analysis. The focus of this work is the evaluation of methods that extract hemodynamic characteristics based on the concentration-time curves of 4D MRA.

State-of-the-art Methods for Determination of Bolus Arrival Time in 4D MRA Image Sequences

The number of publications dealing with determination of the bolus arrival time in 4D MRA is high [8]. Commonly used

approaches for analysis of concentration-time curves can be classified as model-independent or model-dependent.

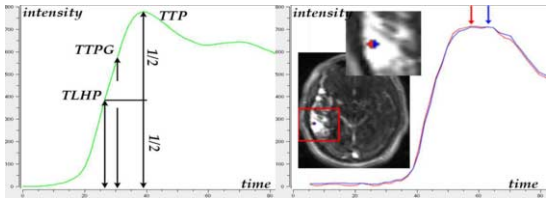

Figure 2- Concentration-time curve with criteria TTP, TTPG and TLHP (left) and the unexpected time difference of two neighbouring vessel voxels using TTP as BAT (right)

Model-independent approaches estimate the BAT directly based on the concentration-time curve. Therefore several criteria have been proposed e.g. time to peak (TTP), time to peak gradient (TTPG) or time of leading half-peak (TLHP) [9]. The major drawback of the model independent criteria is the fixed discrete BAT estimation which depends on the temporal resolution of the used data. Furthermore, it has been reported that due to noise and artefacts e.g. interpolation during the image acquisition these parameters lead to insufficient results, in terms of strong temporal differences between the bolus arrival times of neighbouring voxels [10]. Figure 2 shows the proposed criteria TTP, TTPG and TLHP (left) and the concentration-time curves of two vessel voxels and their temporal difference using TTP as BAT (right).

One *model-dependent* approach is the BAT estimation based on the fit of a gamma variate function

$$C(t) = K(t - AT)^{\alpha} e^{-(t-AT)/\beta} \qquad (1)$$

to the concentration-time curve [10,11]. Eq. 1 is valid for t > AT where t is the independent variable, AT the appearance time, K the constant scale factor and α and β are arbitrary parameters describing the shape. After fitting the gamma variate function to the concentration-time curve the BAT value is determined by extracting one criterion e.g. TTP, TTPG or TLHP of the fitted gamma variate function. Due to the mathematical properties of this function the extracted BAT value is not constrained by the temporal resolution of the given 4D MRA dataset. Unfortunately, the gamma variate fitting can lead to unsatisfying results when applied to concentration-time curves resulting from a rapid injection of a small bolus like in 4D TREAT MRA [12]. Additionally, due to the blood recirculation the realistic concentration-time curves do usually not only consist of the first pass bolus but do also show following bolus passages. So, the concentration-time curve is not as steep as the assumed hypothetical exponential decay [13].

Another *model-dependent* approach was published by Forkert et al. [8]. Here, a patient-individual reverence curve $r(t)$ is generated based on a collection of present concentration-time curves $s_i(t)$. Based on $r(t)$ one criterion is e.g. TTP, TTPG or TLHP is used to define the BAT. Estimating a linear transformation $f(x) = Ax + B$ the concentration-time curves of all vessel voxels were fitted to the reference curve such as $r(t) \approx s_j(f(t))$. The estimated fitting parameter A and B can be used to adapt the extracted criterion to determine the BAT value for the signal curve.

In order to assess the accuracy and precision of the presented methods different approaches were used. In general a qualitative evaluation was done by obtaining clinical datasets from normal volunteers. The results were compared with predicted values based on physiological and anatomical findings [6]. Additionally, series of Monte Carlo simulations were performed using realistic synthetic concentration-time curves with known parameters and covering a range of signal-to-noise ratios (SNR) [14]. As a drawback most studies focused only on the determination of the cerebral blood volume. Also the impact of selecting the optimal criteria, e.g. TTP, TTPG or TLHP for BAT estimation was not investigated.

Aim of this Work

In this paper we evaluate the aforementioned three state-of-the-art approaches with three different BAT criteria and three different pre-processing approaches for determining BAT values in 4D MRA concerning quality and robustness. Therefore, we generate a four-dimensional flow phantom to simulate 4D MRA using an extended version of the established gamma variate function. The quality is assessed by calculating and analyzing the differences between synthetic and extracted BAT values. For the robustness the chosen methods are applied to phantom datasets with different vessel diameter and varying signal-to-noise ratio (SNR). Additionally, we evaluate the optimum criteria for BAT determination.

Materials and Methods

Generation of a 4D MRA Flow Phantom

For generation of a synthetic 4D MRA flow phantom the following steps are applied.

- Extraction of realistic geometric vessel structures based on clinical three-dimensional time-of-flight MRA (3D TOF MRA).
- Generation of a synthetic 3D MRA dataset and definition of bolus-arrival-time for each vessel voxel.
- Simulation of 4D MRA datasets based on the gamma variate function considering the partial volume effects (PVE) and the signal-to-noise ratio (SNR)

These steps are described in detail in the following.

Extraction of Realistic Geometric Vessel Structures

Providing realistic geometric vessel structures a vessel system was segmented based on clinical 3D TOF MRA and a 3D model of a part of the system was generated. Then, a centerline was computed and the vessel bifurcations as well as the endpoints of the branches were detected and organized in a network. The geometrical characteristics of the bifurcations of the 3D vessel model are represented in this network by a parameter set including the position and the diameter. Based on

this information tube structures are used to build a synthetic representation of the original vessel structure. The parameter set e.g. the diameter value for each bifurcation can be adjusted for further evaluation.

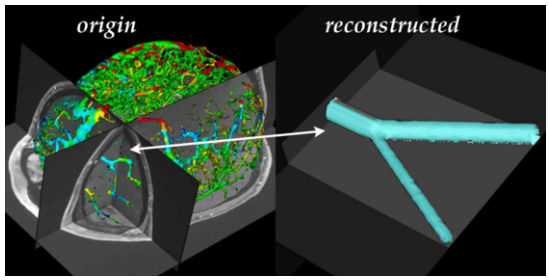

Figure 3- 3D surface model of the original (left) and the reconstructed geometric structure of the vessels (right)

Generation of the 3D MRA and BAT

The generation of a 4D MRA flow phantom dataset requires the definition of bolus arrival times. Therefore, the parameter set was extended by a new BAT entry. Then, the synthetic 3D vessel representation was transferred to a 3D image dataset with high spatial resolution. The image extents and voxels size as well as the intensity values for the vessels, brain structures and background were chosen based on clinical 3D TOF MRA. Additionally, a BAT value was computed for each vessel voxel. Here, a linear interpolation of the BAT of the neighboring bifurcation or end points is used. Figure 3 shows the 3D surface model of the original (left) and the reconstructed geometric structure of the vessels with different diameter (right).

Simulation of 4D MRA

The simulation of spatiotemporal 4D MRA image sequences based on a synthetic 3D MRA dataset requires the simulation of concentration-time curves for each vessel voxel. Therefore, the established gamma variate function (1) is used with $\alpha = 3.0$ and $\beta = 1.5$ regarding to the values published by Chen et al. [15]. In order to address the effect of recirculation of the contrast agent bolus the final concentration-time curve is computed by adding two gamma variate functions with different scaling factors $K_1 = 400$ and $K_2 = 80$ as well as different appearance time points $AT_1 = BAT$ and $AT_2 = BAT + \partial t$ with $\partial t = 8$ frames. Figure 4 shows a clinical concentration-time curve with a fitted gamma variate function (left) as well as a generated signal curve $C(t)$ (right).

Then, a temporal sequence of 3D MRA images is generated where the intensity of each vessel voxel V at time point t_i with $i = 0 \ldots n$ are defined by its concentration-time curve $C_V(t_i)$ leading to a 4D MRA with high spatial resolution.

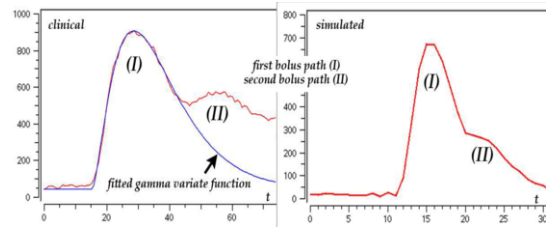

Figure 4- A clinical concentration-time curve with a fitted gamma variate function (left) as well as a generated concentration-time curve (right).

The acquisition of clinical 4D MRA datasets has a tradeoff between temporal and spatial resolution. To improve the temporal resolution the spatial resolution is decreased leading to a partial volume effect (PVE) that can have a significant impact on the accuracy of blood flow measurement [15]. To get realistic synthetic datasets the PVE is simulated be reducing the spatial resolution of the generated 4D MRA as described in [15]. Finally, Gaussian noise with different standard derivation σ is added to simulate the variance of SNR in clinical datasets.

Evaluation Procedure

4D MRA Phantom Datasets

Firstly, the quality of the generated 4D MRA was rated. Therefore, the synthetic image data was visually inspected and compared to clinical image data by two medical experts with experience in 4D MRA image analysis. Related to the clinical datasets the voxel size of the phantom was computed using a spatial resolution of 0.47×0.47×0.5 mm^3 for 3D MRA and 1.88×1.88×4.0 mm^3 with 50 time frames for 4D MRA.

Secondly, different 4D MRA datasets for the evaluation of the BAT determination were generated, one dataset representing four vessels without bifurcation but different diameters (d = 0.5, 1.0, 2.0 mm) to evaluate the robustness concerning vessel thickness and image artifacts e.g. noise. Another dataset was generated representing a part of a vessel system with one bifurcation and different BAT values for each draining vessel to evaluate the quality concerning different flow characteristics.

Also, each dataset is generated with different signal-to-noise ratio (SNR = 5, 10, 20) to evaluate the quality concerning different noise levels. This leads to 20 synthetic 4D MRA datasets for the evaluation process.

Image Pre-Processing

The model-independent and the model-dependent methods were used to compute the BAT values based on the raw concentration-time curves derived from the generated 4D MRA phantom datasets. Furthermore, since concentration time curves are usually affected by noise and other artifacts, the BAT values were also extracted based on B-Spline approximated (degree of 4) and binomial smoothed (1-4-6-4-1) signal curves in order to investigate whether smoothing is useful to improve robustness.

Similarity Measurement

For quantitative evaluation a regression analysis of the extracted and the defined BAT values of all vessel voxels is computed. Here, the correlation coefficient R^2 is used to quantify goodness of the fit. Whereas, a R^2 value near to one indicates a good fit.

For qualitative evaluation the 3D visualization was used. Here, the extracted BAT values are mapped color-coded on the 3D surface model of the vessel system. Due to the fact that the BAT values in between the bifurcations and endpoints are linear interpolated the color gradient should be homogeneous in case of optimal BAT determination.

Results

Quality of 4D MRA Flow Phantom

The generated 4D MRA image sequences were visually inspected by two medical experts. Therefore, 4D TREAT MRA datasets acquired on a 1.5T MR scanner with SNR between 10 and 25 of 20 patients with known AVM are used to compare. Figure 5 shows the comparison of clinical and simulated 3D and 4D MRA images (left) and the color-coded BAT values (right). The images with SNR = 10 were rated as most similar to the clinical one.

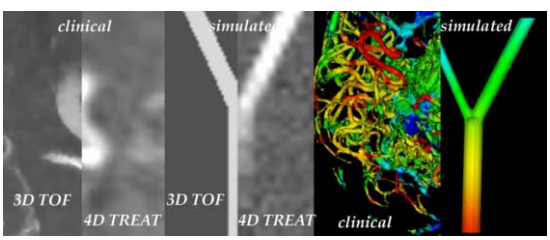

Figure 5- Comparison of clinical and simulated MRA images (left) and its color- coded BAT values (right).

Comparison of the Methods

For comparison of the model-independent (MI), gamma variate fit (GV) and reference based curve fitting (RCF) approaches with three different BAT criteria and three different pre-processing approaches were used to extract BAT values based on the simulated datasets with bifurcation. Table 1 shows the results of the regression analysis (R^2) using different criteria based on the phantom dataset with SNR = 10.

Table 1 – R^2 values for the BAT determination using different criteria (TTP = 1, TTPG = 2, TLHP = 3) computed based on a phantom dataset with SNR = 10.

	MI			GV			RCF		
	1	2	3	1	2	3	1	2	3
RAW	.985	.960	.967	.932	.971	.986	.991	.981	.987
BIN	.970	.970	.977	.975	.968	.978	.977	.980	.979
SPL	.986	.962	.966	.949	.970	.969	.987	.970	.987

Figure 6 shows the regression analysis of MI, GV and RCF using the THLP criteria and the RAW pre-processing (left). The model-independent approach depends on the discrete time points which leads to a step function line representation of the BAT times (R^2 = 0.967). The results in Figure 6 (right) show that the model-dependent methods have the best fit. Generally, the combination of reference-based curve-fitting, RAW pre-processing and the TLHP or TTP criterion leads to the highest accuracy.

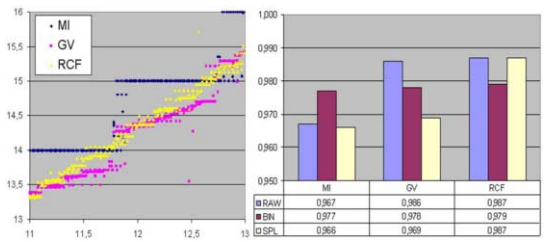

Figure 6- Regression analysis of MI, GV and RCF using the THLP criteria based on the RAW signal curves (left) and the calculated R^2 values for the approaches using THLP (right).

Influence of SNR

For evaluation of the influence of SNR the simulated datasets with tubes generated with different diameters and disturbed by Gaussian noise were used. Figure 7 shows the R^2 values of the regression analysis for MI, GV and RCF using THLP based on a tube structure with d = 1mm. The results show the quality and the robustness of the RCF approach concerning image artifacts in comparison to the other approaches. For SNR = 5 and d > 2 mm the R^2 values of all methods get similar. But, with vessel structures of d = 0.5 mm the value for the MI approach decreased to 0.929 (GV = 0.996 and RCF = 0.998).

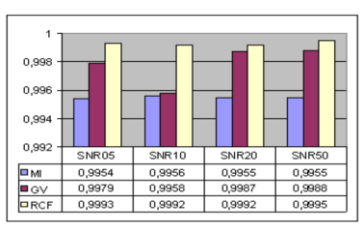

Figure 7- R^2 values of the regression analysis for MI, GV and RCF using THLP based on a tube structure with d = 1mm.

Discussion

We have evaluated three methods for BAT determination based on a 4D MRA flow phantom. Based on the gamma variate function for each vessel voxel a realistic concentration-time curve including the recirculation effect was generated. In a post-process these curves were disturbed by Gaussian noise

and partial volume simulation. The synthetic 4D MRA datasets were rated as similar to clinical 4D MRA by two medical experts.

For the evaluation process a number of 4D MRA datasets were generated with varying parameters like SNR or vessel diameter. The voxel-by-voxel definition of the BAT values enables the validation of BAT determination methods concerning robustness and accuracy. Three state-of-the-art approaches with different BAT criteria and different pre-processing were evaluated based on the 4D flow phantom. The results show that the model-dependent methods have the best potential for extraction of hemodynamic characteristics. In particular the reference-based curve-fitting obtains the most accurate results.

Due to the fact that the gamma variate function is used to generate the concentration time curves the best result was expected to be based on the GV approach. Nevertheless, the simulation of the second bolus and the image artifacts leads to a realistic modified signal curve enabling the evaluation of different methods for BAT determination.

In future the accuracy of the 4D flow phantom concerning physiological aspects should be improved by integrating e.g. poiseuille flow conditions to simulate the dispersion of a bolus during a flow down a tube. Furthermore, the recirculation process should be extended by varying the peak of first and second bolus regarding to the vessel diameter. For the evaluation process more parameters describing hemodynamic characteristics like cerebral blood volume, cerebral blood flow and mean transit time should be integrated.

Acknowledgments

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Automatic Analysis of the Anatomy of Arteriovenous Malformations using 3D and 4D MRA Image Sequences

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Abstract

The cerebral arteriovenous malformation (AVM) is an abnormal connection between arteries and veins without capillaries in between, leading to increased blood pressure which might result in a rupture and acute bleeding. Exact knowledge about the patient's individual anatomy of the AVM is needed for improved therapy planning. This paper describes a method for automatic extraction of the AVM and automatic recognition of its feeders and draining veins and en passage vessels based on 3D and 4D MRA image sequences. After registration of the MRA datasets, the AVM is segmented using a support vector machine based on blood velocity information, a vesselness measure and the bolus arrival time. The extracted hemodynamic information is then used to detect feeders and draining veins of the AVM. The segmentation of the AVM was validated based on manual segmentations for five patient datasets, whereas a mean Dice value of 0.74 was achieved. The presented hemodynamic characterization was able to detect feeders and draining veins with an accuracy of 100%. In summary the presented approach can improve presurgical planning of AVM surgeries.

Keywords:

Intracranial arteriovenous malformations, Magnetic resonance angiography, Computer-assisted image analysis, Anatomy, Blood flow

Introduction

The cerebral arteriovenous malformation (AVM) is a disorder of cerebral vessels, represented by locally missing capillaries between the arterial and venous system [1]. The missing capillaries often lead to changes of the hemodynamic situation and especially increased blood pressure in the draining veins causing dilation, which in approx. 50% of all cases leads to a rupture and following acute bleeding [2].

The aim of AVM therapy is the disconnection of the AVM from the cerebral blood circulation coincided with rupture prevention. The therapy possibilities available include endovascular embolisation, neurosurgical resection, radiosurgery and a combination of these [2]. In any case the detection of the feeding arteries is of major interest. For risk estimation of surgical resections the Spetzler-Martin scale [3] is often used. Here the morphological parameters size and location of the AVM and its drainage patterns are used to classify the patient risk for persistent neurological deficits from neurosurgery according to five grades. Additionally the detection of en passage vessels, which are vascular structures close to the AVM but not directly connected, are important for therapy planning since impairment should be avoided during therapy.

In most cases high resolution CTA or MRA image sequences are acquired to obtain morphological information about the AVM whereas the digital subtraction angiography (DSA) remains the gold standard for evaluation of hemodynamics. Unfortunately DSA is based on ionizing radiation. Furthermore an overall complication rate of 3.89% has been reported by Warnock et al. [4]. The fact that only 2D projections of the vessel system are supplied is another drawback of this technique. Recent development of new MR image acquisition techniques, especially parallel MR and echo sharing, enables the time resolved MRA (4D) imaging of the blood flow with a high temporal resolution close to the DSA but a rather low spatial resolution. The acquisition of 4D imaging might considerably reduce the risk for the patient but due to the high number of acquired images and the complex AVM anatomy the slice wise manual visual inspection for therapy planning is very time consuming and might lead to suboptimal results. A computer based preparation and visualization of image sequences can help the clinicians to obtain improved therapy plans while at the same time reducing the temporal expenses.

Although the arteriovenous malformation is of high interest in neurosurgery and neuroradiology research the number of publications dealing with the computer based analysis is low. For visualization of the AVM Bullitt et al. [5] proposed a combined visualization of surface models of healthy vessels and a representation of the AVM using volume-rendering techniques to enable the visualization of the complicated structure of the AVM. Temporal (dynamic) information of the blood flow is not included. For the estimation of the size and location of the AVM an exact segmentation is needed. For this an approach based on dynamic CT images using factor analysis was proposed by Nyui et al. [6], as a drawback the results have not been quantitative evaluated and also previous knowledge about arterial, venous and noise signals are required.

Materials and Methods

MRA measurements

For development and evaluation of the method proposed 18 datasets of patients with an AVM were available. The MRI measurements were carried out on a 3T Trio scanner (Siemens, Erlangen, Germany) using an 8-channel phased array-head-coil.

New parallel MRA and echo sharing techniques enable the acquisition of 4D TREAT image sequences (time resolved echo-shared MR-angiography technique) after application of contrast agent and is described in detail by Fink et al [7]. These spatio-temporal image datasets serve as the basis for the analysis of the patient individual hemodynamics. The spatial quality of 4D TREAT images with a time resolution of 0.5 s and a voxel size of 1.875 × 1.875 × 5.0 mm^3 is rather low (see Figure 1 b-c).

For this reason the 3D TOF MRA (time-of-ight) image sequence with high spatial resolution (0.469 × 0.469 × 0.5 mm^3) was also acquired. Three-dimensional TOF MR angiography is one of the most commonly used non invasive method for evaluating the intracranial vasculature and offers a superior blood-to-background contrast (see Figure 1a). Therefore a detailed segmentation of the vessel system is possible.

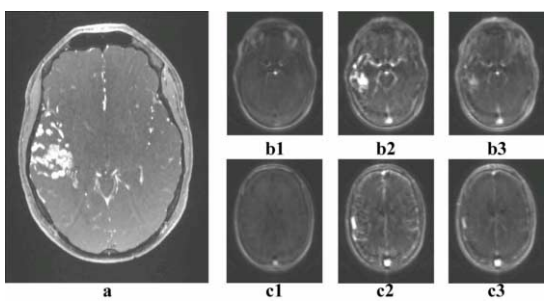

Figure 1 – Slice from TOF image sequence (a), and two slices from TREAT image sequence (b,c) at three different time-points (1-3)

Feature Generation

For segmentation of the AVM nidus several features used for the support vector machine (SVM) classification have to be extracted, which are described in the following.

Computation of the Vesselness Image

Based on the high resolution 3D TOF MRA the multi-scale vesselness filter as proposed by Sato et al. [8] is used to assign every voxel a value based on a vesselness measure based on eigenvalues of the Hessian matrix. This leads to an enhanced display of the vascular structures. Since implicitly the gray value variation of healthy vessels is used in this approach, often malformed vessels are not detected correctly (see Figure 2b).

Segmentation of the Vascular System

The cerebrovascular systems, which serve as the basis for the automatic analysis of the AVM, were automatically segmented for every dataset using an in-house developed fuzzy based method [9]. In this approach vesselness and maximum parameter images are computed first based on the TOF image. These parameter images are then combined with the TOF sequence using a fuzzy inference system. The resulting fuzzy image offers an improved enhancement of small as well as malformed vessels against the remaining brain tissues. Finally, the fuzzy-connectedness approach is used to extract the vascular system (see Figure 2c). Using the Marching Cubes algorithm a surface model of the vascular system can be generated and visualized 3D (see Figure 2d).

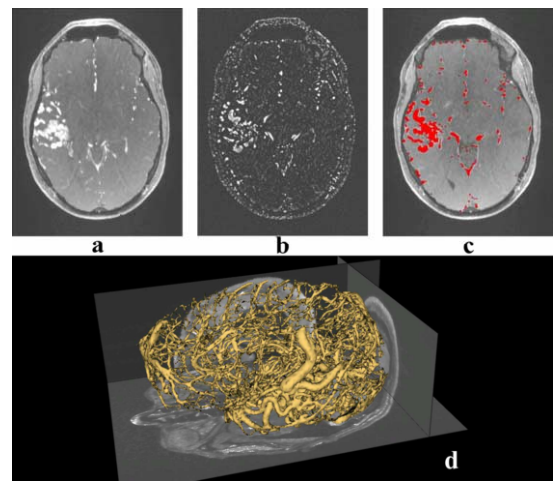

Figure 2 – Slice from TOF image sequence (a), corresponding vesselness image(b), extracted vessel segmentation (c), 3D surface model of the vascular system (d)

Bolus Arrival Time Estimation

The 4D MRA image sequences serve as the basis for the hemodynamic analysis. For every voxel a temporal signal curve representing the concentration of contrast agent at each acquired time point can be extracted from the 4D dataset.

Based on the signal curves several hemodynamic characteristics can be extracted. Whereas the bolus arrival time (BAT) of the concentration time curve is a parameter most important for the assessment of cerebral malformations. For BAT estimation the reference based linear curve fitting as proposed by Forkert et al. [10] was used.

In this approach a patient individual hemodynamic reference curve is extracted from the 4D MRA dataset by fitting and averaging a defined number of signal curves with a standard deviation higher than a given threshold σ. The threshold ensures that only signal curves which exhibit a typical signal process are used for reference curve generation. After computation of the reference curve its reference BAT (rBAT) is es-

timated using the time-to-peak criterion. Then in a following step the reference curve is linearly fitted to each signal curve of the 4D dataset such that the sum of squared differences (SSD) is minimized. Using the parameters obtained by the linear curve fit the reference BAT can be transferred to a target BAT (tBAT) (see Figure 3a).

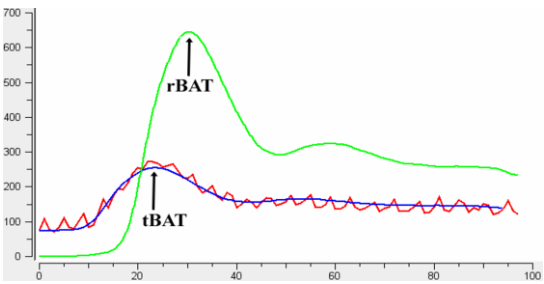

Figure 3 – Example for BAT estimation using reference based linear curve fitting: reference curve (green) signal curve (red) and fitted reference curve (blue)

Registration of 3D and 4D MRA datasets

The combined analysis of information of hemodynamics based on the voxel-wise analysis of the signal curves in the 4D TREAT dataset and anatomical vessel structures in 3D TOF dataset requires the registration of both datasets. For this purpose the method as proposed by Säring et al. [11] was used. In this approach a 3D maximum intensity projection over time (MIPt) is computed based on the 4D TREAT dataset. This projection leads to an advanced representation of the vessel system (see Figure 4a) which is helpful to improve the registration result. In a following step the resolution of the 3D MIPt is adapted to the 3D TOF MRA using a linear resampling. Finally, the transformation field between TOF MRA and MIPt is calculated using a B-spline based 3D-3D registration method with mutual information as similarity measure. The computed transformation field can then be used to transfer the BAT and MIPt datasets into the coordinate system of the 3D TOF image sequence. The transferred BAT values can then also be mapped to the surface model and visulized color coded (see Figure 4b) and dynamically over time using the method described in [12].

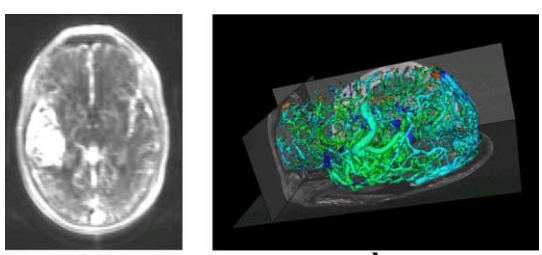

Figure 4 – Slice from the MIPt dataset (a), color coded visualization of the BAT values on the 3D surface model (b)

Support Vector Machine Based Segmentation of the AVM

Assumptions for the Method

The exact segmentation of the AVM is necessary to extract the important parameters size and location of the AVM. Furthermore it is needed for the detection of feeding arteries and draining veins. The method presented in this paper for the segmentation of the AVM is based on three assumptions:

1. The AVM does not exhibit typical vessel morphology. Therefore it can be assumed that the computed vesselness parameter image should exhibit low values for AVM structures while healthy vessels are represented by high values.
2. The missing capillaries of the AVM result in a reduced resistance in the vascular system leading to an increased blood flow velocity and early relative bolus arrival times. Since the intensities of Time-of-Flight image sequences represent the blood flow velocities it is assumed that the AVM is represented by high values in the TOF image. Due to artefacts caused by the TOF image acquisition turbulent or high flow might lead to low output values. Since the MIPt does not suffer from this problem it will be taken into account in the following step too.
3. The AVM is represented by the biggest local cluster of voxels fulfilling the previous assumptions.

These assumptions are used in the method described in the following to extract the AVM from the image sequences available.

Voxel wise Classification using Support Vector Machine

The BAT datasets are not directly comparable due to different injection and acquisition starting times. Therefore normalization of the datasets is required. For this reason the BAT dataset is masked with the vessel segmentation and the mean BAT is computed. Then in a following step the BAT dataset is normalized in terms of calculating relative differences to this mean BAT.

In the last years support vector machines (SVM) increasingly moved into the focus of supervised classification research. The aim of SVMs is to find an optimal separating hyperplane between classes based on training cases which can be used for classification. The optimal hyperplane is defined by the property of leaving the maximum margin between the classes. SVMs have been found to be a powerful recognition method. More detailed descriptions of support vector machines are for example given in [13]. In this study a linear kernel was used for training.

A total of 13 MRA datasets of patients with an arteriovenous malformation have been employed for the training of the SVM. The AVM have been manually defined based on the vessel segmentation by a neuroradiologist. The SVM was then trained voxel-wise using the four features described above, whereas only voxels, part of the vascular system, were considered for this purpose.

After training of the SVM the generated model can be used for voxel-wise classification, whereas the problem of detecting the AVM was formulated as a two-class problem. The output of the classification is a value describing the distance to the optimal hyperplane, whereas positive values represent voxels classified as belonging to the AVM. The SVM is then used to generate a distance map by classifying each voxel based on its exiting features.

After the classification dataset has been generated thresholding at distance zero is performed. Finally largest connected component analysis is used to extract the final AVM volume (see Figure 5).

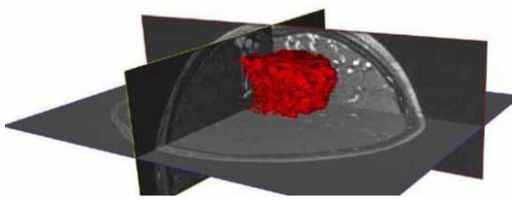

Figure 5 – Example for an automatically extracted AVM

Hemodynamic Characterization

In order to automatically detect feeders and draining veins of the AVM the mean bolus arrival time is computed based on the AVM segmentation. Then for the analysis of the vessels surrounding the AVM the segmentation is dilated. In a first step a connected component analysis is performed, whereas vessels not connected to the AVM are defined as en passage vessels. Then, the AVM segmentation is subtracted from the remaining components and a second connected component analysis is performed. For every extracted component the mean BAT is estimated. If the mean BAT is earlier than the mean BAT of the AVM segmentation the component is defined as a feeder else it is defined as a draining vein. After automatic characterization the different vascular structures can be visualized color coded (see Figure 6) based on the 3D surface model of the vascular system.

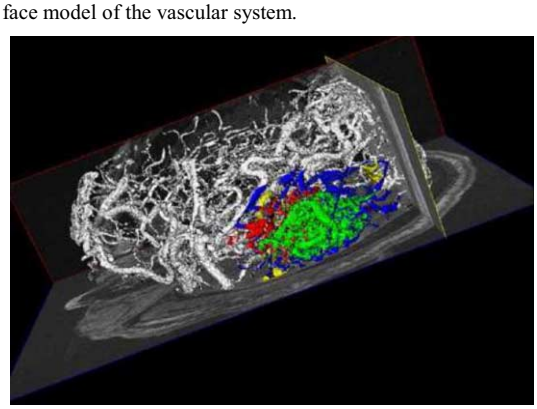

Figure 6 – Example for hemodynamic characterization

Experiments

For evaluation of the method proposed the AVM was defined for all 18 datasets by a neuroradiologist based on the vessel segmentation. 13 datasets (AVM sizes: 0.7 ml – 39.5 ml, Ø 14.1 ml) were used for the training of the support vector machine (approx. 9 mill. samples). The remaining five datasets (AVM sizes: 2 – 32 ml, Ø 13.4 ml) for quantitative evaluation of the results yielded by the AVM segmentation method. For quantitative evaluation of the segmentation results the Dice coefficient D(A,M) was used:

$$D(A,M) = (2|A \cap M|) / (|A| + |M|)$$

whereas A denotes the automatic segmentation and M the manual segmentation. Dice coefficients close to 1.0 denote a good consensus.

For evaluation of the automatic hemodynamic vessel characterization feeder and draining veins were manually defined by a neuroradiologist and compared to the results yielded by the method proposed

Results

Table 1 shows the results from the quantitative evaluation of the AVM segmentation method. A mean Dice coefficient of 0.74 and a projected volume match of 83.6% were achieved. The average time needed for the automatic segmentation procedure took approximately 5 minutes whereas the manual segmentation took between 5 – 35 minutes, depending on the size and complexity of the AVM.

Table 1 - Quantitative results of the AVM segmentation

Dataset	AVM size (in ml)	Segmented AVM size (in ml)	D(A,M)
1	32.83	25.43	0.75
2	16.95	18.99	0.74
3	9.5	11.05	0.85
4	5.71	4.66	0.71
5	3.75	4.48	0.65
Ø	13.39	13.75	0.74

The evaluation of the automatic vessel characterization revealed that feeding arteries and draining veins were detected with an accuracy of 100% for the five datasets analyzed.

Discussion and Conclusion

In this paper an automatic method for the segmentation of the AVM was presented. First quantitative results show that the AVM can be sufficiently extracted from the image data available. Ignoring dataset #3 the results suggest that bigger AVMs are easier to detect than the smaller ones. In order to achieve more significant quantitative results leave-one-out test have to

be performed. More manual segmentations from more observers are necessary in order to be able to make a statement about the inter-observer variability. Additionally it has to be evaluated how the results differ when using other kernels for the SVM, such as polynomial or radial basis function kernels.

The automatic detection and 3D visualization of the feeding arteries, draining veins and en passage vessels was rated to be very helpful for diagnosis therapy planning and can improve the therapy planning in future. Performing the mentioned leaving-one-out tests will lead to more significant results of the vessel characterization. Furthermore it has to be emphasized that the results of the hemodynamic classification rely to a great extent on the extracted vessel segmentation.

The dynamic 3D visualization of the cerebral blood flow can help the clinicians to explore the patient individual blood flow situation (see Figure 7).

A future combination with a functional atlas of the brain might enable an image guided therapy of AVM patients.

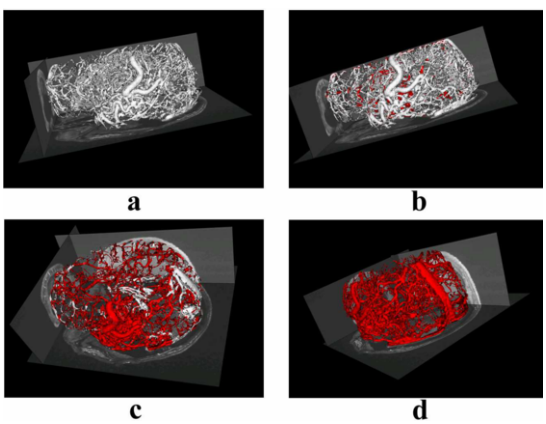

Figure 7 – Selected frames from the dynamic 3D visualization of the cerebral blood flow

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A Web Service for enabling Medical Image Retrieval Integrated into a Social Medical Image Sharing Platform

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Abstract

Content–based visual image access is in the process from a research domain towards real applications. So far, most image retrieval applications have been in one specialized domain such as lung CTs as diagnosis aid or for classification of general images based on anatomic region, modality, and view. This article describes the use of a content–based image retrieval system in connection with the medical image sharing platform MEDTING, so a data set with a very large variety. Similarity retrieval is possible for all cases of the social image sharing platform, so cases can be linked by either visual similarity or similarity in keywords. The visual retrieval search is based on the GIFT (GNU Image Finding Tool). The technology for updating the index with new images added by users employs RSS (Really Simple Syndication) feeds. The ARC (Advanced Resource Connector) middleware is used for the implementation of a web service for similarity retrieval, simplifying the integration of this service. Novelty of this article is the application/integration and image updating strategy. Retrieval methods themselves employ existing techniques that are all open source and can easily be reproduced.

Keywords:
Image retrieval, Medical social web, Visual information retrieval.

Introduction

Images are produced in enormous quantities in all modern hospitals, and they are an essential part of diagnosis and treatment planning [1]. They are also increasingly accessible to non–imaging specialists in hospitals directly through the electronic patient record creating a need for a diagnosis aid based on the images. To better manage the information and extract knowledge from existing cases, new tools are required. Content–based image retrieval (CBIR, [2]) has been proposed in the medical domain several times [3,4]. Still, real use of medical CBIR has been limited to a few examples [5] and most often purely academic tasks such as image classification have been performed [6]. In general, CBIR extracts visual features from the images and then allows for searching visually similar images to one or several examples given, sometimes relevant and irrelevant examples can be given. One of the current problems of image retrieval is the integration of research tools into existing applications such as viewing stations or directly into the patient record. In such an integrated case image retrieval can give access to anonymous and annotated cases from the past (so from the patient record or the literature) to solve a current case. There are of course several hurdles regarding secondary data use to overcome such as legal and ethical questions [7].

The GNU Image Finding Tool used as a visual retrieval engine has an interface for querying and receiving results. The interface language of GIFT is called MRML[1] (Multimedia Retrieval Markup Language) and allows for connecting to a server, choosing databases, parameters for algorithms, and receiving similarity results including identifiers and scores for images. The current implementation has several drawbacks:

• GIFT uses socket–based communication, typically on a port blocked by firewalls.

• MRML is based on XML but its handling is cumbersome and does not follow current standards as it was developed over ten years ago.

In this paper, we present a solution for adding a web service for similarity–based image retrieval with example images that is easy to integrate. The solution follows standards and communicates through port 80, often open in networks for WWW access. A medical Web 2.0 application for sharing case reports (often from radiology) including images integrated this web service to allow for finding similar cases not only based on key words but also on similar images regarding visual similarity. The web portal of MEDTING[2] is commonly used by clinicians and particularly radiologists. For our application, two tasks were implemented:

(1) cumulative indexing of newly added images, and
(2) a web service for finding similar images based on visual similarity.

Cumulative indexing is needed since new images are added daily and need to be integrated into the collection in a simple way. For updating our database MEDTING generates an RSS (Really Simple Syndication) feed containing image URLs (Uniform Resource Locators). A small program reads the feed

[1] http://www.mrml.org/
[2] http://www.medting.com/

daily and indexes any new images. The motivation for a web service is the provision of a simple but flexible interface with WSDL (Web Service Description Language) that is absolutely standard and can be integrated easily in all programming languages.

Materials and Methods

Tools reused

All tools reused for the described implementation are open source and available free of charge, so results can be reproduced easily. The GIFT[3] [8] is an open source tool for visual retrieval in large photo collections. Color plays an important role but GIFT has also been applied for medical image retrieval from collections containing grey–scale images. GIFT employs four groups of visual features for retrieval. Texture features based on Gabor filter responses exist as local features of small blocks and as global features in the form of a global histogram. Color or grey level features in the HSV (Hue, Saturation, Value) color space equally exist as local blocks at various scales and as a global histogram. GIFT uses many techniques from text retrieval such as frequency–based feature weightings and relevance feedback techniques. This creates a fast retrieval of under 0.5 seconds for databases of over 100'000 images on standard desktop computers. MRML is an XML–based query language that allows connecting to a GIFT server.

MEDTING is a social Web 2.0 service allowing clinicians and lecturers to share medical cases including images. Cases can easily be added and annotated via an ontology. Similar cases are proposed to the user when browsing and also comments on particular cases made by other users. The web side allows for a fast navigation including simple image viewing. Started only in 2008, the portal has reached in spring 2009 over 1'800 registered users. Currently, 2'400 clinical cases are stored on the portal with over 20'000 images and over 10'000 accesses per week. Such a scenario requires a stable and fully automatic solution to limit integration work, leaving mainly the possibility to place a button "Show me similar images" next to the images in the interface.

KnowARC[4] (Knowhow sharing with the Advanced Resource Connector) is a project developing a Grid middleware used for computationally expensive tasks in the physics domain but also in medical imaging. One goal of the project is to integrate existing medical applications into clinical real–world applications showing the potential of Grid technologies to make existing research tools faster and more effective. The Grid technologies are mainly used for the offline feature extraction in our case and not for the online querying that is already fast. The ARC [9] middleware of the project offers several tools that are useful, for example to ease the creation of web services.

Database used

The database used in the work described in this article includes all images currently stored on the MEDTING web pages. By summer 2009, well over 20'000 images from more than 2'000 cases are indexed and thus taken into account for similarity retrieval. The images are extremely varied and include almost all medical imaging modalities, drawings, and photographs. The number of images is continually rising. There is no ground truth available to evaluate the performance of retrieval on this database. All employed tools have been evaluated on standard databases for their quality, though.

Results

Main result of this article is not a new retrieval technique but the integration of an existing system (GIFT) into a new application and the creation of a framework for this integration. The same techniques have been used for integrating the same image retrieval application into the viewing stations of the Geneva University Hospital in the past. More on the retrieval quality using GIFT on a standard database can be found on the ImageCLEF[5] web pages.

To limit the amount of integration work we decided to use web services. Web services [10] provide a language independent interface. A useful feature of web services is the use of the WSDL (Web Service Description Language) that simplifies client development. As a web service container (a server that provides the services), we used a component of ARC, a recent development. The web service 'FMEDTING' is invoked by MEDTING when the user views an image of interest and clicks the "Find similar" button. The button calls a client module. fname is the name of the source image file, for instance v_tmp_22042009_14121159.jpg:

```
\$client=newSoapClient(''FMEDTING.wsdl'')
\$res=\$client->image(array('imagefile'=>\$fname));
```

The functionality of the web service can be described as follows:

- The service is invoked with a file name (parameter "imagefile"). Optional parameters indicate the number of results and a similarity threshold.
- The service initiates a connection with GIFT. The IP address of the server and the port number are configured in the configuration file.
- The service sends a query to GIFT, receives result and forwards them to the caller.

[3] http://www.gnu.org/software/gift/
[4] http://www.knowarc.eu/
[5] http://www.imageclef.org/

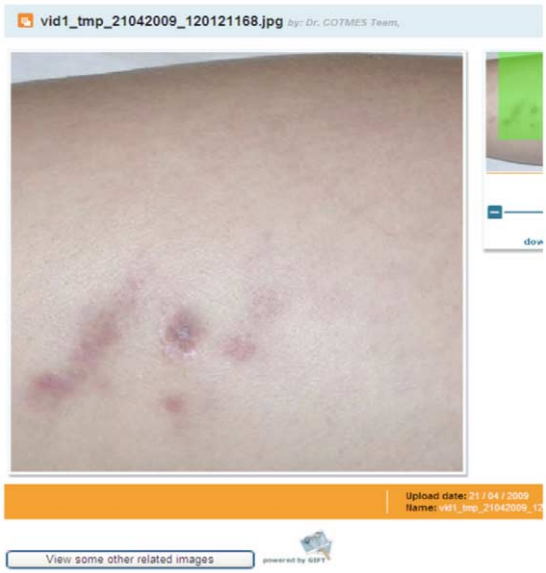

Figure 1 - Screenshot of MEDTING including the button to search for similar images.

Since the web service itself is straightforward, it adds no overhead compared to a situation where GIFT is called directly via socket–based communication. The client's overhead consists of generating the service call from the WSDL file and interpreting the result. On a modern desktop computer, these add 0.2 seconds. Calling the service with a client and receiving the image URLs of the 10 most similar images takes 1.5–2.5 seconds. Image identifiers in GIFT are URLs, and thus the integration is easy using the URLs of images on the MEDTING web site. A screenshot of the functionality integrated into MEDTING can be seen in Figure 1 with the "Show me similar images" button. Figure 2 shows the result of similar images shown to the user and allowing to navigate to other cases with visually similar images.

After an integration of the image retrieval functionality into MEDTING it became clear that besides the retrieval a mechanism was needed to keep the database up to date every day. RSS (Really Simple Syndication) is an XML–based format that allows developers to describe and syndicate content [11]. The syndicated content, called feed, can consist the content itself, or its metadata. MEDTING started to provide an RSS feed containing the images added to its web side towards the end of 2008. The RSS feed contains URLs pointing to two versions (full size and thumbnail) of the images:

```
<rss version="2.0"
xmlns:media="http://search.yahoo.com/mrss"
xmlns:atom=''http://www.w3.org/2005/Atom''>
<channel>
<atom:link rel="next"
href=''http://medting.com/rss/resources.php?
page=2&amp;orderby=lastaddedresources''/>
<item>
<title>v_tmp_22042009_14121159.jpg</title
>
<link>http://medting.com/atlas/view.php?id=2
8428</link>
<media:thumbnail url=''http://media.medting.
com/28/28428_3VGn5Ih7IcoFYo_t.jpg''/>
<media:content url=''http://media.medting.
com/28/28428_3VGn5Ih7IcoFYo_e.jpg''/>
</item>
```

The RSS feed is read daily. If new images are discovered, they are added to the collection to always keep the files up to date. An average of 30 images have been added daily since February 2009. An overview of the entire system is shown in Figure 3.

Conclusion

The work described in this article details the integration challenges when using a research prototype for medical visual information retrieval in the context of a social medical image sharing site. The use of a web service for this simplifies the inclusion of finding similar images. The application is located at a University server and only the similarity search service is provided to the MEDTING web site. An important part of the integration was the automatic addition of new images, and using RSS provides a lightweight solution. For the integration of research prototypes into real applications it is particularly important to provide simple interfaces low in maintenance. This is surely more important than pure retrieval quality. For applications such as a permanently accessible social web site it is also important that the application is available all the time. We sometimes had maintenance stops or changes in the University server room resulting in a downtime and causing errors. In a next step we plan to analyze the usage logs of the system, finding out in which scenarios users search for visually similar images and which key word searches were performed with the system ahead of visual search. Having data of real, routine use can help understand situations in which users prefer to search visually and where key words are preferred. The created prototype allows obtaining direct feedback on visual search, important for a domain going from research to routine applications.

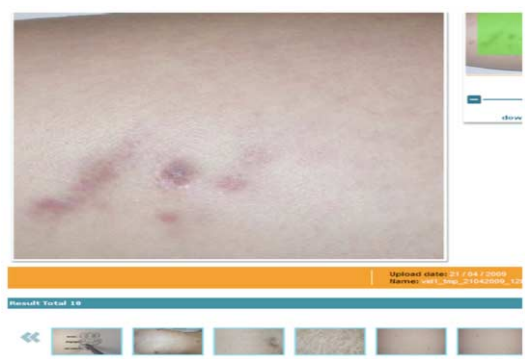

Figure 2 – Visually similar images to an example are shown under the image.

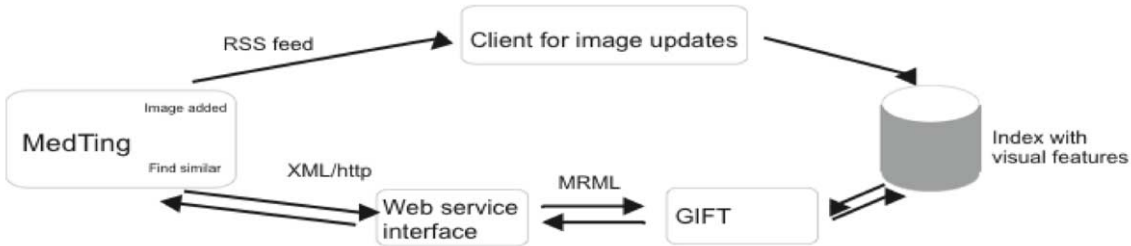

Figure 3-A global view of the system including the update mechanism using RSS feeds and the retrieval functionality integrated with a web service.

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Indexing the medical open access literature for textual and content-based visual retrieval

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Abstract

Over the past few years an increasing amount of scientific journals have been created in an open access format. Particularly in the medical field the number of openly accessible journals is enormous making a wide body of knowledge available for analysis and retrieval. Part of the trend towards open access publications can be linked to funding bodies such as the NIH[1] (National Institutes of Health) and the Swiss National Science Foundation (SNF[2]) requiring funded projects to make all articles of funded research available publicly.

This article describes an approach to make part of the knowledge of open access journals available for retrieval including the textual information but also the images contained in the articles. For this goal all articles of 24 journals related to medical informatics and medical imaging were crawled from the web pages of BioMed Central. Text and images of the PDF (Portable Document Format) files were indexed separately and a web-based retrieval interface allows for searching via keyword queries or by visual similarity queries. Starting point for a visual similarity query can be an image on the local hard disk that is uploaded or any image found via the textual search. Search for similar documents is also possible.

Keywords:
Visual information retrieval, Open access literature, Medical information analysis, Information retrieval

Introduction

Images play an increasingly important role in medical practice. They are used in a large variety of contexts such as screening, diagnosis or treatment planning and also with an increasing variety of modalities and radiology protocols. Through the electronic patient record images are not only accessible to radiologists but for all clinicians, and so new tools providing aid particularly for less experienced clinicians in interpreting images seem necessary [1].

Many open access publishers have become available on the Internet, also through initiatives by the NIH (National Institute of Health) and the SNF (Swiss National Science Foundation) to oblige researchers to make articles of publicly funded research available. BioMed Central[3] is surely the most well known publisher but others such as BenthamOpen[4] or Hindawi[5] also provide open access publishing possibilities. Most (medical) articles containing text and images are provided in the form of a complex format such as PDF (Portable Document Format), although some are also accessible in HTML (Hyper Text Markup Language) format. Large journals often provide several thousand articles in a linked hierarchy on their web pages with bibliographic information and abstracts very often being available directly on the HTML pages. Web pages of journals allow for text search in the articles but a particular image search, or search for articles containing similar images is very often not possible. Textual search for images is also provided by ImageFinder[6] and Biosearch[7] but currently no visual search is possible. Such a visual data access has shown to well complement textual search [2].

To obtain all articles of a particular journal, simple web crawlers can be developed to parse the HTML web pages and then follow the links to the full PDF versions of the articles that can then be analyzed further. To obtain articles from BioMed Central's journals it was necessary to crawl their website to obtain meta information on articles, download the corresponding PDF files and extract their texts and images separately for indexing. In a next step all obtained information was indexed using the Lucene[8] text retrieval engine and the GIFT[9] (GNU Image Finding Tool) visual retrieval system [3].

Information retrieval (IR) has traditionally rather concentrated on textual information and a large number of text retrieval systems exist [4]. Image retrieval started much later and then concentrated on text close to the images searched or manual annotation of images themselves [5]. The next step was (visual) content-based image retrieval that relied solely on visual characteristics in the images for retrieval [6], leading to other problems such as the gap between the simple visual features used and the high-level semantics a user is normally searching for. In the medical domain, visual retrieval was proposed several times [7,8] but real clinical applications are scarce [9]. Access to the medical literature was also proposed in [10]. It

[1] http://www.nih.gov/
[2] http://www.snf.ch/

[3] http://www.biomedcentral.com/
[4] http://www.bentham.org/open/
[5] http://www.hindawi.com/
[6] http://krauthammerlab.med.yale.edu/imagefinder/
[7] http://biosearch.berkeley.edu/
[8] http://lucene.apache.org/
[9] http://www.gnu.org/software/gift/

has become increasingly clear that neither visual nor textual retrieval can solve all the problems alone. Rather, a combination of media is required to optimize performance of IR systems [2,11] in the medical field.

This paper describes an approach for multimodal (text and images) medical IR using open source tools limiting the time required for development and also the costs. For the parsing of web pages, the extraction of images and text from the PDFs, as well as for indexing textual and visual information, existing tools were reused. A web interface using JavaServer Faces (JSF), Javascript, and AJAX (Asychronous Javascript and XML) allows for an easy use for the final interface.

The next section describes the materials and methods used for this project. Then, the results of the web crawling as well as the indexation step are given with a description of the user interface. The article finishes with a critical discussion.

Materials and Methods

Data used

The data used for the system described in this article consists of articles from 24 journals (217 are available in total) from the online open access publisher BioMed Central. The chosen journals were in the fields of medical informatics and medical imaging. Each journal contains between 16 and 2500 scientific articles in PDF format, as BioMed Central is still a very young publisher. All PDF documents were publicly accessible and are free of charge. Information taken from the articles was of textual and visual (images) nature. The mentioned journals were crawled on August 20-21, 2009.

Table 1- Overview of the amount of data indexed.

Measure	Value
Number of journals	24
Number of articles	9403
Min. number of articles per journal	16
Max. number of articles per journal	2495
AVG number of articles per journal	392
Total number of images (after a cleaning step)	37940
Min. number of images per journal	28
Max. number of images per journal	13618
Average number of images per journal	567
Min. number of images per article	0
Max. number of images per article	1659
Average number of images per article	4
Size of all images total	2.81 GB
Average image size	77 KB

Textual information was parsed in HTML format from the description of each article on BioMed Central's webpage consisting of the title, abstract, journal name, publication date, author names and the URL of PDF documents. Extracted information of the PDF documents consists of the entire text in the document and the contained images. The average number of extracted images per article was around 4 (with a total of 9403 indexed articles and 37940 extracted images). The minimum number of images per journal was 28 with a maximum of 13618 and an average of 567. The total size of all extracted images was about 2.8 GB. An overview of the data is given in Table 1.

Technologies used

Goal of the project presented in this article was to reuse well-established existing tools to limit the development time. For text retrieval, the open source Java library Lucene was used, which is easy to integrate and adapt to a variety of scenarios. With Lucene providing the possibility to index more than one field per document it allowed searching in several data fields such as text content, author name, and article title. Several other options Lucene offers were not used in the first prototype described in this paper.

For visual retrieval, the GIFT was chosen that has equally been in use for almost ten years and that has shown to deliver stable visual research results.

The separation of images and text from PDF documents was performed using Apache PDFBox[10]. To parse basic meta information (on the web page) of each article NekoHTML[11] was used. NekoHTML is an open source Java HTML scanner and tag balancer library that enables developers to parse HTML documents and access the information using standard XML (Extensible Markup Language) interfaces. As application server Glassfish v2.1 was used. We relied on Java and JSF for the integration. Other Technologies used on the client side were pure Javascript and AJAX.

For the work described in this article it was not necessary to start from scratch since a previous system for the separation of text and images had already been developed [3]. The current system is an extended version of the previous system with an additional web crawler and changes in the user interface.

The server was a rack server with two Intel Xeon Dual Core 1.6 GHz processors with 2 GB of RAM and total disk space of 244 GB in a RAID array.

Results

This section describes the main results concerning mainly the implementation of our prototype with its search interfaces.

System setup

The work described had six main goals and for all of them existing tools could be combined with an ergonomic web interface that was developed in this project (Figure 1):

[10] http://incubator.apache.org/pdfbox/
[11] http://sourceforge.net/projects/nekohtml/

(1) crawling and parsing HTML pages on BioMed Central and writing the collected information into XML files (one file per journal with information on each article in a journal),

(2) downloading all PDF documents (web addresses of each article's PDF document saved in the XML files),

(3) extracting images and free text from the PDF documents,

(4) indexing the meta information of the articles (saved in the XML file) and of information directly extracted from the PDF documents with Lucene,

(5) indexing the extracted images with GIFT, and

(6) combining the extraction and the retrieval systems in a single interface based on JSF.

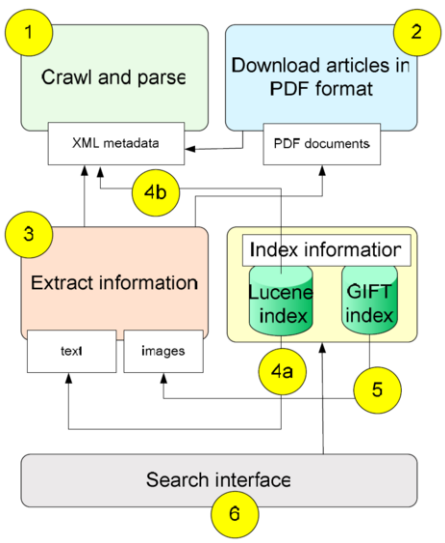

Figure 1 – The six main goals of work in a diagram with the basic system architecture.

Crawling and indexing the dataset

To crawl and parse the pages of BioMed Central, a trivial crawler was developed as a Java console application. The application takes the journal's starting URL and the directory to save the generated XML files as arguments. Starting the application results in the crawler finding all articles of the journal following well-defined links, parse the necessary information and save it to an XML file.

A simple download tool was also developed in Java being able to download all corresponding PDF files of a journal's articles from the URLs stored in the XML file. With all PDF documents downloaded, the extraction and indexation can take place. For this task we use a web interface that lists all XML files in the server's directory of journals. By choosing one of the listed files the application parses the content of a single XML file and each article's information is processed. First, the article's PDF document is located and subsequently the extraction of text and images takes place. Images are stored directly on the hard disk also generating thumbnails at the same time. The next step adds all textual information of the article to the Lucene index. One single step indexes/stores the following information on an article:

- auto generated id,
- title,
- abstract background,
- abstract methods,
- abstract results,
- abstract conclusions,
- online Article URL (if available),
- PDF document URL,
- authors,
- journal name,
- publication date,
- text content,
- image names,
- homepage URL.

The average duration of extracting and indexing one article was about 1 second. After indexing one article, the next article's information is extracted and indexed. This step is repeated until all the XML files are processed. Subsequently, images are indexed with GIFT, taking about 6 hours (around 0.5 seconds per image) with a total of 38'000 images.

One problem regarding the images was the existence of TIFF (Tagged Image File Format) images inside the PDF documents since TIFF is not supported directly by web browsers. We solved this problem by converting each TIFF image automatically to a PNG (Portable Network Graphics) image with the aid of Java Advanced Imaging (JAI). This task is performed directly after extracting a TIFF so before saving the picture and before adding information to the index.

After indexing several journals it was obvious that many articles contained the same or similar BioMed Central logos, which can be considered as irrelevant. To avoid storing the logos, the system discarded all images that were equal to a small set of example images selected manually (comparison of binary data). Another problem in our first extraction phase was a large number of small logos and graphical elements in the articles resulting in over 200'000 images to index. To avoid this problem, only images higher and larger than 32 pixels were considered for indexation, which reduced massively the amount of data to index visually.

It was also found that it was not always possible to extract all images from a PDF automatically. The reasons for this have not been totally investigated but it can be due to the production of the PDF that can be formed in a way not understood by our extraction module PDFBox. A very small number of mirror-inverted images also occurred during the extraction phase due to PDFBox, and we have not found a way to avoid this. However, these problems are expected to be fixed since PDFBox is improved and extended regularly.

Another challenge was parsing the HTML documents on BioMed Central. Although each page had a uniform design and layout we found several differences concerning the position of certain HTML tags, which forced us to take all possible

positions of an HTML element into account and not to rely on the initial structure.

Figure 2 - Screenshot of a purely visual search

Query options

The query interface can be found for testing at MedSearch[12]. A query start is typically a keyword or a new image that can be uploaded to start a visual query. It is possible to switch between a visual and textual query interface and it is always possible to show all images of a particular article (if any images were extracted) together on a single page or to show a link to the full text PDF of this article. After displaying images contained in an article it is possible to launch a visual search by clicking the button "Similar images" below an image. After this start, positive and negative relevance feedback can be used to refine the visual query further. All found images are marked neutral at the start and can be selected as relevant (green) or irrelevant (red) as shown in Figure 2. Another way to start a visual search is to obtain random images of the image database and perform queries by relevance feedback afterwards. It is then possible for the user to select "Show dedicated article" below an image. This will cause the system to switch to the textual search interface and to automatically phrase a query searching for the article the image is contained in. In the same interface the user can phrase his own textual queries with the client afterwards performing a HTTP-GET-request to the server passing relevant query parameters. This can facilitate integration of the system into other web pages. The user may also specify the number of results to show. Once queried, the results screen shows details of the retrieved articles consisting of the following elements (see Figure 3):

- article title with link,
- publication date,
- journal name,
- the first 500 characters of the abstract,
- link to full abstract,
- download link for article in PDF format,
- link to view all images and possibly to launch a visual search,
- search for similar articles based on the text (article search based on similar images not implemented yet),
- link to author names, which causes the system to search for all articles by the same author,
- web address of original article homepage,
- thumbnails of first three images in article (if available); it can be configured to show more images.

The entire retrieval system was installed on a server of the University of Geneva, Switzerland. However it is possible to integrate both into a totally distributed system, as Lucene, the query interface, and GIFT are independent components.

Figure 3 – Screenshot of a single textual search result including images of the found article.

No evaluation of retrieval quality is given in this text as no ground truth of BioMed Central is available. Both GIFT and Lucene have been evaluated on retrieval of journal articles and images in the ImageCLEF competition [2].

Speed measurements

Lucene has been used in many large-scale projects and search times with single key words are in the order of a few milliseconds. In our case it averages 40 milliseconds with more than 9'000 indexed articles, leaving room for much larger databases. Visual similarity search using GIFT was around 0.5 seconds for single image queries using our database with about 38'000 images. This allows for fast querying and good usability. When using new images to query, the feature extraction takes another 0.5 seconds. In total, results are usually shown in a second.

Conclusion

This article presents a solution for visual and textual IR from the open access publisher BioMed Central's online journals. Meta information of articles was available in HTML format, and the articles themselves were crawled directly in PDF-Format. Crawling, parsing and extracting text and images separately were essential parts. For all implemented tasks open source components could be used. The goal of the system is to collect information on scientific medical articles and to make this search interface available publicly to medical students and clinicians. A combined visual and textual search interface should optimize the reuse of all existing knowledge including text and visual parts. Currently, only 24 of the over 200 available journals on BioMed Central were indexed. Considering this and also the several other publishers of open access arti-

[12] http://medgift.unige.ch:8080/MedSearch/faces/Search.jsp

cles, the system is extendable to include a much larger body of knowledge. The resulting system was achieved by developing a loosely coupled architecture that stores information in XML files after crawling and parsing. The component-based architecture allows the extension of the system simply by replacing the crawler or adapting it to a new structure of journal web pages. All web-components can be integrated into a distributed environment easily. Besides open access publishers there is also an increasingly large number of articles available in full text by traditional publishers, very often 6-12 months after the original publication data.

The current system only indexed some of BioMed Central's journals. A next step is to index all 217 journals with their images. With data collected of the current system we can estimate a total size of all images of ~25 GB and a total size of the Lucene index of 4.8 GB. The estimated time to index all journals would be ~18 hours, crawling and downloading time excluded. Including the crawling and downloading this should still remain less than two days.

Of course there is not only a single open access publisher on medical journals on the Internet. The next step is to consider other open access publishers such as Bentham Open or Hindawi into our index. Indexing all abstracts of PubMed[13] would be another step further. As the full-text articles are linked if available, a semi-automatic crawling could be developed for this. Still, particularities of single publishers would then need to be taken into account.

Another important aspect is to keep the system up to date as new articles are published very regularly. An automatic update function has so far not been included into our system. The system would have to crawl (e.g. every week) the publisher's sites detect new articles, then download and index them.

Regarding the query options it would be good to add mixed visual and textual into the system, so search based on visual and textual characteristics combined, for example to find similar documents. A visual search could also be limited to articles containing a particular keyword.

The current implementation does not use all functions of Lucene, yet. However, it allows for an easy expansion of the functionality. Language detection of the documents to be indexed can be integrated to allow for a multilingual indexing and retrieval. Currently, this is of little importance as the published open access articles are mainly in English. Still, when adding medical texts from clinical routine in a country like Switzerland, there are documents in several languages.

The implemented system responds to the needs of crawling, parsing and separating BioMed Central's articles into visual and textual components for an efficient visual, textual and combined search. The entire system is based on open source components and can easily be reproduced.

Acknowledgements

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A Block-matching based technique for the analysis of 2D gel images

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Abstract

Research at protein level is a useful practice in personalized medicine. More specifically, 2D gel images obtained after electrophoresis process can lead to an accurate diagnosis. Several computational approaches try to help the clinicians to establish the correspondence between pairs of proteins of multiple 2D gel images. Most of them perform the alignment of a patient image referred to a reference image. In this work, an approach based on block-matching techniques is developed. Its main characteristic is that it does not need to perform the whole alignment between two images considering each protein separately. A comparison with other published methods is presented. It can be concluded that this method works over broad range of proteomic images, although they have a high level of difficulty.

Keywords:

2-D gel electrophoresis, Block-matching, Proteomics, Computer-assisted image processing

Introduction

The images of 2D gels [1] resulting from electrophoresis are a powerful biomedical diagnosis mechanism. This process is based on the separation and analysis of proteins extracted from tissues, blood, cell, etc. This type of image is obtained by staining the proteins that have been separated in a polyacrylamide gel after applying electrical potential difference to it. The separation follows a bidimensional pattern according to their molecular weight and isoelectrical point.

When analyzing images from 2D gels, there is a reference image that represents the distribution of a sample of proteins in reference conditions (normal or healthy status). In such case, molecules are labelled and their spatial location is known. Test images are then presented. In this case, the spatial location of the proteins is unknown. Usually, the comparison between a test image and the reference image is performed in order to establish the correspondence between proteins. Subsequently, both images are compared in order to establish a diagnosis based on the differences in the pattern of the identified proteins.

Images, such as 2D gels, are increasingly used in the biomedical field. The analysis of such images is difficult due to the variability of the different electrophoresis processes. Consequently, images with an apparently complex correspondence may be obtained. Location, shape, size and intensity of a given protein may vary from one image to another, it may not even appear, so the correspondence can be difficult or it might not be established. Due to this reasons, computational techniques are essential for image analysis.

There are several current software packages which try to solve this problem (i.e.: Nonlinear Dynamics Samespots [2], Decodon Delta2D [3] and Genebio Melanie[4]). These approaches tend to perform the whole alignment between two images. This is done by using several image transformations. The user must correct manually possible misalignments in order to obtain reliable results in later stages of the analysis. The system marks each protein with the same edge over all the gels of the same experiment. In this way, the user can select the spots of interest and compare them over the different images and obtain several conclusions based on their differences.

Most of those software packages do not indicate the identifiers or the names of the proteins in the test images, so the user must identify visually the proteins from a labelled reference image.

Apart from the software packages, there are different image analysis methods to align 2D gel images. They can be divided in two groups: those which use landmarks and those which use intensity information.

Two key concepts should initially be defined. A landmark refers to a characteristic of the image from which information is intended to be obtained. In proteomic images, landmarks are identified as proteins (dark spots on a clear background) with an unknown spatial location which will then be obtained. Intensity relates to the function that describes the grey level values corresponding to each pixel in the image.

The approach based on landmarks is a research line applied by several previous works. In [5], the detection of coordinates for the protein centres is firstly performed using an approach based on gradient and Watershed transformation (which performs the image segmentation according to its grey levels). Typical protein characteristics are also considered for molecule detection, like circular or elliptic rim. A local matching process between the reference image and the test image based on the Delaunay triangulation is then performed. This technique consists of a network of triangles where the circumferences circumscribed to each triangle do not contain any vertex of other triangle. A system based on matching the spot centres is presented in [6]. In this case, the rim detection has been carried out, as in [5], by considering different characteristics of the proteins in order to separate protein overlapping. The matching based on the coordinates of the protein centres is also carried out in [7] by following the approach known as fuzzy matching. This approach calculates the nearest protein to every reference protein within a certain range.

Other approaches are focused on the image intensity distribution in order to perform the matching between two gels. With the present approach, the cost of the landmarks extraction process is avoided. The principal objective of [8] is to find the alignment using regional matching (rectangles containing several molecules) instead of spots matching. In [9] the matching is performed by calculating the crossed correlation between the intensity distributions of the test image and the reference image. The strategy followed for image registration is an iterative solution based on the gradual selection of images' resolution, obtaining at each step a more precise transformation. There are two more recent works [10, 11], which are based on Robust Automated Image Normalization (RAIN).

There are new techniques that merge the two previous groups, that is, hybrid approaches. Particular cases of the Iterative Closest Point algorithm [12] (used for solving the alignment between the spots of a test image and the reference image using the Euclidean distance) were presented in [13] and [14]. Both works propose new distance metrics that combine the Euclidean distance with information related to the shape and the intensity of the spots. The aim of [15] is to find a function that makes image alignment possible using a nonlinear deformation model (B-splines). The optimization is based on Levenberg-Marquardt (LM) [16]. This method performs an iterative parametric fitting taking into account a predetermined mathematical model. In [17], some pairs of corresponding spots of both images are selected. The information about the correspondence of the landmarks is introduced as part of the energy function, which is minimized to perform the transformation. The centres are detected by modelling the proteins as 2D inverted Gaussian functions using LM fitting (as in the previous case). A new version of this work [18] was presented in 2008. This work uses the Navier equation, which represents the regularization of the deformation field. It is used with the aim of considering the crossed effects of some gel deformations.

As a consequence of this analysis, the main objective of this work was to find a new method which allows the clinicians to identify automatically the spots, where the alignment of the images is not necessary.

Methods

Establishing a correspondence between molecules of two different gel images might be a difficult task. As has been previously mentioned, this difficulty is due to potential displacements or appearance changes between proteins in two different images.

Several techniques have been studied with the aim of finding a solution for this type of scenario. These techniques, used for movement estimation, consist of mathematical procedures that analyse the intensity changes of a sequence of images

Block-Matching

Among the optical flow estimation techniques, regional fitting (Block-Matching) has been chosen because it is suitable for measuring displacements due to nonlinear movements with a high degree of deformation. Due to their characteristics, these techniques are especially suitable for fluid analysis. A good performance in this context is expected as the proteomic images are obtained from viscous fluids (polyacrylamide gels).

The Block-Matching approach considers a reduced space of the correspondence problem in order to achieve a better approach rather than the global case. These techniques usually work as follows [19]: the image is divided into some regions; different criteria might be followed to perform this division. The simplest approach implies selecting non-overlapping regions of predetermined size, known as blocks. The aim of the next step is to calculate the displacement for each region between two images. This is done assuming that the local distortions caused by the displacement are almost negligible. Thus, considering a region small enough and a time lapse short enough, the characteristics of each region will not be affected by the movement. This is the only assumption made in relation to the movement which will be calculated. Every block of an image is then compared with several possible blocks of the following one, maximizing a similarity measure or minimizing a distance measure.

Modified Block-Matching

As the previous process is general, it does not fit closely to the 2D gel scenario. This is due to the assumption made by the generic Block-matching algorithms: despite the displacement, within an area small enough, the visual texture of a region remains unaffected. In the field of 2D gels this hypothesis is not fulfilled because the images are not part of a temporal sequence affected by movement. In those sequences there are few changes from an image to the next one. In proteomics, the images are independent. Besides, the variability is increased due to the previously mentioned changes experienced by the protein samples in different images. Due to this, the use of certain similarity measures presents some restrictions, because

the difference between a region and its corresponding region in the other image is very high in 2D gels. Although the result of the exploration might be correct, it might not meet the minimum difference criterion. Because of that, the system will assume that the displacement produced is not detected. A similarity measure based on the statistical distribution of the intensity levels is then required. This measure needs to be robust despite those factors that vary among samples.

Due to the reasons explained previously, a new Block-Matching-based method has been developed. This method proposes different specific strategies to adapt Block-Matching to proteomic images of 2D gels. The process, show in figure 1, is carried out as follows:

- Firstly, the method needs as input the list of coordinates of the spots in the reference image. This part can be done in different ways: getting the output of a spot picking robot, such as GelPix [20], or using several image analysis techniques. Present work does not focus on this phase, but on the modified block matching technique explained as follows.
- The system refines the coordinates in order to match exactly spots' centres. They are also the centres of the blocks into which the image is divided (the whole image is not divided into blocks, unlike in Block-Matching algorithms; only some blocks are marked: as many as the spots extracted). To perform this task LM fitting has been used. Therefore, it is necessary to define an area that might contain, with high probability, the centre of the protein. The coordinates of the centre of that area are also extracted and used as the initial estimation in LM fitting. That area is determined using wave search, which is carried out as follows: a minimum radius is established. The initial coordinates represent its centre. This radius is increased (to a maximum) until it reaches the rim (an intensity value up to a certain grey threshold) and contains the protein centre (an intensity value less than a certain grey threshold). The minimum intensity point in the delimited area is used as the provisional centre for each iteration.
- Once this area has been established, the centre of the protein is located using LM fitting. It was necessary to find a fitting function for the proteins' grey level. Then, an inverted bidimensional Gaussian function was chosen as it is a continuous function which is adequate to describe the distribution of the molecule intensity. This model determines the protein centre (the darkest value and therefore the lowest grey level) as the minimum in the inverted Gaussian curve. The fitting function undergoes a rotation geometrical transformation because the molecule can turn towards different directions.
- The protein centre adjusted in the previous phase is the central position of the search block for the modified Block-Matching algorithm. The size of the block is defined by specifying its dimensions using the Block Size parameter (in pixels). Using each block as a centre, a search region is defined. This region is demarcated by a maximum range of displacement (Search region).
- In the search region, a spiral exploration strategy has been followed. Thus, starting at the block coordinates of the first image, hops determined by the Search hop parameter are performed following a spiral. Each hop represents one pixel, in such a way that the whole space of states will be explored obtaining always the best possible value for the comparison criterion, the Pearson correlation coefficient which is a typical statistical coefficient used to calculate the linear relationship between two quantitative variables. It is immune to changes in the medium grey level and it is independent of the value scale used. It has also proved to be robust when there is noise.
- Once the correspondence with a block in the test image has been established, the position of the centre of this destiny block will be refined in order to match the protein centre, as was done at the beginning for the reference image. The output is showed in the Figure 2.

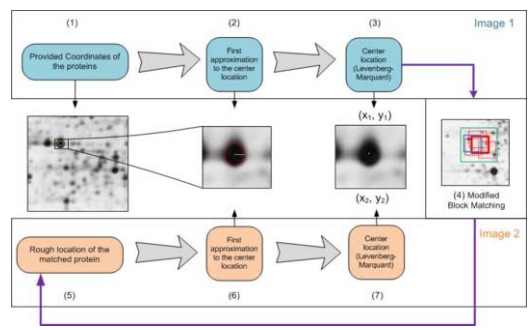

Figure 1 –Modified block-matching diagram

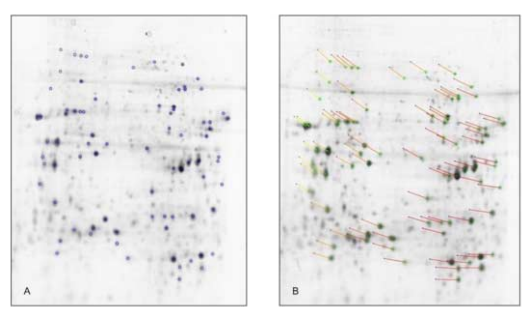

Figure 2 – System output. A) Marked molecules. B) market molecules in the test image, with a vector that indicates not only direction, but also the magnitude of the displacement in relation to the corresponding protein in the reference image

Results

The proposed system has been implemented using Open Source Computer Vision Library (OpenCV) [21] and has been tested in order to compare our results to those of other articles.

The Table 1 show the results, represented as success rates, of the comparison between the proteins in the reference and the test image. In order to understand better the results, it is necessary to define the following terms:

- It is considered a success when the centre calculated by the algorithm is included within the perimeter of a protein in the test image. In addition, this protein must match, according to the expert's criterion, its corresponding protein of the reference image, based on its spatial location and characteristics.
- It is considered failure when the calculated centre is out of the body of the protein which matches the reference one (according to the expert's criterion).

Test

In order to check the accuracy of the method presented in this paper, the results obtained were compared to those obtained in [18]. This work shows the success rates of a proposed hybrid method and those obtained with an approach based only on intensity. In [18], their results are compared to the results obtained in a previous work [17], which includes a hybrid approach and an intensity-based one.

The test bed was built by using the images of G.-Z. Yang (Royal Society/Wolfson MIC Laboratory, Department of Computing, Imperial College of Science, Technology and Medicine, London). This test bed consists of a group of images of 2D gels from different types of tissues and different experimental conditions.

The test bed used in the present work was built grouping these images in pairs in order to perform their alignment. Every couple was assigned a complexity level according to the criterion of an expert. As a result, the following groups were obtained:

- Five pairs of images where the visual correlation of the proteins between every reference image and test image is simple.
- Five pairs of images where most of the proteins can still be visually correlated, but, in this case, it is harder to establish the correlation.
- Five pairs of images of high complexity, where most of the proteins cannot be visually correlated

The comparison function, block size, search region and search method parameters were chosen according to previous tests on synthetic images. The values chosen for the parameters were Pearson Correlation as comparison function, wave search as search method, block size of 75x75 in easy and medium complexity images and 150x150 in complex images and search region of 75x75 in easy and medium complexity images and 125x125 in complex images.

We have selected [17] and [18] because their tests use images extracted from the Wolfson MIC Laboratory test bed. However, in both, only one pair of images was selected for each type of complexity (no results of high complexity images were published). In these works, 208 proteins were selected in order to test the results in low complexity images, and for the medium complexity pair 158 proteins were selected. After that, the number of proteins correctly and incorrectly identified was obtained. The success rate was then calculated. In order to fairly compare the results obtained in [17] and [18] to the results obtained in our work, the same pairs of images were used. As they do not show which proteins have been selected, it was carried out as follows: for the low complexity pair, 212 identifiable molecules were found. From these, 208 were selected. As a result, at the most, 2.4% of the molecules may vary. From the medium complexity pair, 158 proteins were selected from the 160 identifiable ones. In this case, at the most, 1.27% the proteins may vary. As these rates are minimal, the results can be considered comparable. The pair of high complexity images chosen in [17] was also selected, despite none of the papers having mentioned any related results. We have chosen 55 identifiable proteins for this pair. This number is not very high because most of the proteins have a high overlapping rate that prevents establishing a reliable correspondence.

Table 1 – Comparative with other methods

	Easy			Medium			Complex		
	n_{cor}	n_{inc}	%	n_{cor}	n_{inc}	%	n_{cor}	n_{inc}	%
[17] Intensity	187	21	89.9%	137	21	86.7%	-	-	-
[17] Hybrid	201	7	96.6%	149	9	94.3%	-	-	-
[18] Intensity	200	8	96.2%	150	8	94.9%	-	-	-
[18] Hybrid	203	5	97.6%	153	5	96.8%	-	-	-
Modified BM	207	1	99.5%	154	4	97.4%	47	8	85.4%

Test results

The number of correctly (n_{cor}) and incorrectly (n_{inc}) identified proteins are presented in Table 1 with the corresponding success rates.

The results obtained in the present work are slightly better than those obtained in the approaches published in [17] and [18]. Even more, these two works do not present results for high complexity images, as they do not consider them suitable due to their complexity. There are several differences between these methods and the one presented here: in [17] and [18], a manual selection process of certain proteins from the reference image and the corresponding ones in the test image is performed. This user-supplied matching information is used to refine the registration in regions where the information about intensity is not enough. Then, the alignment is performed on the whole gel. However, in this work, the process is fully automatic and the system performs the association between the proteins of interest, it does not carry out the whole gel alignment.

Conclusion

The aim of the present work has been to obtain an effective method in order to calculate the correspondence between the proteins of 2D gel images obtained using an electrophoresis process. An approach based on regional fitting techniques has been developed. The generic Block-Matching technique was modified in order to apply it to the 2D gel scenario. The success rates obtained after executing the required tests using real biomedical images were higher than the rates reached by previous works using the same test bed. This method performs the identification over each protein separately, and it does not perform the whole alignment. Thus, the identification could be performed over a subset of proteins because many times only some proteins are important for establishing a diagnosis. Since this method works at spot level, it could be easier to transfer protein labels between images, so the manual labelled process would be avoided. In this way, it could be very useful for protein information retrieval systems.

Acknowledgments

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The original proteomic images used in this work are courtesy of Prof. G.-Z. Yang, Royal Society/Wolfson MIC Laboratory, Department of Computing, Imperial College of Science, Technology, and Medicine, London/UK.

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Three-Dimensional Morphometric Analysis of the Distal Femur: A Validity Method for Allograft Selection Using a Virtual Bone Bank

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Abstract

Tumor excision is the primary treatment of aggressive or recurrent benign bone tumors and malignant bone sarcomas. This requires a surgical resection with the potential for large residual osseous defects that could be reconstructed using fresh frozen allografts. Virtual bone banks enable the creation of databases allowing a 3D pre-surgery evaluation of such allgorafts, based on segmentation of DICOM-CT images. This study demonstrates the usefulness of patient specific 3D models for an accurate host–donor allograft match. We describe one way to select the best match according to size and shape. The results suggest that a robust and realiable technique has been established. Since it is difficult to plan an allograft on a distal femur deformed by the tumor, we propose to plan the surgery on the contralateral side. Our results support this limb symmetry hypothesis. The use of this measurement protocol enables accurate selection of allografts from a contralateral healthy femur 3D CT model achieving the best match possible considering the geometry of available allograft candidate femur specimens.

Keywords:
Bone transplantation, Bone bank, Computer-aided surgery

Introduction

Tumor excision with wide surgical margins is the primary treatment of aggressive or recurrent benign bone tumors and malignant bone sarcomas [1]. This requires a surgical resection, with the potential for large residual osseous defects that could be reconstructed using fresh frozen allografts [2].

As diagnostic and therapeutic techniques improve, patients with musculoskeletal sarcomas should expect increased survivals, decreased complications and side effects, and an improved quality of life. That is why functional longevity of the reconstruction becomes a major concern, especially in young and physically active patients. Emphasis has been placed on biologic reconstructive alternatives due to concerns involving the durability of prosthetic materials, and the increasing survivorship of patients with sarcomas. Poor anatomical matching of both size and shape between the host and the donor can significantly alter joint kinematics and load distribution, leading to articular fractures or joint degeneration [1,2]. Determination of the distal femur size and shape is critical to obtain an appropriate allograft. In addition to this, it is difficult to plan an allograft on a distal femur deformed by the tumor.

The objective of this study was to develop a protocol to search and select of the best match (distal femoral allograft) from a virtual bone bank system, and to verify its intra- and inter-observer reliability. The feasibility of such protocol is based on our hypothesis, which states that the symmetry of the contralateral distal femur will provide the best match in preoperative planning allograft selection.

Materials and Methods

A total of thirty-three fresh-frozen whole femora were selected from the bone bank for this IRB-approved study, 15 right and 18 left (age range: 16-58 y.o., 35.9 ± 12.0 y.o.; 22 males and 11 females) were used in this study. 3D reconstructions of all specimens were created from CT images (Figure 1). The following distal femur morphometric parameters were measured with specialized 3D software (Mimics, Materialise, Belgium) on a plane perpendicular to the long axis of the bone: 1. Transepicondylar axis (A): the distance between the most medial point in the medial epicondyle and the most lateral point in the lateral epicondyle. 2. Medial condyle distance (B), determined as the distance between the most anterior and most posterior points, respectively, in the anterior-posterior direction. 3. Lastly, the length of the lateral condyle (C) determined with the same method used for the medial condyle (Figure 2).

Intra- and inter-observer reliability of this protocol was assessed measuring 33 and 20 femora, respectively, and was evaluated using an intra-class correlation coefficient.

Size symmetry was evaluated using R square coefficient between right and left A-B-C measures from the same donor in 10 cases (Figure 2).

Shape symmetry of the distal femur was evaluated also in the 10 cases by comparing a left femur model and a mirror image model of a right femur in each pair (Figure 3).

Point-cloud models were created from the surface polygon mesh model by using vertex points of the polygon (Figure 4). The 3D left femur model and the 3D right mirror femur model were registered by using a volume merge method [3].

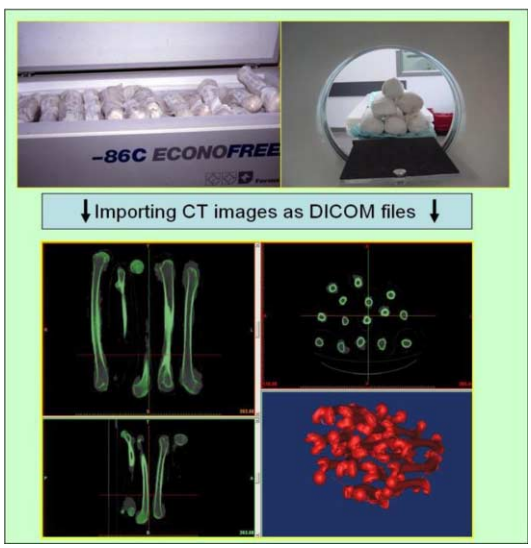

Figure 1 -Images from the CT scanner are imported and reconstructed as 3D objects with Mimics software

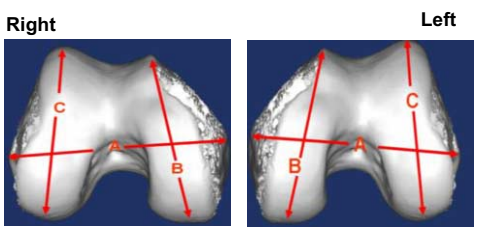

Figure 2 - Distal view: A-B-C size analysis parameters between right and left sides. A: Transepicondylar axis, B: Medial condyle distance and C: length of the lateral condyle.

The volume merge method was created with custom software program in Microsoft Visual C++.NET 2003 with Microsoft Foundation Class programming environment (Microsoft Corp, Redmond, WA). In the volume merge method, the right mirror femur (the moving femur) was virtually rotated and translated towards the left femur (the stationary target). These rotations and translations of the femur were conducted in 0.1° and 0.1 mm increments, respectively, until the moving femur merged with the stationary target. The degree of volume merging was maximized in real-time through rotation or translation of the moving femur using the following algorithm. A voxel with a dimension of 1.0 x 1.0 x 1.0 mm was created for each point of the stationary target. The number of points of the moving femur that fell within the voxel of the stationary target was determined and the percentage of volume merge was defined by a ratio of the number of the voxels including the moving femur points to the total number of the voxels on the stationary target [3]. The accuracy of the volume merge method was evaluated using a phantom with 8 precision ceramic balls (19 mm in diameter). The phantom was placed on a high precision 4-degree of freedom table. The phantom was scanned at 5 translated positions in x-direction with 0.1 mm increment up to 0.5 mm and at 10 translated positions in z-direction with 0.1 mm increment up to 1.0 mm. It was also scanned at 10 rotated positions about x-axis with 0.1° increment up to 1.0° and at 5 rotated positions about z-axis with 0.1° increment up to 5°. A total of 30 scans were analyzed using the volume merge method and system accuracy was determined using translations and rotations. The values were compared with the known translation and rotation values and errors in these calculations were evaluated. Mean absolute translation error was less than 0.1mm in x-direction and z-direction. Mean absolute rotation error was less than 0.2º about x-axis and z-axis. The translation in x-axis and rotation about z-axis correspond to transformation in axial-plane and the translation in z-axis and rotation about x-axis correspond to transformation in the sagittal plane [3].

Following the registration of the left and the right mirror distal femora, a closest distance algorithm was used to evaluate 3D shape matching between the left femur and the right mirror femur [4,5]. Distances between one point in the point-cloud model of the left femur and all points in the right mirror femur were calculated in 3D space. The closest distance at the point in the left femur was defined as the least distance among all distances. This procedure was repeated for all points in the left femur and mean closest distance from all measured closest distances of the closest distances was determined for each pair of the distal femur (Figure 5 and Figure 6).

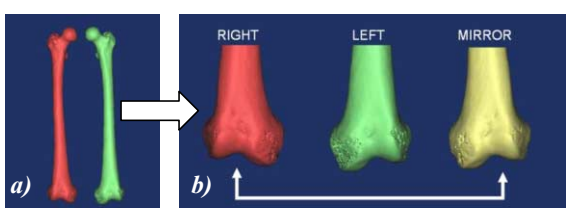

Figure 3 - Volume Merge Method. a) Pairs of femurs from the same donor, b) mirror image.

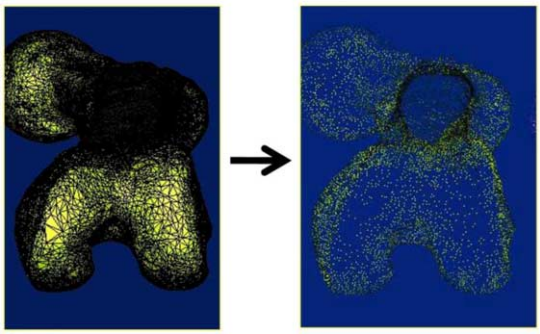

Figure 4 - 3D bone reconstruction exported as a point- clouds model.

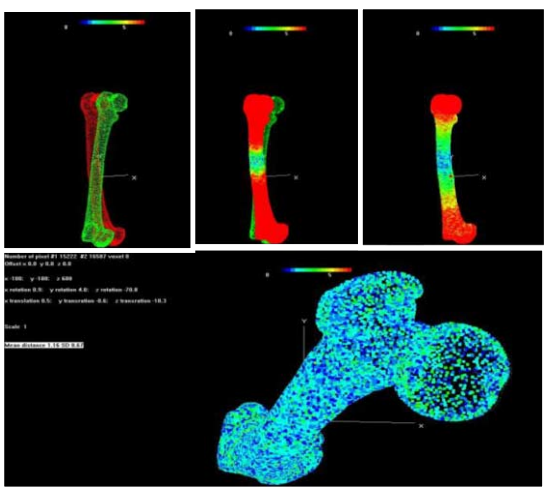

Figure 5 – Using the point – cloud model, a pairs of femurs from the same donor overlapped using our custom software able to recognize mean closest-point distances.

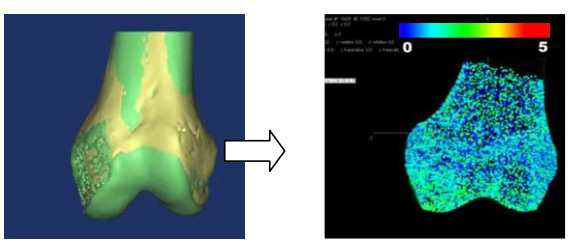

Figure 6 - Volume Merge Method, a) overlapping distal femurs and b) Volume merge superposition. Color scale: 0 to 5 mm: Dark blue indicates closest proximity (best match) between two superimposed point clouds.

Results

Protocol metrics: A single operator was tested for intraobserver repeatability while using the above-mentioned A-B-C protocol twice on thirty-three distal femoral allografts, obtaining an intraclass correlation coefficient of 0.99 in almost all measures (Table 1). Interobserver consistency of two separate observers was quantified when they measured the A-B-C parameters of twenty distal femoral allografts leading to an intraclass correlation coefficient of 0.99 in all measures (Table 2). R square coefficient between right and left side was 0.99 in the ten pairs evaluated (Figure 2).

Shape compliance: Evaluation of the overlapped original and mirror point-cloud models with the custom C++ program found that the average closest distance between points was 0.89±0.07 mm. (Figure 7). This result is within the CT slice thickness of 0.5 mm and CT resolution of 0.625 mm/pixel.

Table 1 - Intraobserver analysis using A-B-C protocol.

Distance	Femurs	n	Intraclass correlation	95% CI	
				Lower Bound	Upper Bound
Transepicondylar	Right	15	0.997	0.991	0.999
	Left	18	0.999	0.998	1.000
Medial Condyle	Right	15	0.963	0.869	0.988
	Left	18	0.997	0.991	0.999
Lateral Condyle	Right	15	0.995	0.873	0.985
	Left	18	0.998	0.996	0.999

Table 2 - Interobserver analysis using A-B-C protocol

Distance	Femurs	n	Intraclass correlation	95% CI	
				Lower Bound	Upper Bound
Transepicondylar	Right	10	0.999	0.996	1.000
	Left	10	0.999	0.995	1.000
Medial Condyle	Right	10	0.996	0.982	0.999
	Left	10	0.997	0.968	0.999
Lateral Condyle	Right	10	0.997	0.986	0.999
	Left	10	0.997	0.990	0.999

No.	Mean	SD
1	0.91	0.57
2	0.84	0.56
3	0.97	0.62
4	0.80	0.55
5	0.87	0.58
6	0.89	0.58
7	0.79	0.54
8	1.03	0.61
9	0.93	0.58
10	0.89	0.56

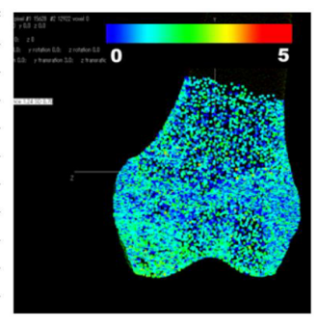

Figure 7 - Shape Compliance: mean of distal femur differences in millimeters.

Discussion

The selection of the bank allografts has been closely related to the progress of the current visualization method. During the first decades traditional X-rays were used, assuming a transplantation selection error that reached the centimeter scale. Then donor-recipient two dimensional measurement protocols were established in CT scan images that narrowed down the bias to the millimeter scale.

More accurate data and a more precise donor-recipient selection can be achieved using various complementary techniques such as the multislice CT scan–digital representation of subject-specific models and CAD (computer aided design), software, moving a step closer to the creation of a virtual interactive musculoskeletal system (V.I.M.S.) [6].

The volume merge technique used in the current study for the registration of between the left and the right mirror femora has been used for kinematic analyses of lumbar spine, cervical spine, ankle joint, and and shoulder joint [3,7,8]. This technique also allows registration of the organ taken by different imaging modalities [7].

In the closest distance analysis, only the magnitude of the distance vector was evaluated and not its direction. Therefore, the distance was not evaluated in the normal direction to the surface of the femur and the distance may be overestimated. Especially, when the closest distance is small, overestimation is expected to be larger. However, this amount of overestimation does not exceed the spatial resolution. Calculation of the distance between a point to the polygon surfaces may improve shape matching evaluation. However, the random orientation of each individual polygon mesh element may vary significantly on the complex and irregular bone surface. Future studies will be required to establish better algorithms to evaluate bone surface geometry matching. Nonetheless, due to large macroscopic differences in size and geometry expected in a clinical setting, the magnitude of the error associated with the current method would be negligible for practical purposes and ready to be used with a virtual bone bank system (Fig. 8). Additionally, another limitation of this study is the small amount of samples.

Conclusion

This work demonstrates the usefulness of three-dimensional models when searching for the best similar host–donor allograft match and proves our symmetry hypothesis. The results suggest that a robust, reliable and most importantly, repeatable technique, has been established.

On the other hand, the results stemming from the use of this measurement protocol enable accurate selection of allografts from a contralateral healthy femur CT achieving the best match possible considering the geometry of available allograft candidate femur specimens (Figure 8). This newly developed method is a good example of translational research that can be readily applied to the patient with minimal effort.

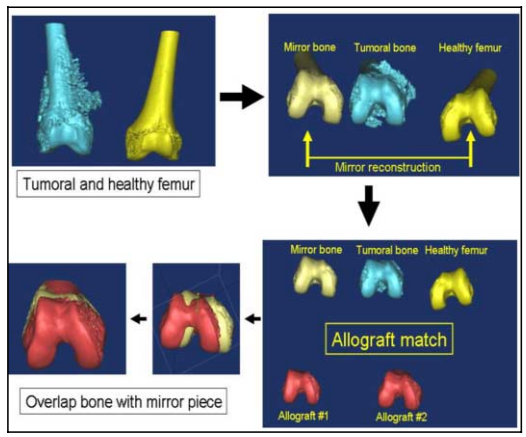

Figure 8 – Searching and selecting the best match in a Virtual Bone Bank System.

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Using Local Context Information to Improve Automatic Mammographic Mass Detection

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Abstract

Despite their promising application, current Computer-Aided Detection (CAD) systems face difficulties, especially in the detection of malignant masses–a major mammographic sign for breast cancer. One of the main problems is the large number of false positives prompted, which is a critical issue in screening programs where the number of normal cases is considerably large. A crucial determinant for this problem is the dependence of the CAD output on the single pixel-based locations initially detected. To refine the initial detection step, in this paper, we propose a novel approach by considering the context information between the neighbouring pixel features and classes for every initially detected suspicious location. Our modelling scheme is based on the Conditional Random Field technique and the mammographic features extracted by image processing techniques. In experimental study, we demonstrated the practical application of the approach and we compared its performance to that of a previously developed CAD system. The results demonstrated the superiority of the context modelling in terms of significantly improved accuracy without increase in computation efforts.

Keywords:

Breast cancer, Computer-assisted decision making, Mammography.

Introduction

Breast cancer is a disease that no woman wants to be diagnosed with, but if it does occur, finding it as early as possible can save woman's life. Worldwide there have been developed screening programs where mammographic exams are performed in asymptomatic women. The enormous workload and the very low incidence rates of breast cancer (3-10 per 1000) in these programs, however, create various challenges for radiologists in the interpretation of mammograms.

The current advances in computer technology and screening digitalisation led to the rapid development of Computer-Aided Detection (CAD) systems. In screening programs these systems might be especially useful as a second reader for improving the mammographic analysis [1]. Essentially, the working principle of current CAD systems comprises a multi-stage process based on identification of regions of interest using image processing and pattern recognition techniques, extraction of a feature vector for each of these regions and classification of the regions as cancerous (abnormal) based on supervised learning techniques such as neural networks.

Computerized programs are currently employed for the detection and classification of masses and microcalcifications–the two major mammographic signs of breast cancer. Applications have shown that CAD tends to perform better in identifying malignant microcalcifications compared with masses [2]. Masses are more difficult to detect due to the great variability in their physical features and similarity to the breast tissue, especially at early stages of development. Hence, the prompt of the current CAD comprises not only the cancer but also a large number of false positive (FP) locations–undesired result in screening where the reading time is crucial.

In this paper, we focus on improving mass detection on mammograms by reducing the number of FPs while keeping the true detection rates high at the very first step of CAD–detection of suspicious pixel-based locations. In our previous work this selection is mostly based on the information provided by a single pixel [3], [4]. This contradicts, however, the basic decision-making principle of radiologists, accounting for context information in the region of interest. To incorporate this knowledge into a CAD system, we propose a novel approach for mass detection by explicitly modelling the dependencies of the neighbouring pixel features and classes. We use Conditional Random Fields (CRF), introduced in [5], as a powerful probabilistic tool to represent context dependencies using undirected graphs. CRFs model the class distribution given a set of observed features, which makes them especially suitable for sequential labelling and classification tasks such as mass detection. The main advantage of CRFs over generative models such as Markov Random Fields (MRF) is their conditional nature, relaxing the need for making a lot of independence assumptions among the observed features, required by MRFs to allow tractable inference.

A number of previous works considered context information for breast cancer detection. In [6] the authors propose an approach using MRF to segment breast masses achieving 90% sensitivity at 2 FP detections per image. In [7], a random field model is used to detect microcalcifications on mammograms. Alternative directed-graph approach based on Bayesian net-

works has been proposed in [8] to predict the type of breast cancer represented by microcalcifications, reaching prediction performance of a human expert.

In contrast to the previous studies where only the dependencies between the neighbouring labels are considered, in this work we also account for the dependencies between the observed features in the neighbourhood employing the CRF representation. In such a way we can better represent the mass characteristics and tackle the problem of noise in the labelling. Next we present our mammographic CRF model.

Materials and Methods

Mammographic Discriminative Model

In screening mammography, it is known that cancer develops mostly in one of the breasts and at one location. In the initial stage of development, malignant masses are often small and may have subtle characteristics, which hardly distinguish them from the surrounding tissue. This implies that scanning the whole breast for a mass would be a cumbersome task in terms of time and computation efforts. Therefore we propose to consider not the whole image but only those parts of it, which indicate certain cancer characteristics. Hence our method consists of two main steps: (1) Detection of suspicious pixel-based locations (PxL) and (2) Building a CRF model for each of the detected PxLs.

Initial pixel-based mass detection

In this step we use the pixel-based mass detection scheme from the CAD system presented in [3]. For all pixels in the segmented breast area, this algorithm calculates at each location i a set of 5 local mass features: 3 for stellate (star-like) lesions and 2 for focal masses. A 3-layer neural network classifier, supervised by the pixel labels $\in \{-1, 1\}$, combines these features into the so-called mass likelihood l_i – the likelihood that a mass is present at location i. The method is applied at a high sensitivity level to ensure that most masses are found. This implies that a large number of FPs would also be observed because the detection was based on 5 features only.

CRF modelling of the initially detected local masses

To further filter out the FP locations, for every selected pixel q we build a CRF model, which is defined with respect to a system of neighbourhood around q. The CRF modelling we propose in this paper is based on the approach in [9], which we extend to account for the specifics of the mammographic mass detection.

For every image we define a set $Q = \{q \mid q \in B,\ l_q > \theta\}$, where B is the set of all pixels in the breast area and θ is a threshold value. We then use every $q \in Q$ as a central point to construct a region (grid) R_q with a size of $M \times N$ pixels. Since the pixel information is very sensitive to small variations, we create non-overlapping groups of $m \times n$ pixels and we call these pixel groups *sites*. For every site s we compute the feature vector $\boldsymbol{y}_s$ as the mean of the feature values of the pixels in the site. We compute the site label x_s by assigning –1 (cancer) if sufficient cancer information is available in the site (e.g., 40% or more of the pixels are cancerous) and 1 otherwise.

Based on this construction we define a CRF over the labelling $\boldsymbol{x}$ given the observations $\boldsymbol{y}$ as an undirected graph with a set S of vertices corresponding to the random variables x_s, which satisfy the Markov property with respect to the graph stating that $p(x_s \mid \boldsymbol{y}, x_{S\setminus\{s\}}) = p(x_s \mid \boldsymbol{y}, x_{\mathbf{N}s})$ where $S\setminus\{s\}$ is the set of vertices excluding $\{s\}$ and $\mathbf{N}_s$ is the set of neighbours of s. In other words, the random variable x_s is conditionally independent of all other variables given the observations and its neighbours. We represent the neighbourhood (direct dependencies) of s in the graph by the set of edges between s and the 4 nearest neighbour sites. Then the conditional distribution of the labelling $\boldsymbol{x}$ given the observations $\boldsymbol{y}$ is factorised into a product of two potential functions, capturing the compatibility of a certain variable configuration: one local potential associating given site with a certain class ignoring the site neighbours and one interaction potential for the site dependencies. After log-transformation, the conditional distribution is defined as:

$$p(\boldsymbol{x} \mid \boldsymbol{y}) = \frac{1}{Z}\exp\left(\sum_{s\in S}\varphi(x_s, \boldsymbol{y}_s) + \sum_{s\in S}\sum_{r\in \mathrm{N}_s}\psi(x_s, x_r, \boldsymbol{y})\right). \tag{1}$$

where Z is a normalizing constant ensuring that p is a valid probability distribution, φ is the local potential and ψ is the interaction potential.

To account for the feature dependencies between the sites, for each site s we consider 2 scales at which $\boldsymbol{y}_s$ is computed–the original $m \times n$ scale and $2m \times 2n$ scale. This results in the doubled feature vector $\boldsymbol{Y}_s$. Next we define $\boldsymbol{t}_s = h(\boldsymbol{Y}_s)$, where h is a second-degree polynomial expansion, to explicitly model feature interdependencies. Given the computed features, the potentials are then defined by

$$\varphi(x_s, \boldsymbol{y}_s) = \exp(x_s \boldsymbol{w}_s \boldsymbol{t}_s) \tag{2}$$

$$\psi(x_s, x_q, \boldsymbol{y}) = \boldsymbol{\beta}\Phi(x_s x_q \boldsymbol{v}_{sq} \boldsymbol{t}_{sq}), \tag{3}$$

where Φ is the probit function, $\boldsymbol{t}_{sq}$ is the edge feature vector created by concatenation of $\boldsymbol{t}_s$ and $\boldsymbol{t}_q$, and the parameters $\boldsymbol{w}_s$ and $\boldsymbol{v}_{sq}$ are weight vectors. Note that we modify the standard definition of the edge potential as done in [9], by adding a parameter set $\boldsymbol{\beta}$ in order to account for different weights with respect to the label interaction. This set contains four values corresponding to the four label combinations. Since we aim at mass detection, the pairwise cliques for which $x_s = x_q = -1$ are expected to get larger potentials, facilitated by the larger value of $\beta_{-1,-1}$. Schematic presentation of the CRF modelling for mass detection is presented in Figure 1.

Parameter learning and inference

The parameters that need to be optimised in the learning process are $\Omega = \{\boldsymbol{w}, \boldsymbol{v}, \boldsymbol{\beta}\}$. Since in the construction of CRFs the observed features are dependent, the corresponding parameters need to be learned simultaneously. This implies that the

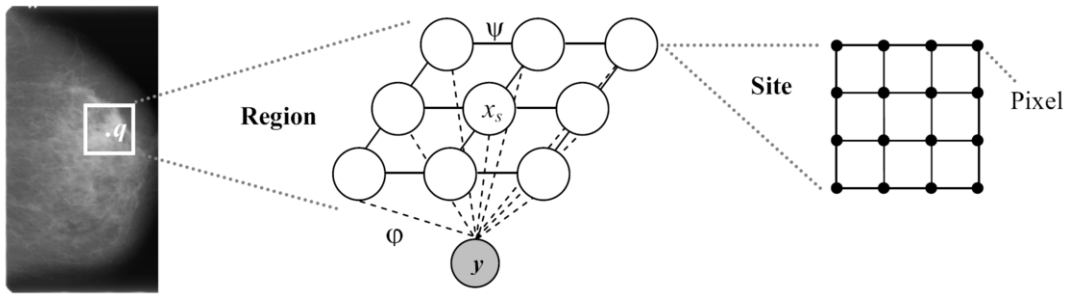

Figure 1- CRF modelling for automatic mass detection

evaluation of Z in Equation (1), which sums over all assignments, becomes intractable for exact inference. Various approximate techniques have been used to overcome this problem: mean-field, loopy belief propagation, stochastic gradient. Here we consider the stochastic gradient descent technique, which has shown fast converging properties. The true gradient is approximated by computing the gradient at an individual training sample. After each step, the new parameter set is adjusted using the approximated gradient based on the update rule of the form $\Omega_d = \Omega_{d-1} - \eta\nabla\Omega_i$, with d ranging over the number of training samples, ∇ being the gradient and η being the learning rate. As prior parameters we assumed that the values of $\boldsymbol{w}$ and $\boldsymbol{v}$ are drawn from the normal distribution with zero mean and variance σ^2.

The goal of inference in our modelling scheme is to find for a new test region the most likely output label sequence $\boldsymbol{x}^*$ over the region sites given the observed site features. We use as inference method belief propagation. To compute the single label probability of the whole region we take the mean over the label sequence on 16×16 window around the centre q. Only the pixels in the close proximity of q are considered as they are most likely to contribute to the correct classification.

Experiments and Results

Design

The proposed approach was evaluated using data collected in the Dutch breast cancer screening program. The dataset consists of mammograms for 164 cases from which 118 were with biopsy-proven cancer and 46 were normal. The total number of images was 220 from which 93 were normal. For every image, which has been digitized at 200 micron (0.2 mm) spatial resolution, the breast area was segmented by the CAD system and a likelihood image was created. The pixel-based locations with a mass likelihood ≥ 0.5 were selected as most suspicious. This resulted in 494 pixel mass locations from which 361 (73%) were normal. Each of these locations was then used as centre to construct a region of size 128×128 pixels (~2.5×2.5cm) for CRF mass detection modelling. Every region was partitioned into 32×32 non-overlapping sites and site features were computed as described above.

Given the classification problem at hand, we trained the CRFs using a random subset of 88 locations with cancer only. Our choice was motivated by the fact that the regions built on normal locations do not provide information about the difference in the labels and features of the sites. The remaining cancerous and all normal regions were used as a test set, accounting for 61% normal test cases. We note that *no* FPs from cancerous cases were used in training and testing, since in the evaluation procedure at a case level they are not included. The results presented next are based on the test data.

We compare the results of the CRF modelling scheme (CAD-CRF) with those obtained from CAD on the likelihood image (CAD-Lik) at two levels: region and case. We evaluated the performance at a region level by the Free-response Receiver Operating Characteristic (FROC) curve whereas at a case level we used the Receiver Operating Characteristic (ROC) [10]. The Area Under the Curve (AUC) is used as a standard evaluation technique. The CRF modelling was done using the freely available CRF toolbox for Matlab [9], where we applied necessary changes to implement the proposed model.

Results

Accuracy

Region level. Figure 2 shows test sample regions and the results on their detection obtained by CAD-CRF. In the test samples the black areas represent cancer whereas the white regions are FP regions detected by CAD-Lik. Clearly a large number of FPs are filtered-out by CAD-CRF, as indicated by the grey regions in the test results on Figure 2. Figure 3 presents the results from both CAD-CRF and CAD-Lik at a region level. We observe improvement in the mass detection rate for the proposed method, starting already at a FP rate of 0.023 per image. At a FP rate of 0.1 per image, for example, CAD-CRF detects 84.6% of the masses whereas for CAD-Lik the detection rate is 71.8%. Furthermore, the context modelling allowed the detection of all masses at a FP rate of 0.3 per image, whereas for the original likelihood image this was achieved at a FP rate of 0.58. The areas under the FROC curves for the FP range [0.01,1] are: AUC(CAD-CRF) = 0.782 and AUC(CAD-Lik) = 0.705, indicating considerable improvement in the detection of the cancer at a local level.

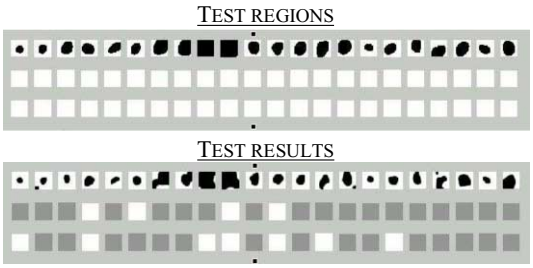

Figure 2- Test regions and corresponding results obtained from CAD-CRF. The black areas represent cancer, the white regions are FPs and the grey regions are true negatives

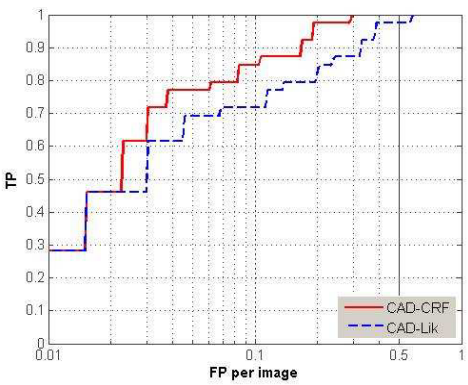

Figure 3- FROC curve for the performance of CAD-CRF and CAD-Lik at a region level

Case level. The probability for a case being cancerous is computed by taking the maximum probability for the regions in the case. Figure 4 presents the ROC curves with the respective AUCs for CAD-CRF and CAD-Lik at a case level. We performed a one-side statistical test for the difference between the AUCs using ROCKIT [11]. The obtained *p*-value is 0.6%, with 95% confidence interval of (0.01, 0.09) indicating the significant improvement in the cancer detection rate achieved by CAD-CRF. Figure 5 also demonstrates the improved performance of CAD-CRF based on filtering out the FP regions detected by CAD-Lik on two normal cases.

Next we examine the effect of the parameters $\boldsymbol{\beta}$ in Equation (3) on the performance of CAD-CRF. After training the model we obtained a vector $\boldsymbol{\beta}$ with values $\beta_{1,1} = 25.03$, $\beta_{1,-1} = 0.5$, $\beta_{-1,1} = 0.5$ and $\beta_{-1,-1} = 50.06$. These results confirm our expectation that the better classification of cancerous regions is facilitated by the large weight for cancerous neighbour pixels. Further evidence supporting this hypothesis is obtained by comparing the results obtained from CAD-CRF where all values of $\boldsymbol{\beta}$ are fixed to 1, as done in [9]. Then the case AUC drops to 0.786 because 17 cancerous test cases are missed.

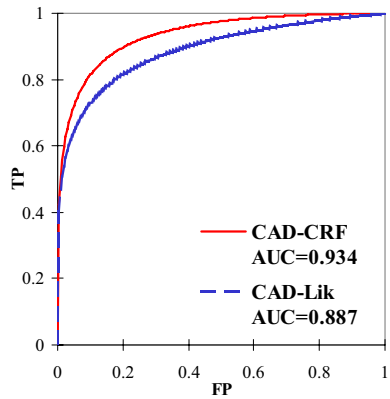

Figure 4- ROC curve for the performance of CAD-CRF and CAD-Lik at a case level

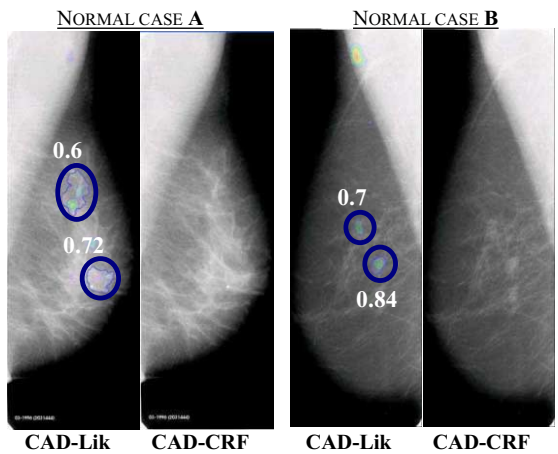

Figure 5- Performance of CAD-CRF and CAD-Lik on two normal cases. The numbers represent the pixel-based likelihoods computed by CAD-Lik for detected FP locations. For the same locations the likelihood computed by CAD-CRF is 0

Computational issues

The learning took 15 iterations in 4.8 minutes on a 2.33GHz Intel Core™2 Duo machine. The learning parameter η was set to 0.0009. The average time of processing a test region was 0.22 ± 0.04 seconds. This implies that for an image with an average number of 3 detected mass locations the testing takes around a second. Thus the improvement in accuracy achieved by using CRF modelling comes at *no* computational costs and can easily be applied in the screening setting.

Discussion

The motivation for the experimental study was to show that extending an existing CAD system by using context information (1) provides significantly better prediction decisions at a region and case level (2) without increasing the computational time. On the one hand, modelling context information leads to significantly better distinction between masses and FPs in comparison to the original CAD system, leading to considerable reduction of FPs while maintaining the high sensitivity rate reached by the CAD system. This improvement is crucial for screening programs where the number of normal cases is much larger than the number of cancerous cases and the sensitivity of human eye decreases with increasing the case disproportion. We also note that the proposed system obtained 100% sensitivity at a FP rate of 0.3 per image, which falls in the radiologists' operating FP range and it is considerably better than the result obtained in [6], for example. Next the current CAD-CRF makes better decisions based on a set of only 5 original pixel-based features. This might also explain the imperfect segmentation achieved by CAD-CRF as shown in Figure 2. However, region segmentation is performed in the subsequent stage of the CAD system once the suspicious pixel-based locations are detected. On the other hand, the extended system remains efficient since the added filtering step does not require additional computational time for providing the prediction decision. This makes the proposed context-based approach also attractive to apply in a screening program where time is an important factor.

Current problem in the original CAD system, which remains in its extended context version, is that a cancerous lesion can be detected by multiple regions. One solution is to perform the testing of the learned classifier for a new region on a larger area consisting of overlapping windows of fixed size. Additional advantage of this approach might be that cancers missed by the CAD-Lik system can eventually be detected.

Conclusion

We presented a novel approach for mass detection based on CRF modelling using local image-based context information. We tested the approach on screening data and compared the results with those obtained from the likelihood image built by a CAD system. The proposed method outperformed the benchmark by reducing significantly the number of FP regions and misclassified normal cases while maintaining high cancer detection rates. The additional filtering step added to the CAD system showed no increase in the computational effort. These results are encouraging for building reliable, fast and accurate CAD systems, which can be employed for assisting radiologists in mammographic screening programs. To make progress in this direction, future work aims to extend the proposed model by including temporal information on the mass development and conducting large-scale experiments with digital screening data.

Acknowledgments

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Chapter 19.

Informatics for Biomedical Research

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The Clinical Research Data Repository of the US National Institutes of Health

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Abstract

The US National Institutes of Health (NIH) includes 27 institutes and centers, many of which conduct clinical research. Previously, data collected in research trials has existed in multiple, disparate databases. This paper describes the design, implementation and experience to date with the Biomedical Translational Research Information System (BTRIS), being developed at NIH to consolidate clinical research data. BTRIS is intended to simplify data access and analysis of data from active clinical trials and to facilitate reuse of existing data to answer new questions. Unique aspects of the system includes a Research Entities Dictionary that unifies all controlled terminologies used by source systems and a hybrid data model that unifies parts of the source data models and include other data in entity-attribute-value tables. BTRIS currently includes over 300 million rows of data, from three institutes, ranging from 1976 to present. Users are able to retrieve data on their own research subjects in identified form as well as deidentified data on all subjects.

Keywords:

Clinical research, Data repositories, Controlled terminologies and ontologies, Data reuse

Introduction

The United States National Institutes of Health (NIH) consists of 27 institutes and centers (ICs) dedicated to biomedical research for improving the health of the public. Most ICs are located wholly or in part at the main NIH campus in Bethesda, Maryland, just north of Washington, DC. All clinical research on the Bethesda campus is coordinated through the Clinical Center (CC), the 242-bed, 90-day-station hospital of the NIH.

Much of the information collected on human subjects at the CC exists in the Clinical Research Information System (CRIS). Many researchers also collect data in other locations, including IC systems, laboratory systems within the ICs, and even individual researchers' computers and notebooks. This data distribution causes two problems for researchers. First, CRIS is primarily an electronic medical record system, concerned with the tasks involved in patient care. Although it can support tasks related to research protocols, it is not designed to support research data analysis (e.g, queries for data across subjects in a clinical trial). Second, distribution of data across multiple sources complicates the ability of researchers to use the data to answer their research questions.

The clinical research data at NIH are also of interest to researchers besides those who are collecting them in the course of active trials. The US government mandates the sharing of clinical data that have been collected with federal funding, yet there is no mechanism at NIH to share the data that have been collected here for over half a century.

This paper describes the new NIH Biomedical Translational Research Information System (BTRIS), which has been providing investigators with access to clinical research data since July of 2009. Although still in evolution, BTRIS contains a substantial database and makes use of unique data models and terminology management techniques to merge data from multiple, disparate sources, to support active clinical trials and reuse of data.

Background

NIH Efforts to Consolidate and Reuse Research Data

NIH initiatives have recognized the need for a clinical research data repository to support reuse and sharing of data for clinical research, including the NIH Roadmap NECTAR project,[1] the CABIG project through the National Cancer Institute[2] and the current Clinical and Translational Science Awards (CTSA) program.[3] Based on researcher requirements as well as a business case, the NIH endorsed the concept of a clinical research data repository for aggregation and re-use of data collected at the NIH itself (as opposed to data collected by NIH-funded projects at other institutions). Initial funding for the project was received in 2007 and the development of BTRIS began in earnest in 2008.

The Columbia University Clinical Data Repository

The initial design of BTRIS has been based on experience with the creation of the Clinical Data Repository (CDR) at the Columbia University Medical Center in New York.[4] That system has accrued patient care data since 1988 from many different sources, including laboratories, pharmacies, radiology departments, order entry, and clinician documentation. Over the years, the repository has supported a number of systems for clinical care[5] and clinical research.[6]

All data in the Columbia CDR have been merged using a single, common relational data model that simplifies representation of disparate data while maintaining important distinctions and details.[7] The model makes extensive use of the "Entity-Attribute-Value" (EAV) approach, which allows specifications about the meanings of data to be stored with the data themselves, rather than being modeled as tables or columns in the data model. This method provides great flexibility for accommodating changes in data sources.[8]

The data in the Columbia CDR are represented with a single coding system, called the Medical Entities Dictionary (MED),[9] that unifies terminologies from all the sources providing data to the CDR. The MED provides a one-to-one mapping of individual concepts from each source and organizes them into a multiple-hierarchy ontology that provides definitional information about the concepts and supports data aggregation and inferencing functions.

Design Considerations

System Architecture

The first issue to be addressed in the BTRIS design was whether we should attempt to create a single, centralized repository (as was done at Columbia) or seek to create a federated system in which individual sources systems could be queried to provide data on demand. Although there are potential advantages to the federated model,[10] we quickly realized that most of the sources we would be dealing with (including archived repositories from defunct systems) would be incapable of participating in a federated design. We therefore proceeded to design a centralized repository.

Data Model

In designing the BTRIS data model, we considered the various advantages and disadvantages of traditional modeling approaches and the EAV modeling approach. We chose to take a hybrid approach in which data from disparate sources (for example laboratory test results from CRIS, from archives of the system that preceded CRIS, and from various IC systems) are analyzed and commonalities (such as the fact that all laboratory tests have primary times and results) are represented with columns in tables, while distinct source-specific differences are captured in EAV tables.

In addition to data collected from research subjects, we recognized that we would need a repository of information about the subjects themselves, including the protocols with which they are affiliated and the dates of those affiliations. While some of this information is available from CRIS, much is missing and some individual data may be "tagged" with protocol affiliations that do not match the CRIS database.

Data Acquisition, Extraction, Translation and Loading

The approach to adding data to the BTRIS database is a fairly typical *extraction, translation and loading* (ETL) process. Acquired data are dissected into their component elements and converted into a form compatible with the BTRIS database. They are then stored in the appropriate tables, rows and columns, according to a set of mapping rules. Sources include archived files, copies of active databases, and collections of transaction messages (typically in HL7 format). Sources may provide data on a one-time basis (from archives) or on a periodic basis (typically, daily or weekly). Mapping rules are created manually for each source, based on careful analysis of the source systems' documentation and the actual data provided (which do not always match the documentation).

Data Coding

Early in the project, we established a repository of controlled terminologies used by source systems to represent their data (for example, laboratory codes for tests and unique names for medications). This "Research Entities Dictionary" (RED) is based on the experience with Columbia's MED: each source term corresponds to a unique concept in the dictionary, with additional knowledge about the terms represented in hierarchical and non-hierarchical semantic relationships between concepts. The ETL process maps individual data elements to their corresponding entries in the RED so that the RED Codes can be stored along with the original data. Although the source systems do not use standard terminologies, concepts in the RED are being mapped to international standards to facilitate data sharing, including those contained in the US National Library of Medicine's Unified Medical Language System (UMLS).[11]

Data Reporting

Another key early decision in the system architecture was to determine that BTRIS users would perform retrievals themselves, using predetermined queries that could be tailored by the users for their specific needs. Given that a number of mature commercial "business intelligence" tools currently exist to support such capabilities, we evaluated several options and ultimate chose one to be our user interface to the database. System developers create query templates with general retrieval strategies (for example, to obtain demographic information or laboratory test results) and search filters (e.g., an age range, date range, type of laboratory test, or type of medication). Users provide values for the search filters when running the query to limit retrieval to specific subsets of data.

Queries were developed in response to a variety of perceived information needs. Some of these were identified in the original requirements gathering process for CRIS (see above), while others were developed through interactions with a BTRIS user group composed of interested NIH investigators.

Progress to Date

The BTRIS project officially began in January of 2008, with assembly of the development team in March, acquisition of sample data from several systems in May, and demonstration of a proof-of-concept prototype in July. The initial prototype used SQL Server (Microsoft, Redmond, WA) as the database management system, Terminology Development Editor (Apelon, Mountainview CA) for the RED, and Business Objects (SAP, Newton Square, PA) as the reporting tool.

Experience with the BTRIS prototype informed a number of changes in database design and user requirements, which led to the selection of Cognos (IBM, Armonk, NY) as the reporting tool. Based on the performance and user feedback with the prototype, approval for the project was secured in October. The first version of the actual BTRIS system was released on July 30, 2009 to PIs with active clinical protocols.

The Research Entities Dictionary

Each data source incorporated into BTRIS has one or more controlled terminologies that have been added to the RED. For example, the radiology system has a list of codes for procedures, while the laboratory has codes for tests, panels, organisms, antibiotics, specimens, and results. The RED currently contains 120,636 concepts with 155,321 hierarchical relationships (i.e., each concept has, on average, 1.3 parents).

Database Design

The BTRIS database contains five general sections, with information about investigators, protocols, subjects, the RED, and subject data. Investigator, protocol, and subject tables are related to each other in a typical manner.

Subject data are considered *measurable* (for data with normal ranges, such as laboratory tests), *substance* (for data with routes of administration, such as medications), and *general* (everything else). Data stored in *event* tables (for "things that happen", such as orders and procedures) and *observations* (for "things that report something", such as results and dosages given). Most events are associated with one or more observations. Each table has an associated EAV table (Figure 1); thus, there are a total of 12 tables for subject data (three event tables, three observation tables, and an EAV for each).

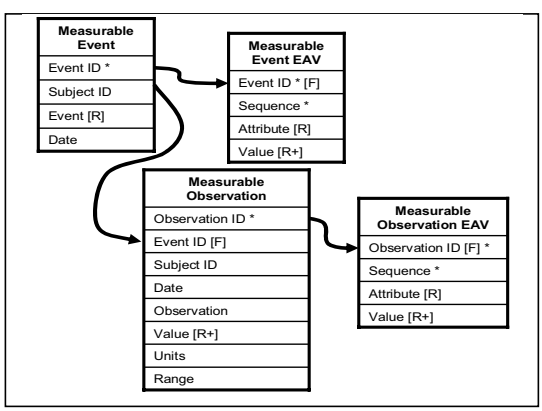

*Figure 1- Simplified view of part of the BTRIS data model. * = primary keys, [F]=foreign keys, [R]=elements coded in RED, [R+]=multiple column elements*

The six main tables include information common to all data from all the sources, such as subject ID, source, name, etc. These tables also include data elements that have been judged to be similar enough across sources that they form part of the merged data model. For example, each source provides one or more times (including date) for observations; for each source, we choose one of these to be the primary time. For radiology procedures, it is the time the procedures were performed. For laboratory tests, it may be the specimen collection time, or it might be specimen analysis time. Other times for each source are retained in the EAV tables.

Another example of the merged data model can be found in the way results of observations are treated. In the BTRIS model, results of observations that have normal ranges (such as laboratory test results and vital sign measurements) are all stored in the same table. Separate columns are used to store the result (or parts of the result) that are numeric, text, controlled terms, and comments. Controlled term results are stored as they appear in the data and as the corresponding RED Codes. Observations without normal ranges, whether nurse's notes, radiology reports, or discharge summaries, are all included as text results in the general observations table.

The RED is represented in two particularly interesting tables. One table relates every concept in the RED to one or more data sources, such that an identifier (such as a laboratory test code from the laboratory system or a medication name from the order entry system) can be uniquely mapped to a particular RED Code. This information is managed in the RED (see below) and exported to this table for use by the ETL process.

Another important RED table is the ancestor-descendant table. This table is derived from the RED hierarchy and supports class-based queries of the subject data. Figure 2 shows a simplified example of the use of the ancestor-descendant table for class-based queries. As of this writing, there are 1,214,646 ancestor-descendant relationships (that is, each concept subsumes, on average, ten concepts including itself).

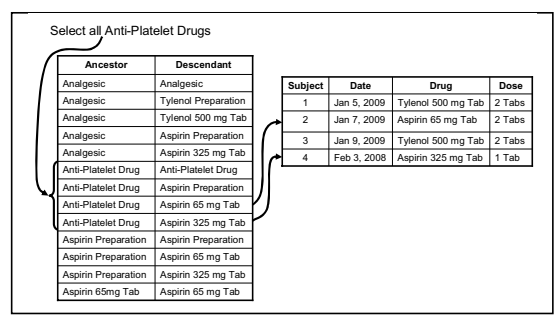

Figure 2- Class-based query for "Anti-Platelet Drugs" using ancestor-descendant table.

Figure 3- Example of text-based terminology searches in BTRIS. Note that each of the selected terms will be used to query against the Ancestor-Descendant table.

Database Content

As of this writing, data have been accrued from three ICs: the Clinical Center (including CRIS and archived tapes of CRIS's predecessor), the National Institute of Allergy and Infectious Diseases (NIAID), and the National Institute of Alcohol Abuse and Alcoholism (NIAAA). Data types include demographics, vital signs, laboratory test results, medication orders, medication administrations, medication lists, and problem lists. Additional data to be added in the near-term include clinical documents (e.g., progress notes and discharge summaries) and procedure notes (radiology, pathology, etc.). Next steps include obtaining radiology image data and gene sequence and expression data from the National Cancer Institute (NCI). Thus far, there are over 86 million rows in event tables, 180 million rows in observation tables, and 855 million rows in EAV tables. Data are derived from 436,422 subjects, 196,036 of whom have been affiliated with one or more of the 9,055 protocols involving 3180 investigators, for a total of 393,447 protocol-subject affiliations.

Reports

Thus far, we have created three types of reports for identifiable data: summary reports (enrollment inclusion report for the Institutional Review Boards (IRBs)), detailed data reports (demographics, vital signs, laboratory test results, and medication data) and "list" reports (which create lists of patients, tests and medications that can be used as filters for other reports). Summary reports and detailed reports for all of these data have been created for de-identified access as well. When running reports, users interact with the RED in one of two ways. A text-based search produces a list of terms from which users may select terms (Figure 3). The users may also browse the RED hierarchy to select terms (Figure 4).

User Experience

Currently, BTRIS has been providing access to identified data for 30 weeks; 111 users have logged on to date. Of the 4,349 reports run thus far, 3,015 have been to retrieve laboratory test results, 303 to retrieve medication information, 275 to retrieve vital signs, and 310 to create summary reports for IRBs. De-identified data have recently been made available. User feedback been extremely positive. Additional reports have been requested; the current BTRIS model appears to be capable of supporting these requests.

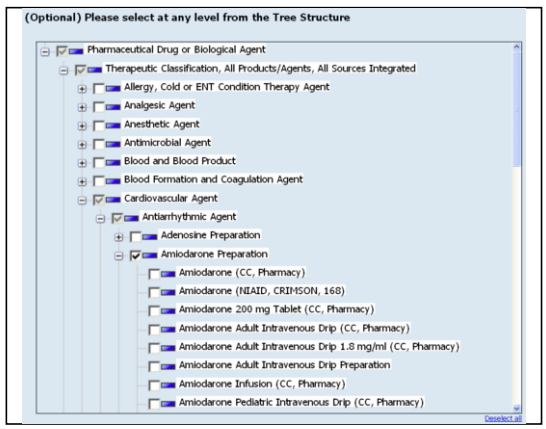

Figure 4- Example of tree-based terminology search in BTRIS. A subsequent query will use the ancestor-descendant table to select all data with any of the 12 amiodarone medications.

Discussion

BTRIS is intended to encompass all clinical research data collected on subjects at the NIH. We began with some initial assumptions about design requirements and desired functionality and have proceeded rapidly through design, construction, and deployment. Our hybridization between column-oriented and EAV data models has allowed us to accommodate diverse data from disparate source in a way that supports aggregation across multiple data sources. The use of the RED and the EAV tables allows us to maintain the distinct aspects of data that are unique to their sources. The combination of the hybrid data modeling and the rich terminology representation provides a novel approach to the creation of a multi-purpose clinical data repository.

Thus far, BTRIS appears to be meeting the needs for researchers to obtain identified data on active clinical protocols. BTRIS is poised to provide access to de-identified

NIH data, across protocols, to analyze old data in new ways and ask new questions. We do not yet know how our researchers will make use of such functionality, but we believe that it will be in creative, unforeseen ways. BTRIS is designed to be flexible enough to meet a wide variety of such needs.

In particular, coding data with the RED supports queries that can aggregate or distinguish data as needed for the users' purposes. For example, instances of the administration of a 325mg aspirin tablet will be retrieved when a user requests that specific information, or all instances of the administration of any aspirin, any analgesic, any antipyretic, any platelet inhibitor, or simply any drug of any kind.

Elements of different data sources that have been stored in common columns in our six main tables have been carefully chosen to support what we believe will be the kinds of data aggregation that researchers are likely to want. For example, a user interested in the use of aspirin in a set of research subjects can request all instances of aspirin administration from the CRIS system, all instances of aspirin orders from the CRIS system, all instances of aspirin on a subject's medication list from the NIAID system, or a combination of any of these. Together with the flexible class-based queries supported by the RED, users have a range of ways to retrieve desired data.

The commercial reporting tool we have chosen (Cognos), allows us to create a variety of reports that appear to meet many of the users' needs, while giving them the power to tailor their queries and immediately obtain results. However, we fully expect that there will be information needs that will not be easily met with this approach. For example, a user may require a complex query that makes use of data from several main tables and EAV tables. In these cases, we may create specialized reports within Cognos, or we may perform retrievals, directly against the database, on the user's behalf.

In addition to the technical challenges, the development of BTRIS has required addressing a variety of policy issues that are beyond the scope of this paper. We have been successful at overcoming these issues in ways that address human subjects protection, privacy, data ownership, data access, and data sharing concerns. Solutions have required combinations of administrative and technical methods.

As with any system, BTRIS is faced with a number of potential limitations, particularly with regard to scaling (as we add image and genomic data), scope (as we add new data from institutes) and performance. Thus far, however, we have been able to address these issues and are not yet close to reaching capacity. BTRIS is still very much in development, as we add new reports for identified data, explore creative ways to reuse de-identified data, and expand to include new sources and types of data. The NIH has demonstrated deep commitment to creating a repository that serves all of the NIH community and eventually the research community at large, for the betterment of the health of humankind.

Conclusion

BTRIS addresses a long-standing need to consolidate clinical research data across the NIH for a variety of purposes. Our design includes a combination of novel approaches, development has been rapid, and it is already successfully addressing the information needs of NIH researchers.

Acknowledgments

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Scientific discovery workflows in bioinformatics: A scenario for the coupling of molecular regulatory pathways and gene-expression profiles

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Abstract

Scientific workflow technologies and tools have become an important weapon in the arsenal of the bioinformaticians and computational biologists. To support this view we present a typical exploratory data analysis scenario involving the combination of information from Gene Regulatory Networks and gene expression data. We further describe the implementation of this scenario using the Workflow Environment implemented in the context of a large EU funded project. In this process desirable features that similar environments should offer are identified and analyzed. The ICT platform presented is evaluated using the chosen scenario as a benchmark. Finally we conclude with an outlook to future work.

Keywords:

Bioinformatics, Semantics, Grid, Web services, Scientific workflows

Introduction

In the new era originated with the successful completion of the human genome sequencing projects molecular biology research has moved from the experimental laboratory bench to systems biology approaches enabled by the *in-silico* (computer-based) study of the huge biological data sets produced by the high throughput technologies such as DNA microarrays [1,2]. To tackle these challenges some new computational tools and techniques have been developed to offer complex data analysis and visualization. Scientific workflows [3,4] present an "umbrella" term to describe the use of computational tools that help to automate data collection, analysis and processing tasks of scientific experiments.

This paper aims to present a complex, yet characteristic bioinformatics scenario and its implementation through the scientific workflow environment implemented in the context of an FP6 EU funded project with the acronym ACGT (Advancing Clinico-Genomic Clinical Trials on Cancer: Open Grid Services for improving Medical Knowledge Discovery, http://www.eu-acgt.org/). The objective of the ACGT project is to develop and test an ontology driven, semantic grid services infrastructure enabling efficient execution of discovery-driven analytical workflows in the context of multi-centric, post-genomic clinical trials [5].

An indicative bioinformatics scenario

One of the most significant sources of genomic functionality stems from Gene Regulatory Networks (GRNs). The compilation of GRNs known today was a complicated effort since it demands the combination and distillation of numerous and dispersed source of information originating mainly from the biomedical literature. As a side effect, devised GRNs are far from complete since, not all genetic interaction are known and the one that are already modeled have not been fully documented. Another issue concerns the fact that each GRN models a separate cellular functionality but this abstraction is rather obsolete. Today, while we move towards the realization of the systems biology vision, we tend to view genetic interactions as parts of a holistic and general mechanism that govern the cellular functionality. Therefore, we need to locate all the different interactions depicted in GRNs and to examine them out of the context of a specific and isolated cellular function (i.e. apoptosis, cell cycle, signaling etc) and move to a more unified and systemic point of views [6].

Decomposition

The first step of our approach is the decomposition of known and established GRNs. Using as our major source of GRNs the KEGG repository [7], we acquired all available regulatory networks related to cellular processes in their special KGML format (http://www.genome.jp/kegg/xml/). As regular XML files, the GRNs encoded through KGML can easily be parsed and modeled as a usual directed graph where, vaguely speaking, genes are the nodes and molecular interactions are the edges. Through the devise and utilization of a specific algorithm we can identify all possible paths contained in each graph. A path is a sequence of nodes and edges that could be followed in a graph in order to form a route from one node to another. Just a single presentation of a node or an edge is permitted in a path. In our effort to manage the paths as molecular functions, we assigned additional values to each gene according to its functional state in the path. We assume that each gene possess a particular functional role either by being in an "ON" or "OFF" state [8]. These values represent the possible activated/non-activated states or, expressed/non-

expressed levels of a gene during a certain cellular process. Moreover, these values are determined by the semantics of the interaction between two genes. Namely, the characterization of a gene in a path as being on an "ON" or "OFF" state is unambiguously specified by its preceding direct regulatory links (edges) with other genes. According to the semantics of the KGML file there are various types of gene interactions but since the functionality of many of them is similar we narrowed down to four basic different kinds of molecular interaction: 'activation', 'inhibition', 'association' and 'disassociation'. These interactions determine the "ON" / "OFF" state of a gene according to the following rules: If a gene is the first node of a path then it should be "ON". Otherwise, if its preceding relation is 'activation' then this gene should be "ON", and if it is 'inhibition' it should be "OFF". In case that the previous relationship is 'association' then the gene is considered to posses the same state as the previous gene in the path whereas, for a 'disassociation' relation, the gene is considered to posses the opposite state of its preceding gene in the path. The intuition that underlies these rules is that: if a gene is on an "ON" or "OFF" state there should be a reason for this. The linear reasoning that we provide goes opposite the direction of the path. As a generalization we could say that the state of a gene depends on two things: the state of its directly preceding genes in the path, and on the nature of its direct preceding interaction that govern its regulation. Thus, each path can be perceived as a history of events that explain the state of each gene.

Microarray Discretization

The set of paths with "ON"/"OFF" annotated genes comprise a functional decomposition of the available GRNs. Our aim is to verify the conditions under which these functions either "work" or "stay idle". This validation can be done by incorporating knowledge from microarray gene expression measurement over tissue samples pre-classified against two phenotypic categories, let "A" and "B". In order to validate the "ON"/"OFF" values of the genes in the paths we discretized the gene expression values into "High" and "Low" values [9, 10].

Combination

For each path Pi originating from the functional GRN decomposition we can determine if it is in an "operational" or in an "idle" (passive) state for any microarray sample Sj as follows: path Pi is considered to be operational for sample Sj, if (and only if) the genes that have "ON" values in Pi have "High" values in Sj, and respectively, the genes that have "OFF" values in Pi have "Low" values in Sj. If there is any misalignment between the "ON"/"OFF" values in the path and the respective "High"/"Low" values in the sample then, the path is considered to be idle for this sample. Applying this procedure for all samples then we can form a contingency table between the operational/idle states of a path and the "A" / "B" class phenotypes of the samples. Each entry in table represents the number of the microarray samples that belong to the "A" (or "B") class and are operational (or idle) in the path. By calculating the contingency table's Fisher's exact test figure we assess the significance of this association. Specifically, paths with low p (<0.001) indicate that they represent cellular functionalities that behaves differently between tissues belonging to class "A" and "B". Thus, by sorting all the paths in ascending p-value order, we gain insight to the cellular mechanisms that explain this differentiation.

Materials and Methods

It is common knowledge that the requirements for the management of the biological data are very demanding because of their size and complexity, quality properties (missing values or noisy data are frequent), and the inherent heterogeneity of the domain. These new requirements have given rise to modern software engineering methodologies and tools, such as the Grid [11] and the Web Services. These new technologies aim to provide the means for building sound and scalable data integration, management, and processing frameworks.

In order for these new technologies to become exploitable by the biologists and bioinformaticians a user friendly environment needs to be in place. This is an already recognized need, and a number of tools have been developed, such as the Taverna Workbench [12], Kepler [13], and Triana [14] to offer efficient and effective scientific workflow environments. The posted challenges related to the provision of state of art discovery processes in scientific workflows are well documented in [15]. In particular a major requirement is that the system should support the "reproducibility" of the results so that the same or other scientists can validate the whole process. Security and trust is another very important aspect of these environments, which means that the users trust the tools that will not inflict harm to their data or that their private data will be subject to unintended analysis by other users.

More specifically for the implementation of the scenario described above the following requirements should be satisfied:

- Secure controlled access to the user data. Although the general consensus is that the data should be shared in order to accelerate the scientific discovery process it is of course the right of the data curator not to share their data especially when sensitive patient information is the case. The microarray data used in the experiment are stored in the Grid Data Management System [16] in the user's private storage area and respective access rights require user's credentials.
- Access to "third party" publically available information sources. In particular the scenario requires the retrieval of the relevant gene regulatory networks from online stores such as the Kyoto Encyclopedia of Genes and Genomes (KEGG) [7].
- A number of processing steps need to be performed: decomposition of networks, discretization of microarray data, etc. For some of these tasks (e.g. discretization) there are available tools but for others the user should be able to enhance the functionality of the system by incorporating custom and reusable analytical methods and tools.

- The reliability and scalability of the system should guarantee that the end user would get the outcome of experiment in a logical time frame in spite of the complexity of the analyses or the size of the involved data sets.
- The system should be intuitive and reflect the user's way of thinking and assist to achieve his/her goals. Specifically, user friendliness and presentation of information at more domain specific and abstract user's conceptualization levels are important characteristics.
- Interoperability issues and heterogeneities among the tools and data sets should be resolved at the minimum cost and disturbance of the user. The use of metadata for the specification of additional aspects such as intent, policies, "meaning", etc., is a critical factor and ease to overcome such difficulties [17].

The ACGT Workflow Environment

To assist bioinformaticians in building their complex scientific workflows, a Workflow Editor and Enactment Environment, called WEEE [18], have been designed and implemented. They consist of a suite of graphical tools that allow a user to combine different web services into complex workflows. This environment is accessible through the ACGT Portal and therefore features a web based graphical user interface. It supports searching and browsing of a tool (service) registry and of respective data sources, as well as their orchestration' and composition through an intuitive and user friendly interface. The created scientific workflows can be stored in a user's specific area and later retrieved and edited so new versions of them can be produced. The designed workflows can be executed in a remote machine or even in a cluster of machines in the Grid so there is no burden imposed on the user's local machine since the majority of computation and data transfer of the intermediate results are taken place in the Grid where the services are run. The publication and sharing of the workflows are also supported so that the user community can exchange information and users benefit from each other's research. WEEE is based on the BPEL [19] workflow standard and supports the BPEL representation of complex bioinformatics workflows.

In the following section we discuss the approach we have followed in ACGT in order to support these requirements using the scenario described in the introduction as a "yardstick".

Results

The workflow implementing the bioinformatics scenario described above is shown in Figure 1. The workflow consists of various web services, each implementing a functional unit of the whole workflow scenario. The core services (activities) are the DiscretizationService ("EntropyDiscretize"), the DecompositionService ("decompose") and the CombinationService ("combine") which independently implement the corresponding functions mentioned previously. Besides these core activities, additional entities are introduced to either make feasible the interconnections between the activities or to further enhance the functionality. In the former case the FileService ("writeFile") is used for data retrieval and storage on the Grid and in the latter case a Biomoby service [20] is used for visualizing the GRN as an image. We have used the BioMoby web service called "getKeggPathwayAsGif", which, given a KEGG network identifier, returns a GIF image of the corresponding pathway.

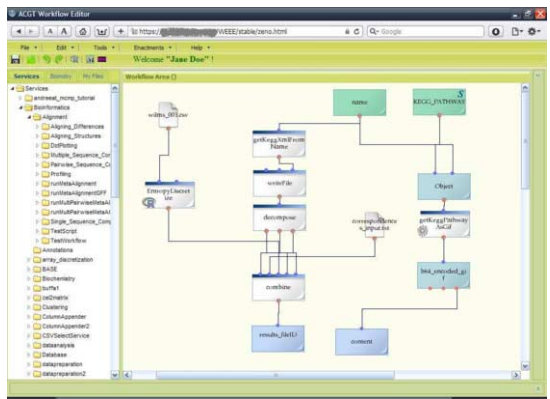

Figure 1 - The workflow implementing the coupling GRN/gene-expression scenario as realized in the ACGT Workflow Editor

The information is passed from one service to another by reference, using files on the Grid. This is done not only for performance reasons, but also for having a means to monitor and document the execution of the workflow, store intermediate results and re-use of data. Since BPEL supports the parallel execution of tasks, some of the services of the workflow are executed simultaneously by the Enactor engine of the ACGT Enactment Environment [18]. This inherent parallelization along with the usage of Grid resources, both in computation and storage terms, permits simultaneous execution of the same workflow with different parameters or input data resulting in significant up scale of the execution speed and the overall performance.

The implemented scenario was applied on an indicative Wilm's tumor gene-expression study [21]. We target the apoptosis GRN (KEGG identifier: hsa04210) as it engages prominent regulatory mechanisms for various cancer types and tumor states. The resulted significant paths are shown in Figure 2. As it can be observed, all the paths have a tendency to move towards the "Survival" or the "Death Genes" regions of the pathway. A pathological situation that leads constantly to the "Survival" or the blocking of the "Death Genes" region can be presumed to lead into endless proliferation of the cell. This finding can act as an indication for further analysis and research in this area.

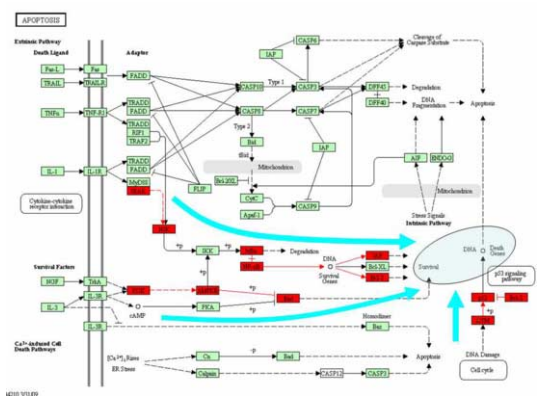

Figure 2 - If we portray the identified paths (red frames and connectors) as a layer on top of the apoptosis GRN then three primaries generic paths (light blue arrows) are emerged that lead towards cellular segments that are known to play vital role in the development (or suppression) of various types of cancer.

Discussion

The design and implementation of the workflow using the ACGT Enactment Environment, enables us to meet most of the above mentioned functional requirements

- The execution of the workflow is performed in a secure manner, using a Public Key Infrastructure (PKI) and access to private data is done only from authorized users. All activities are accessed using the end user Grid credentials and therefore authentication, authorization, and privacy are guaranteed.
- The design of the workflow is intuitive, following a data-flow analysis of the scenario and designing it using a "drag 'n' drop" web based visual editor. In particular the use of web technologies enables ubiquitous access and the straightforward sharing of the constructed scientific workflows.
- The decomposition of the GRN scenario to smaller functional steps enables the composition of the workflow by re-using existing ACGT tools and services, invoking also third-party services and accessing publicly available data, along with the private data on which only the user has access.
- The use of metadata, service, and domain ontologies, although not explicitly demonstrated in this scenario, enables the high level composition and orchestration of data analysis tasks.
- And finally the usage of grid resources and the parallel execution of various BPEL tasks, both of which has a proven record in terms of performance and scalability, results in a reliable execution of the scenario, which scales in a logical manner along with the scale of the input data.

Conclusion

The presented scenario tries to combine two already known sources of biomedical information in order to produce novel knowledge. The decomposition can be perceived as a disassembling of a partly known device into chunks of sub-mechanisms that can be more easily be tested and verified. Our testing platform is the microarray experiments conducted for certain disease types. In our application to Wilm's tumor, the identified paths revealed a more general and abstract path that might give more insights in the genomic regulations that happen during the advancement of the disease. The methodology does not only present an approach for the functional enrichment of microarray data - based on their abundance in specific pathways but also, it is able to reveal and identify regulatory-mechanisms (paths in gene regulatory networks) that discriminate and 'govern' the expression of specific phenotypes.

The presented methodology was also applied and tested on various clinico-genomic studies. In [22] it is utilized in the context of the breast-cancer (BRCA) domain and the gene expression profiling of BRCA patients targeting the Estrogen Receptor (ER) phenotypic categories. In [23] the methodology was applied on a well-known microarray study that targets the distinction between AML (Acute Myeloid Leukemia) and ALL (Acute Lymphoblastic Leukemia) leukemia sub-types. The ACGT scientific workflow environment was also utilized in the context of a real-world genotyping study that targets the discrimination between BRCA and normal patient samples through the identification of 100 SNPs (single nucleotide polymorphisms), measured with the Affymetrix 10K platform [24].

In this exercise the ACGT technologies and tools have succeeded in implementing such a scenario to its entirety and this fact gives more validity to the specific choices we have made and the approach we have followed. Nevertheless we acknowledge the fact that future work is needed in order to enhance the functionality and the utility of the system to the practicing bioinformatician. A particular aspect we are working on is with respect to the "reproducibility" of the workflow results which is strongly connected to the storage and management of the "provenance" information. Furthermore the use of graphical tools for the specification of complex experiments has its limitations. An experienced user may feel more "at home" if some scripting environment allows him/her to easily present his/her workflows in a declarative manner and it's on our agenda to research this direction further in the future.

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A Framework for Comparing Phenotype Annotations of Orthologous Genes

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Abstract

Objectives: Animal models are a key resource for the investigation of human diseases. In contrast to functional annotation, phenotype annotation is less standard, and comparing phenotypes across species remains challenging. The objective of this paper is to propose a framework for comparing phenotype annotations of orthologous genes based on the Medical Subject Headings (MeSH) indexing of biomedical articles in which these genes are discussed. Methods: 17,769 pairs of orthologous genes (mouse and human) are downloaded from the Mouse Genome Informatics (MGI) system and linked to biomedical articles through Entrez Gene. MeSH index terms corresponding to diseases are extracted from Medline. Results: 11,111 pairs of genes exhibited at least one phenotype annotation for each gene in the pair. Among these, 81% have at least one phenotype annotation in common, 80% have at least one annotation specific to the human gene and 84% have at least one annotation specific to the mouse gene. Four disease categories represent 54% of all phenotype annotations. Conclusions: This framework supports the curation of phenotype annotation and the generation of research hypotheses based on comparative studies.

Keywords

Phenotype, Comparative study, Medical informatics computing, Medical subject headings.

Introduction

Scientific discoveries for improvement of human health typically begin "at the bench" with basic research, then progress to the clinical level. Studies using animal models play an important role in the generation of research hypotheses based on comparative genotype, phenotype and functional analyses, later tested in human clinical studies [1, 2]. The growing importance of animal models in translational research has given rise to the development of large, species-specific knowledge bases containing curated functional and phenotype annotations, in addition to gene sequences [e.g., 3, 4, 5].

Tools for comparing and contrasting annotations of orthologous genes have started to emerge as part of portals developed by model organism communities (see, for example, the graphs representing the functional annotations of genes across species on the Mouse Genome Informatics system[1]). The Gene Ontology has brought standardization to the functional annotation of gene products, making it relatively easy to compare functions across species. In contrast, phenotype annotation is less standard and the comparison of phenotypes across species remains challenging [6].

Data mining approaches to identifying gene-phenotype associations have been used [7] and orthology has been exploited in some studies [8]. In contrast to the word-based approach in [8], we specifically take advantage of the hierarchical structure of MeSH in order to aggregate diseases into high-level categories to facilitate the analysis of the results.

The objective of this paper is to propose a framework for comparing phenotype annotations of orthologous genes based on the MeSH indexing of biomedical articles in which these genes are discussed. The framework is applied to mouse and human orthologs. We outline two possible applications of this work, namely to support the curation of phenotype knowledge bases and to help researchers with hypothesis generation.

Materials

Several publicly-available data sources are used to relate phenotype annotations across species. Mouse to human orthology information is acquired from MGI. The association between genes and biomedical articles is provided by Entrez Gene. Finally, MeSH index terms corresponding to diseases are extracted from Medline.

MGI

The Mouse Genome Informatics (MGI) system is a knowledge base about the laboratory mouse developed at the Jackson Laboratory [4]. Among the information provided is mammalian orthology and, in particular, curated and uncurated lists of human genes corresponding to mouse genes. In addition to gene identifiers in the MGI system, cross-references to Entrez Gene identifiers are provided.

Entrez Gene

Entrez Gene is the gene-centric knowledge base developed at the National Center for Biotechnology Information (NCBI)

[1] http://www.informatics.jax.org/function.shtml

[9]. In addition to basic information about genes (e.g., symbols and names), Entrez Gene provides cross-references to other components of the Entrez system and to external resources. In particular, Entrez Gene compiles bibliographic references for each gene (with links to PubMed). These references are specific to a given gene cited as evidence for functional annotations, from the GeneRIFs[2], protein databases and model organism databases (GOA[3] for human genes and MDG[4] for mouse genes).

Medline and MeSH

Medline is a bibliographic database developed at the US National Library of Medicine, containing over 16 million citations. Medline citations are indexed with terms from the Medical Subject Headings (MeSH) thesaurus and are available through PubMed in the Entrez system.

The current version of MeSH contains 25,186 descriptors, 4,409 of which correspond to diseases (somatic and mental disorders). The hierarchical structure of MeSH makes it easy to aggregate diseases into top-level disease categories (24 including mental disorders).

Methods

Acquiring phenotype information

Starting from the list of orthologs, we use links established between Entrez Gene and PubMed to retrieve Medline citations for each gene, from which we extract the MeSH index terms corresponding to diseases. An overview of the links among resources is presented in Figure 1.

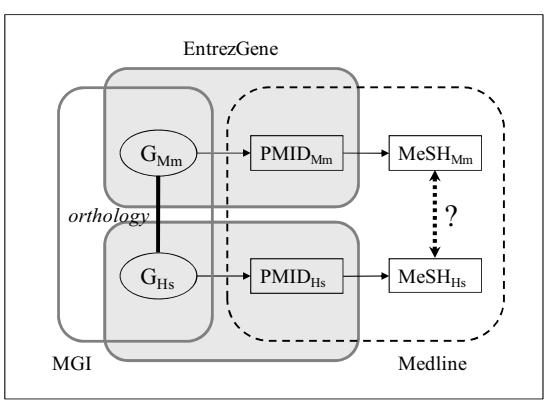

Figure 1- Overview of links among resources

List of orthologous genes

The list of human genes orthologous to mouse genes was downloaded from MGI[5]. Of the 17,796 pairs of genes, 24 were eliminated because no cross-reference to Entrez Gene was provided. Three additional pairs were discarded, in which multiple human orthologs were listed for a given mouse gene. In this case, the curated orthology pair was selected over the computed one. A total of 17,769 pairs of genes remained. Entrez Gene identifiers were available for all 35,538 genes.

Bibliographic references for genes

The association between genes from Entrez Gene and Medline citations from PubMed was queried from the Entrez system using the Entrez Programming Utilities[6]. More specifically, we used the *elink* service to retrieve links from the *gene_pubmed* table. The resulting XML file was processed with XSLT transformation in order to extract pairs of identifiers for the gene (Entrez Gene ID) and the related Medline citations (PubMed identifier or PMID). At least one bibliographic reference was available for all but 552 genes. Orthologous human and mouse genes were associated with a total of 357,008 unique Medline citations.

Disease categories for genes

These 357,008 Medline citations were downloaded in XML format using the *efetch* service and post-processed with XSLT transformation in order to extract the MeSH descriptors from each citation. A total of 5,862,632 MeSH descriptors were extracted and mapped to their identifiers and top-level categories using a local MeSH database. The position of each MeSH descriptor in the hierarchy is indicated by a "tree number". The first node of the tree number refers to the top-level of the hierarchy. For example, the tree number for the descriptor *Megacolon* is C06.405.469.158.701, indicating that it is part of the category *Digestive System Diseases* (C06). Diseases can be related to more than one category.

Linking genes to disease categories

As shown in Figure 1, the various datasets under investigation all share some identifiers: Entrez Gene identifier between orthology data and Entrez Gene, PubMed ID between Entrez Gene and Medline, and MeSH identifiers between Medline and the MeSH thesaurus. These shared identifiers make it possible to chain the various datasets in order to create a link between a given gene and the MeSH disease categories through bibliographic references for this gene. The MeSH disease categories for a given mouse gene can easily be compared to the MeSH disease categories for its human ortholog.

We used Semantic Web technologies (RDF, the Resource Description Framework and related tooling) to process these datasets, because it is well adapted to handling linked data. In practice, the various datasets were converted to "N triple" format. A total of 1.4 million triples were generated and loaded in the open source triple store Virtuoso[7]. We used the RDF query language SPARQL to query the triple store (Figure 2). Two queries were used to retrieve all MeSH disease categories for each gene in a given pair of orthologous genes. A total of 106,454 such associations were exported for further analysis.

[2] http://www.ncbi.nlm.nih.gov/projects/GeneRIF/GeneRIFhelp.html
[3] http://www.ebi.ac.uk/GOA/
[4] http://www.informatics.jax.org/mgihome/projects/overview.shtml
[5] ftp://ftp.informatics.jax.org/pub/reports/HMD_Human5.rpt
[6] http://eutils.ncbi.nlm.nih.gov/corehtml/query/static/eutils_help.html
[7] http://virtuoso.openlinksw.com/

```
PREFIX mesh:   <http://nlm.nih.gov#MeSH>
PREFIX pubmed: <http://www.ncbi.nlm.nih.gov/PUBMED:>
PREFIX gene:   <http://www.ncbi.nlm.nih.gov/GENE:>
PREFIX mor:    <http://mor.nlm.nih.gov#MOR:>
select distinct ?gene_h ?gene_m ?species ?mesh_name_h
from <http://mor.nlm.nih.gov/PHENOTYPE>
where {
       ?gene_h mor:orthologous_with ?gene_m .
       ?gene_h mor:species ?species .
       ?gene_h mor:described_in ?pmid_h .
       ?pmid_h mor:indexed_with ?mesh_h .
       ?mesh_h mor:has_category ?dis_cat_h .
       ?dis_cat_h rdfs:label ?mesh_name_h
}
```

Figure 2- SPARQL query for retrieving associations between human genes and disease categories

Comparing phenotype information

Two major types of analyses were carried out, from the perspective of genes and from that of phenotypes. For each pair of orthologous genes, we compared the vectors of disease categories between the two genes in the pair in order to determine if phenotype annotations tend to be the same at the level of disease categories. We considered that a gene was associated with one disease category as soon as the gene was associated with one disease from this category. In practice, we recorded which disease categories were common to the two genes in the pair and which were specific to each species. (No similarity metrics were used to compare the vectors of disease categories for pairs of orthologous genes).

For each disease category, we computed the number of pairs of orthologs for which both genes are annotated to this disease category and, conversely, the number of pairs for which the phenotype annotation was specific to one species.

Results

Of the 17,769 pairs of orthologs under investigation, 11,111 exhibited at least one phenotype annotation for each gene in the pair. The remaining pairs were discarded because no phenotype annotation was available for the mouse gene (1241 pairs), the human gene (3625 pairs) or both genes (1792 pairs).

Perspective of genes

Overall, 26,459 disease categories were common to both orthologous genes, 21,854 were specific to human genes and 20,032 were specific to mouse genes. The number of disease categories per pair of orthologs ranges from 0 to 15, with a median of 2 disease categories common to both genes. There is a median of 2 disease categories specific to the human and mouse orthologs. The percentage of disease categories in common between human and mouse genes is 55% for human genes and 57% for mouse genes. Details of the distribution are shown in Figure 3.

Among the 11,111 pairs of orthologous genes with both human and mouse phenotype annotations, 81% have at least one one phenotype annotation in common, 80% have at least one phenotype annotation specific to the human gene and 84% have at least one phenotype annotation specific to the mouse gene.

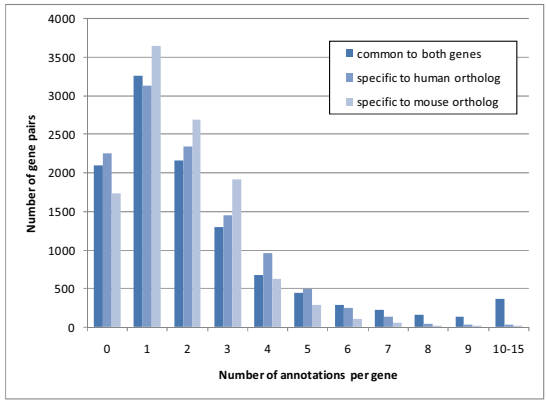

Figure 3- Distribution of the number of phenotype annotations per gene (for the 11,111 pairs of genes)

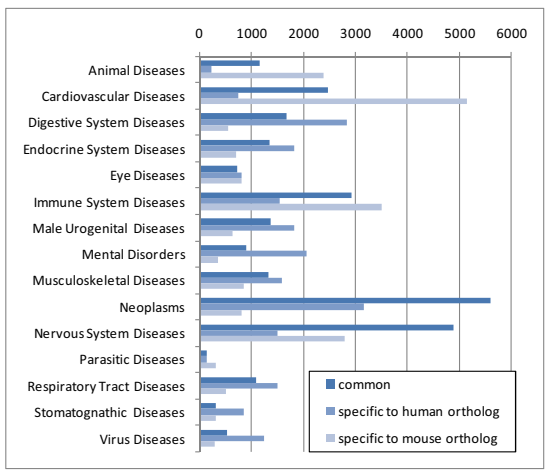

Figure 4- Distribution of the number of gene for each top-level disease category.

Perspective of phenotypes

Of the 24 top-level disease categories in MeSH (including mental diseases), 15 were reached through the phenotype annotations of the 11,111 orthologous genes. As shown in Figure 4, four disease categories represent 54% of all phenotype annotations. These are *Cardiovascular Diseases*, *Immune System Diseases*, *Neoplasms* and *Nervous System Diseases*. Within each category, the repartition between common and species-specific annotations varies widely, with a majority of common annotations for *Neoplasms* and *Nervous System Diseases*, and mostly mouse-specific annotations for *Cardiovascular Diseases*.

Extended example

A clinical researcher interested in the molecular genetics of congenital hypothyroidism could go to Entrez Gene, type "congenital hypothyroidism" and get back such human genes as TPO, TSHR and TG. A translational researcher would easily find out that their mouse orthologs – Tpo, Tshr and Tg – are also associated with the same phenotype.

The translational researcher might be further interested in identifying mouse genes associated with congenital hypothyroidism for which the human ortholog is not. Such genes would indeed be potential candidates for association with congenital hypothyroidism in human.

Using our framework, we start from the MeSH term *Congenital Hypothyroidism* and identify the PubMed articles indexed to this term for which there is a link to a mouse gene. A list of 28 such mouse genes is obtained. We then use orthology relations from MGI to point to the human orthologs of these genes. Ten human orthologs including TPO, TSHR and TG are associated with *Congenital Hypothyroidism* through one or more PubMed articles and are discarded, because their link to the disease is already known. The remaining 18 genes are potentially novel human genes for congenital hypothyroidism.

Among the 18 genes is THRB, ortholog of the mouse gene Thrb associated with congenital hypothyroidism. Although no GeneRIF or functional annotation links THRB to any PubMed article indexed with *Congenital Hypothyroidism* (as of October 15, 2009), a search on PubMed for "THRB AND congenital hypothyroidism[mh]" yields one recently published article (PMID: 19318451) [10], indexed with *Congenital Hypothyroidism*, confirming the association between congenital hypothyroidism and THRB mutation. This example illustrates the lag between the publication of an article and the availability of the knowledge extracted from this article in model organism knowledge bases.

Finally, there are also 12 human genes associated with *Congenital Hypothyroidism,* for which the mouse ortholog is not. The 12 mouse genes could be investigated for potential association with congenital hypothyroidism in the literature in order to ensure the completeness of phenotype annotations for the mouse genes.

Discussion

Applications

Supporting phenotype annotation

By linking genes to MeSH phenotypes, this framework provides a tool to biocurators responsible for phenotype annotation. Starting from a given gene, it helps retrieve relevant articles based on the MeSH indexing of diseases. Curators responsible for a group of genes can easily scan new disease-related articles and flag them for review. Conversely, curators responsible for a group of diseases are provided with the list of genes in relation to which a given disease was discussed.

This study shows that there is a large reservoir of species-specific annotations, i.e., annotations to a given disease category in one species for which there is no equivalent in the ortholog. This information could be used for inferring phenotype annotation from sequence similarity in a way similar to functional annotations to GO "inferred from electronic annotation" (IEA).

Both supporting curation and transferring annotations from other species contribute to address the incompleteness of annotations [11].

Generating novel hypotheses

In the era of translational research, easy access to comparison of phenotype annotation between orthologs can help researchers generate novel hypotheses. Phenotype annotations specific to the mouse with potential therapeutic implications can be explored in humans. Conversely, the set of mouse-specific genes associated with a given disease in the mouse provides candidates for exploration in humans for the same disease. Moreover, annotations specific to the human species may be used to evaluate the molecular markers involved in processes in a mouse model that mimics essential elements of human diseases and to analyze mutant mice carrying specific alleles [12].

Limitations

In our present investigation, the level of granularity for phenotypes is limited to a few dozen disease categories, which is too coarse for a detailed comparison of phenotypes across species, as no single gene is responsible for cardiovascular diseases as a whole. This limitation can be easily addressed by our framework in which all MeSH disease terms are recorded before being aggregated into disease categories for analysis. The example presented earlier demonstrates that a disease such as congenital hypothyroidism can be analyzed individually. However, it might also be useful to extend the framework to physiological phenomena (e.g., bone growth) for phenotypes for which no clinical information is available. Such preclinical phenotypes would also be easier to align with annotations to the Mammalian Phenotype Ontology [13]. In future work, we also plan to investigate the use of semantic similarity measures among MeSH terms for the aggregation of diseases into finer-grained classes.

Generalization

In this paper, we focus on phenotype annotation of human and mouse genes. However, the framework we propose can easily be extended to other species. Orthology relations available from Entrez Homologene can be used in the absence of (or in complement to) curated orthology relations. GeneRIFs are recorded regardless of species and functional annotations to the Gene Ontology (with reference to biomedical articles) are provided by several dozen model organism databases. Finally, MeSH indexing is available throughout Medline. Therefore, links between genes and disease categories can be established for virtually any species. As mentioned earlier, this framework would benefit from being extended to the annotation of physiologic phenomena in addition to diseases, especially for non-mammalian species, such as yeast and fruitfly, for which phenotype information may be recorded at a preclinical level.

Technological considerations

In our experience, Semantic Web technologies including RDF and triple stores greatly facilitate the integration of datasets, especially when shared identifiers are present across datasets. The SPARQL query language was useful for formulating basic queries (e.g., list the disease categories for each gene) and export the data, with satisfactory performance (under one minute). More complex queries could be formulated (e.g., list of the disease categories common to orthologous genes). However, the absence of straightforward mechanisms for expressing negation in SPARQL makes it difficult to formulate queries such as listing disease categories specific to one species. We resorted to simple *ad hoc* programming (including differences between files) in order to carry out the analysis of annotations specific to a given species.

Conclusions

In this paper, we propose a framework for comparing phenotype annotations of orthologous genes based on publicly-available resources integrated through Semantic Web technologies. We show that there is a large reservoir of species-specific phenotype annotations for mouse and human orthologs. The proposed framework supports the curation of phenotype annotation and the generation of research hypotheses based on comparative studies. In contrast to popular resources such as Entrez Gene or GeneWiki, this integrative framework not only supports navigation between gene and phenotype resources, but also the computational analysis of the annotations.

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Discovering Novelty in Sequential Patterns: application for analysis of microarray data on Alzheimer disease

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Abstract

Analyzing microarrays data is still a great challenge since existing methods produce huge amounts of useless results. We propose a new method called NoDisco for discovering novelties in gene sequences obtained by applying data-mining techniques to microarray data. Method: We identify popular genes, which are often cited in the literature, and innovative genes, which are linked to the popular genes in the sequences but are not mentioned in the literature. We also identify popular and innovative sequences containing these genes. Biologists can thus select interesting sequences from the two sets and obtain the k-best documents. Results: We show the efficiency of this method by applying it on real data used to decipher the mechanisms underlying Alzheimer disease. Conclusion: The first selection of sequences based on popularity and innovation help experts focus on relevant sequences while the top-k documents help them understand the sequences.

Keywords:

Information retrieval, DNA microarrays, Alzheimer disease

Introduction

Alzheimer's disease (AD) is one of the most common forms of dementia. In 2006, more than 26.6 million cases of Alzheimer were declared. Due to the increasing number of cases (expected to be multiplied by 4 in 2050), discovering genes involved in AD is becoming a priority for the biomedical community [1,2].

In recent years, DNA microarrays have been successfully used for numerous applications. They allow researchers to compare gene expression in different tissues, cells or conditions [3,4] and provide some information on the relative levels of expression of thousands of genes among samples (usually less than a hundred). Nevertheless, due to the amount of data available, processing them in a way that makes biomedical sense is still a major issue. Data mining techniques, such as [5,6,7], play a key role in discovering previously unknown knowledge and, in this context, it has been shown that they could be of great help to biologists in identify subsets of microarray data that could be useful for further analysis [8]. However, the amount of results obtained with these techniques is still huge and cannot be easily analysed by the experts.

In [8], we proposed a general process, called *GeneMining* based on the mining of sequential patterns. The process starts with a table produced thanks to static experiments we conducted to check the levels of expression of the genes. Each column corresponds to a microarray and each line to a gene. Each microarray measures the intensity of the gene that corresponds to the numerical value in a given cell. We describe in [9] an efficient algorithm to extract frequent patterns of correlated genes ordered according to their level of expression. We extract only patterns that distinguish classes of individuals (e.g. AD vs. healthy). An example of such a pattern is *<(MRVI1)(PGAP1,GSK3B)>,80% AD,10% H* meaning that *"For 80% of AD individuals and 10% of healthy individuals, the level of expression of gene MRVI1 is lower than those of PGAP1 and GSK3B, whose levels of expression are very close".* Although this method was useful, the way to select relevant patterns was not efficient. Depending on the values of parameters, we obtained from 1,000 to 100,000 patterns that were not easy to interpret.

In addition to the problem of the number of patterns, biologists have to face other difficulties. First, they have to link the spot on the microarray to a gene. As no standard exists for specifying names of genes, this is a difficult task. Second, they have to look for relevant publications concerning the genes that interest them. Although some tools are now available to automatically extract information from microarray data [11,12], there is no user-friendly tool to search the literature for sequential patterns.

In this paper, we focus on sequential patterns and our aim is to discover novelties to help biologists analyze how genes interact. Our contribution is three-fold: (i) We first help biologists select relevant sequences according to a specific topic and then to identify both popular genes (often available in the literature) and innovative genes (associated with popular genes in the patterns), (ii) for each sequence, we propose the top-k

relevant documents in the literature for their interpretation, (iii) we propose a visualization tool to underline the relationship between a pattern and its associated documents.

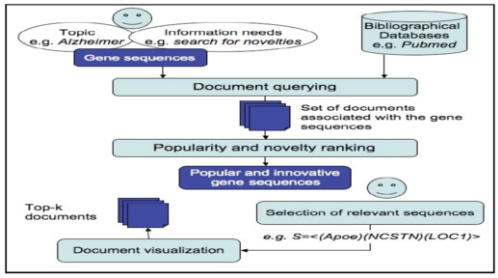

Figure 1- The NoDisco general process

General Process

Figure 1 illustrates the general process of NoDisco, an aid-tool for discovering innovative genes. Entries of the system are gene patterns obtained with an algorithm such as [9], some user information (e.g. study of Alzheimer disease) and a web-service to a bibliographical database such as PubMed. The workflow is organized in the following steps:

1. Document querying: Depending on the topic of interest `T` (e.g., Alzheimer), the tool generates a set of queries (for each sequence `S`) in order to extract documents associated with the topic denoted $Qset_{S,T}$.
2. Popularity and Novelty Ranking: For genes and gene sequences, a popularity rank (taking into account the number of references to the gene in the literature) and a novelty rank (non popular genes linked to popular ones) are computed.
3. Selection of Relevant Sequences: Popular and innovative sequences are proposed to the expert so he can select some of them depending on the information he is looking for.
4. Document Visualization: Top-k documents associated with selected sequences are organized in a sophisticated way for visualisation.

We now describe the process in more detail.

Document querying

For each sequence, a query is submitted to the PubMed Web Service to compute a popularity and novelty score for the sequence. Queries are defined as follows:

Query syntax: A query based on *n* terms with *n-1* operators returns *m* documents:

$$Q(term_1\ op_1\ term_2\ op_2\ \ldots\ op_3\ term_n) \rightarrow \{d1,\ldots,dm\}$$

The operators can be: 'AND, 'NOR' and 'OR'. The number of documents retrieved by a query is denoted $|Q(Terms)|$.

Gene designation: As detailed in [13], recognizing biological objects in natural language is a very difficult task for many reasons: The general lack of annotator agreement and naming conventions, excessive use of abbreviations, frequent use of synonyms and homonyms, biological objects often have names consisting of many individual words, such as '*human T-cell leukaemia lymphotropic virus type 1 protein*', etc. For all these reasons, in the query, it is not possible to directly use the names of a gene embedded in such a sequence. So, with the Entrez gene[1] Web Service, we first look for all aliases of the genes and store them in a contextual Gene Dictionary called $DicG_{all\_id}$ (a dictionary by type of microarray). For example, in $DicG_{all\_id}$ one alias for the gene *Apoe* is *Apolipoprotein E*.

Query about sequences: To build a query associated with a gene (e.g. *Apoe*), we group all aliases found in $DicG_{all\_id}$ with the operator *' OR'* (e.g. *Q(Apoe OR Apolipoprotein E)*) . To build a query associated with a sequence (e.g. *<(Apoe)(VAMP2)>*) , we compose the previous aliases of the two genes with the operator '*AND*' (e.g. *Q((Apoe OR Apolipoprotein E) AND (VAMP2)))*. In the rest of this article, we use the term *Q(gene1)* for $Q(gene_1\ OR\ al_1\ OR\ al_2\ OR\ \ldots)$ where $al_1, al_2, \ldots$ are aliases of the gene $gene_1$.

Topics of interest: Not all the documents retrieved using the name of a given gene will be relevant for the biologist. Their number can be reduced by using the parameters available in the PubMed search engine such as:

- Standard parameters: Author, date, journal publication, language, accessibility (full or free text, abstract).
- Parameters about the topic: Type of article (clinical trial, editorial, etc.), species (human, animal), sex (male, female), journal topic, etc.

For example, to build a query associated with the sequence *<(Apoe)(VAMP2)>* and the topic *T= ' Alzheimer'* , we compose the preceding query and the topic with the operator *' AND'* : *Q((Apoe OR Apolipoprotein E) AND (VAMP2) AND Alzheimer).* Operators can also be used to specify the terms of the topics (e.g. *T= " human AND female").*

Popularity and Novelty Ranking

We use the number of documents retrieved for each gene to rank them according to their popularity and novelty.

Popularity of a gene: A gene G_i is *popular* if the number of documents dealing with this gene in the literature is greater than the defined threshold *pop_min_gene*. For each gene G_i in $DicG_{all\_id}$, its popularity, $Pop_{Gi,T}$, according to a topic T is obtained as follows:

$$\forall G_i \in DicG_{all\_id},$$

$$Pop_{G_i,T} = \begin{cases} 1 & \text{if } |Q(G_i,T)| > pop\_min\_gene \\ 0 & \text{otherwise} \end{cases} \quad (1)$$

[1] http://www.ncbi.nlm.nih.gov/sites/entrez?db=gene

For example, if *pop_min_gene=100* and $|Q(ApoE,Alzheimer)| = 3805$ then *ApoE* is popular.

Popularity of a sequence: A sequence S_i is *popular* if the proportion of popular genes in S_i is greater than the defined threshold *pop_min_seq*. For each sequence S_i, we compute its popularity, $Pop_{Si,T}$, according to a topic T. Let PS_i be the set of popular genes in a sequence S_i:

$$\forall S_i \in SP,$$
$$Pop_{S_i,T} = \begin{cases} 1 & \text{if } \frac{|PS_i|}{|S|} > pop\_min\_seq \\ 0 & \text{otherwise} \end{cases} \quad (2)$$

For example, *S=<(Apoe)(NCSTN)(LOC153222)>* is a popular sequence for *pop_min_seq=0.5* because *Apoe* and *NCSTN* are popular ($|PS_i|/|S|=2/3$).

Innovative genes: A gene G_i is in *an innovative relation* with popular genes if the number of sequences associating G_i with popular genes is greater than the defined threshold *new_min_gene*. For each gene G_i of $DicG_{all\_id}$, we compute its novelty, $New_{Gi,T}$, according to a topic T. Let $Pseq_{Gi}$ be the set of popular sequences containing G_i:

$$\forall G_i \in DicG_{all\_id},$$
$$New_{G_i,T} = \begin{cases} 1 & \text{if } |PseqG_i| > new\_min\_gene \\ 0 & \text{otherwise} \end{cases} \quad (3)$$

For example, *PUM1* is an innovative gene because it is present in more than *new_min_gene* popular sequences.

Innovative sequences: A sequence S_i is *innovative* if the proportion of innovative genes in S_i is greater than the defined threshold *new_min_seq*. For each S_i, we compute its innovative score, $New_{Si,T}$, according to a topic T. Let NS_i be the set of innovative genes in a sequence S_i:

$$\forall S_i \in SP,$$
$$New_{S_i,T} = \begin{cases} 1 & \text{if } \frac{|NS_i|}{|S|} > new\_min\_seq \\ 0 & \text{otherwise} \end{cases} \quad (4)$$

For example, if *new_min_seq*=0.5 then s*=<(Apoe) (LOC90624)(PUM1)>* is an innovative sequence as *PUM1* and *LOC90624* are two innovative genes ($|NS_i|/|S|=2/3$).

At the end of this step, we have reduced the initial set of sequences to two sets, popular and innovative sequences, which can be proposed as relevant sequences for the experts.

Top-k documents: To help the expert analyze a sequence S_i, we look for the Top-k documents. To this end, we ask PubMed to retrieve all documents D associated with genes in S_i and we rank them using the two following methods.

First, we compute the score S_{di} for a document d_i published in *the year d* and dealing with the g genes. Let *MinA* (resp. *MaxA*) be the year of publication of the oldest document (resp. the year of publication of the most recent document). Let *MinG* (resp. *MaxG*) be the minimum (resp. maximum) number of genes cited in the documents of D. $\langle$ is a coefficient. We then rank the documents according to the equation 5. $S_{di} \in [0,1]$. $\langle \in [0,1]$. The value $\langle=1/2$ gives the same weight to both components of the formula.

$$S_{d_i} = (1-\alpha) * \frac{(MaxA-d)}{(MaxA-MinA)} + \alpha * \frac{(MaxG-g)}{(MaxG-minG)} \quad (5)$$

Second, in the documents described by the two criteria (year of publication and number of genes), we look for the Pareto points [14]. These points correspond to documents that are not dominated by others considering both criteria (i.e. they are the best ones considering one criterion alone and the best compromises based on both criteria). We then select k documents in these points. Finally, for the top-k documents, we obtain a rank that can be used by the expert to analyze a sequence[2].

Experiments

Case study

In the framework of the PEPS-ST2I Gene Mining project, we mined real data produced by analysis of DNA microarrays (Affymetrix DNA U133 plus 2.0) [10]. The aim was to decipher brain aging mechanisms. Aging is the primary risk factor in neurodegenerative disorders such as Alzheimer's disease. We analyzed the transcriptome from the temporal cortex of *Microcebus murinus*, a relevant primate model because as they age, some of them present the same lesions observed in human brains affected by Alzheimer's disease. Primates were divided into 3 groups: 6 young adults, 10 healthy aged and 2 aged with Alzheimer's disease lesions. We used DBSAP [10] to discover sequential patterns with several parameters. In the worst case, we obtained approximately 50,000 gene sequences. The longest sequence was composed of eight genes. These sequences can be used to distinguish between AD animals and healthy animals. However, as this number of sequences is too huge, the process of interpretation described in [9] cannot be directly applied on these sets of sequences.

Evaluation of popular and innovative sets

To identify relevant sequences, we analyzed popular and innovative genes and gene sequences. The topic we sued was "Alzheimer" and we varied the four other parameters: *pop_min_gene* (10, 50, 100), *pop_min_seq* (0.25, 0.5, 0.75), *new_min_gene* (5, 10, 30), and *new_min_seq* (0.25, 0.5, 0.75). We obtained quantitative results that varied with the values of

[2] Information on the visualization tool is available at: http://www.lirmm.fr/~bringay/Bringay/MedInfo/MedInfo.html

the parameters[3]. For example, from a set of 50,000 sequences, with the parameters *pop_min_gene=100, pop_min_seq=0.5, new_min_gene=10,* and *new_min_seq=0.5*, we obtained *336* popular and *208* innovative sequences. The important issue is that we defined two sets of sequences in a quantity which allows the use of the process described in [9]. The choice of the parameters depends on the number of sequences we define at the beginning of the process.

Evaluation of the ranking documents

In the first part of these experiments, we showed that we were able to help experts to select relevant patterns. The next step was to evaluate the quality of the NoDisco documents associated with these patterns. To this end, we arbitrarily selected five popular sequences (see figure 2) and studied them in collaboration with experts. We built three sets of ranked documents: (i) We ranked them according to their S_{df} score ($\langle$=1/2), (ii) We chose the first Pareto points, (iii) We extracted the first documents returned from PubMed using the names of the genes.

seq 1: ADAMTS9-APOE-KCNC1-PTPRA-LOC284214
seq 2: GSTO1-VAMP2-SMARCA2-PTPRA-UBE1DC1-CART
seq 3: ADAMTS9-PML-UBN1-FAT-SRRM2
seq 4: ADAMTS9-PML-PRLH-FAT-NBS1-RBX1-LOC284214
seq 5: ADAMTS9-PLXNA2-GSK3B-FAT-FLJ11029-DNAJB6

Figure 2- Five gene sequences

Are the documents returned by the different methods the same? For each pair of methods, we computed the number of shared documents considering the 10, 20 … 100 first documents in each ranking list (see Table 1). Results corresponded to the average number of documents obtained by the five sequences. For instance, we compared the 30 first documents sorted by PubMed and S_{doc}. In this case, we obtained an average of 4% of shared documents with both methods. Table 1 shows that the three approaches returned different documents (i.e. we extracted new knowledge that was not discovered by querying PubMed alone). These experiments were based on a large number of documents (1,083 different documents returned using our approaches).

Finally, the number of documents returned by the different approaches with the five sequences was very different. Table 2 shows that method S_{doc} returned a larger number of documents. This specific retrieval task (i.e., by generating a specific query) may be very useful for experts. This result can be explained by the fact that our method S_{doc} takes into account synonyms to extract relevant documents. The number of documents returned by the Pareto method was low because this method rejects all documents that are not in the Pareto front (i.e. dominated documents [14]).

[3] Due to lack of space, all results are not reported here, but are available at: http://www.lirmm.fr/~bringay/Bringay/MedInfo/MedInfoResults.pdf

Table 1- Search for shared documents with the three methods

No. of doc.	10	20	30	40	50	60	70	80	90	100
%PubMed vs. S_{doc}	0	2	4	4	4.8	4.3	4.2	4.2	3.7	3.4
%PubMed vs. Pareto	2	2	2.6	2	1.6	1.3	1.1	1	0.9	0.8
%Pareto vs. S_{doc}	0	0	2	2	2.8	7	6.5	5.7	5.1	4.6

Table 2- Number of documents retrieved with the 3 methods

Methods	PubMed	S_{doc}	Pareto
Number of doc.	404	537	225

Are the documents returned by our methods relevant? To go deeper into the analysis of the documents, we asked an expert to analyze the abstracts of the first documents retrieved. He manually analyzed the 10 first abstracts retrieved by *seq1* and *seq2* using our three ranking methods (60 documents were manually analyzed). He classified them in five groups: (1) *Relevant*; (2) *Too old* (e.g. documents published before 2000 were not relevant because they were published before the creation of the Affymetrix DNA microarray) (3) *Semantically not relevant* (e.g., documents with the term CART in their summary meaning Classification And Regression Tree instead of the gene CART) (4) *Off the topic* (e.g. documents retrieved in a journal of acupuncture are not relevant for biologists) (5) *Not related to the sequence.* When no term corresponding to one of the genes or to one of the aliases occurred in the abstract, the expert was unable to evaluate the relevance of a document. The classification is summarized in Table 3.

Table 3- Evaluation of the documents by the expert

Evaluation	PubMed	S_{doc}	Pareto
1	13	6	9
2	0	4	0
3	2	6	0
4	1	1	2
5	4	3	9

Queries based only on PubMed returned the best rate of relevant documents but the results of the two other methods (S_{doc} and Pareto) can be easily improved: The noise corresponding to irrelevant documents can be easily reduced by adding domain knowledge to our method.

First, we can consider documents published before 2000 to be less important. For example, we retrieved several documents dealing with PTP (Pancreatic Thread Protein), published before 1999. These documents were not relevant for the biologists concerned, who were looking for information about PTPR4, Tyrosine Phosphatase Receptor, tested with microarrays. These two proteins are linked by the same alias, but we can distinguish between them by the publication date.

Second, we can extend the topic to similar topics. For example, we did not retrieve any documents with the association VAMP2 and AD but had better result with “aging”. When a query does not produce the expected result, the topic can be extended by consulting a list of related topics. The concept of

family can be used in the same way. The genes are organized according to their properties or functionalities. For example, KCNC1 did not produce result with AD, but KCNC (subunit of the potassium channel family) did produce results. Thus, when there is no result, the query can be extended by using the family as the term of the query instead of its alias.

Discussion

Some tools are now able to mine the biological literature. BioMinT [15] is an easy-to-use information retrieval and extraction tool targeted at online biomedical literature. This tool retrieves relevant documents and proposes a range of relevant outputs. However, the tool is not dedicated to the analysis of genes. From a set of genes defined by the user, MedMiner [11] filters and organizes large amounts of textual and structured information retrieved by public search engines (GeneCards and PubMed). GoMiner [12] goes a step further and uses the Gene Ontology (GO) to identify biological processes, functions and components in a list of genes, and generates hypotheses to guide further searches.

Although existing tools are very powerful, they are not dedicated to the analysis of gene sequences produced by analysis of DNA microarrays. With NoDisco, popular sequences can be identified that will be useful to biologists to validate the gene sequences they identify. Indeed, these sequences are composed of genes that have already been linked in the literature and are well known. It is also possible to identify innovative sequences, revealing surprising associations of genes, which can draw the attention of the biologist to unknown gene interactions. For example, the expert who collaborated with us identified an innovative gene ADAMTS9. This gene is not yet known to be involved in Alzheimer disease (i.e. there is no publication dealing with ADAMTS9 and "Alzheimer"). However, in the sequences, this gene is linked to popular genes that are well known for their implication in Alzheimer disease. Moreover, the expert underlined the fact that two other genes in the same family, ADAM9, ADAM10 and ADAM17, have already been linked to Alzheimer disease, so the link between ADAMTS9 and Alzheimer needs to be studied.

Conclusion

The development of DNA microarray technologies and the explosion of online scientific biological literature overwhelm the ability of researchers to take full advantage of available knowledge. In this paper, we presented the NoDisco process which enables biologists to select relevant sequences obtained from DNA microarray analysis. According to a topic, biologists can identify popular and innovative genes along with the sequences in which these genes appear. We also linked gene sequences to the top-k documents in order to facilitate their interpretation. As discussed in the Experiments section, the relevance of the ranking in NoDisco can be easily extended to include domain knowledge. Moreover, NoDisco can be extended to other areas involving medical or pharmacological information. More generally, NoDisco can be used to organize the information retrieved from any arbitrary PubMed search.

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Designing a Concept for an IT-Infrastructure for an Integrated Research and Treatment Center

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Abstract

Healthcare and medical research in Germany are heading to more interconnected systems. New initiatives are funded by the German government to encourage the development of Integrated Research and Treatment Centers (IFB). Within an IFB new organizational structures and infrastructures for interdisciplinary, translational and trans-sectoral working relationship between existing rigid separated sectors are intended and needed. This paper describes how an IT-infrastructure of an IFB could look like, what major challenges have to be solved and what methods can be used to plan such a complex IT-infrastructure in the field of healthcare. By means of project management, system analyses, process models, 3LGM²-models and resource plans an appropriate concept with different views is created. This concept supports the information management in its enterprise architecture planning activities and implies a first step of implementing a connected healthcare and medical research platform.

Keywords:

Medical informatics, Hospital information systems, Integrated advanced information management systems, Biomedical research, Clinical trials, Information management, Systems analysis, Information system models, Translational medicine.

Introduction

Integration of inpatient and outpatient Care in Germany

From an information management point of view, healthcare in Germany is strictly separated in two sectors: outpatient (practitioners and specialists) and inpatient (hospitals) treatment. Both sectors have had different information systems, no common communication standards, no harmonized electronic health records and no common IT-infrastructure which they can share. Because of demographical change, improvements in medicine and following increase of costs, the German government started at least two major strategies to reform this situation. One example is "Integrated Care" which allows process-oriented, interdisciplinary and trans-sectoral networks between practitioners and hospitals [1]. The second example is the German electronic health insurance card and the underlying IT-infrastructure which will provide a shared platform for administrational and medical data [2].

Integration of Healthcare and Medical Research in Germany

Likewise there is a strict separation between care and research. Medical research is commonly organized in clinical trials and studies. To coordinate studies competence networks with focus on selected diseases were built [3, 4]. A competence network consist of a coordination center which controls the trials and collect the medical data from the study centers (about 20-100) which are performing the trials [5-7]. To avoid reinventing the wheel in every competence network the German Telematikplattform für Medizinische Forschungsnetze (TMF) e. V.[1] gives support in common issues like legal, ethical and questions of quality management furthermore in IT-projects, biobanking and privacy concepts [8].

The next and current integrative step is to improve medical research by considering cause and effect of a disease and encouraging translational medicine as a two-way road between research and treatment [9]. Since 2008 this has been done in Germany by funding "Integrated Research and Treatment Centers" (IFB) by the German Ministry of Education and Research (BMBF) [10]. Translation here means accelerating knowledge transfer between basic research, patient-oriented research and clinical application. An IFB is focused on a selected disease like a competence network but in a wide (cause and effect) and interdisciplinary way flanked by offers for young researchers and professional education. To obtain these goals new structures in organization and infrastructures especially IT-infrastructures are needed.

Major Challenges

Establishing an IT-infrastructure for better integration of patient care and medical research, i.e. for efficient support of translational medicine leads to considerable challenges. These challenges range from technical to financial issues [11].
In this paper we will focus on the Integrated Research and Treatment Center at Leipzig University Medical School and Leipzig University Hospital (LUH). This center integrates

[1] http://www.tmf-ev.de

research and treatment for adiposity diseases. We will deal with the challenges by answering the following questions:

- *Screening and Tagging*: How to identify patients as being at risk of adiposity? How to recruit the identified patients as attendees for clinical trials and refer them to the IFB for treatment?
- *Integration of information systems*: How can medical data of patients being treated within the IFB be collected in the respective information system of the hospital and afterwards made available in the information system of clinical trial management organization?
- *Pseudonymization:* How medical data originating from patients' treatment can be reused for research and clinical trials without violating patients' privacy?

Methods

Based on an analysis of the business processes the architecture of the IT-infrastructure can be designed. Doing so we applied the following methods:

Process Modeling

Flow charts [12] have been used for modeling the business processes. Note that 'business' does not imply a focus on administrative aspects but implies a holistic view on the patient related processes constituting the business of an IFB.

The simplicity of flow charts is their advantage. So even persons involved in IFB who are not familiar with business process modeling can understand it and are able to collaborate specifying the processes.

After having modeled the processes we enhanced the resulting flow chart with assignments of information system components to be used.

The enhanced FC (eFC) served as a specification for the architecture of the IT-infrastructure.

Modeling Enterprise Architectures

There are several modeling approaches to support information managers in healthcare in enterprise architecture planning. Based on our experiences in modeling information systems of institutions in healthcare [13] we decided to use the three layer graph-based meta model (3LGM²) [14] for this integrated IT-infrastructure as well. Based on 3LGM² the 3LGM²-tool [15] was developed to support modeling of information systems in health care. 3LGM² distinguishes an information system in a domain layer to describe enterprise functions and processed information, a logical tool layer to describe application components and the communication between them and a physical tool layer to describe hardware components. Interdependencies between concepts of different layers are described as so called inter-layer-relationships. 3LGM²-tool has important features to work with sub-models and doing analyses on the modeled information system.

In order to link the process model to the architecture model we extracted the 'activities' of the eFC and mapped them onto functions at the domain layer of the 3LGM² based architecture model.

Systems Analyses

Existing 3LGM²-models of the Leipzig University Hospital (LUH) and reference models for information system architectures [16] were used for system analyses. Furthermore models and experiences from previous projects in competence networks in the Center of Clinical Trials Leipzig[2] and from activities in the TMF [17] were included.

Results

Process model

There are several processes in the IFB needed to subscribe patients and to analyze their data with respect to the referral to IFB. The process model in Figure 1 shows some of these processes, their requirements and the data used. The processes at IFB can be divided into two steps. At first step, there is a need to identify, tag and follow-up patients during the conventional treatment at LUH (light gray boxes). The second step is to enclose these patients in trials at the IFB (dark grey boxes). Both processes need a seamless integration of application systems in LUH and application systems in clinical research. It is indicated where single processes are located by assigning annotations of information system components to processes (links with dotted lines).

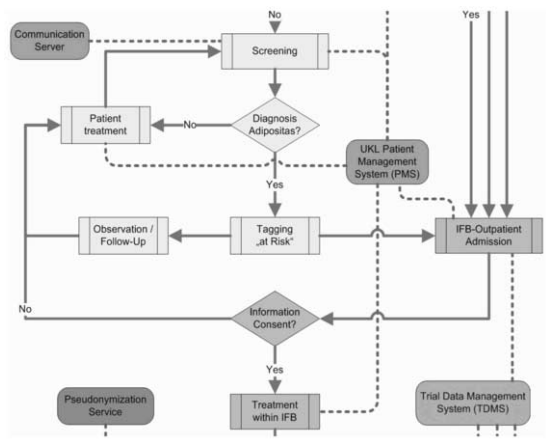

Figure 1 – Model of workflow

The processes consist of sub-processes, which give detailed information about single steps. The process "Screening" for example describes how patients could be identified from a hospital information system [18]. To achieve this, patient records have to be scanned for relevant items. Based on this item data, scores (e.g. body mass index) and ratings were calculated. These scores and ratings are required to support a doctor's decision of the following processes. So she/he can decide

[2] http://www.zks.uni-leipzig.de

whether the patient continues the conventional care process or is suitable for treatment within IFB.

All processes have to comply to legal aspects of data privacy and data security.

Domain layer

The process model is a good preparation for 3LGM²s domain layer. In this layer a more detailed view on the processes is possible. In Figure 2 relations between functions (rectangles) and object types (ellipses) are modeled. Activities of the eFC have been mapped onto respective functions.

This approach leads to a clear understanding of the information objects and how they are linked with functions and therefore activities from the process model.

In the part of the domain layer shown in Figure 2 there is a function called "test person administration". This function is a sub-process of "IFB-Outpatient Admission" from eFC. It is linked with several object types like "master data", "covering letter" and "target date" which are needed for this task or which are interpreted.

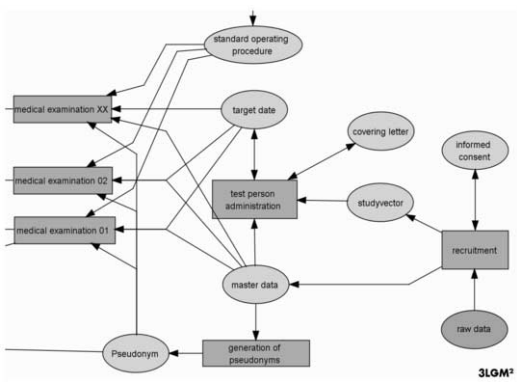

Figure 2 – 3LGM² domain layer

Logical tool layer

The concept for the information systems architecture at its application systems' layer is outlined in Figure 3. This concept includes not only Leipzig University Hospital (LUH) but third parties contributing to this project as well. Patient care in LUH and at third parties is supported by their application systems for patient management (PMS), intensive care unit management (PDMS), laboratory (LIS) and so on. Trial data is stored and trial management is supported by the trial data management system (TDMS).

There are two ways for data capturing. First data collected in PDMS and LIS can be sent to the TDMS. The second way is to capture data using electronic case report forms (eCRF) provided by the software used for the TDMS. The eCRF modules will be used in the context of clinical documentation and therefore in parallel to using the PMS. Integration can be provided by "context integration" techniques; but it still has to be decided whether the HL7 related CCOW standard or service oriented portals shall be used [19].

According to data privacy and security constraints the separation of data in treatment and research contexts will be guaranteed by using Study Identification Codes (SIC) in the context of trials instead of Patient IDs, which are used in the treatment context. A Pseudonymization Service [20, 21] will provide an appropriate SIC for a PID on request. The Pseudonymization Service will store a list of PIDs and corresponding SICs, but no more identification data.

MDAT delivered to TDMS may be passed to the Biobank Management System where applicable.
Because of the high amount of data of high throughput sequencers their data is stored in a separate application system which is designed to handle genetic data (GeWare).

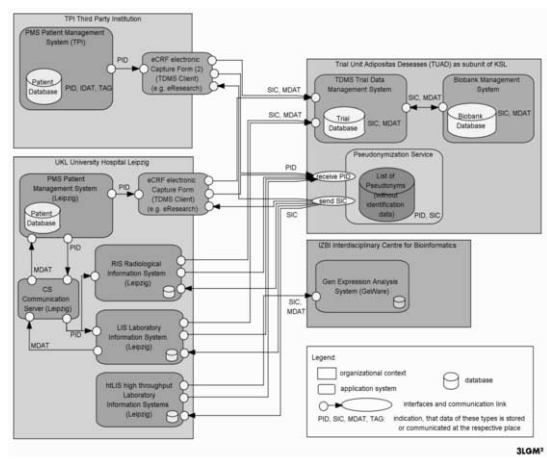

Figure 3 – 3LGM² logical tool layer

The sub-model of application systems in Figure 3 is related to the activities in the workflow as described in Figure 1 and linked with the domain layer in Figure 2 as part of the whole 3LGM²-model. These links associate functions with application systems and object types with data bases, interfaces and communication links. In summary the logical tool layer explains how the activities will be supported by application systems.

Physical tool layer

3LGM² also supports modeling hardware components of an information system. A part of the physical tool layer of IFB is shown in Figure 4. Hence an overview of the planned network components, servers, laboratory hardware and workstations is modeled (boxes in Figure 4). Locations, information about network links (e.g. network type, link speed), operating systems and a lot of additional metadata is included, too.

Inter-layer-relations to the logical tool layer describe for example links between application systems and physical hardware. In this way it is modeled that e.g. TDMS and LIS is

planned for installation on a dedicated server with defined parameters on a specified location and environment.

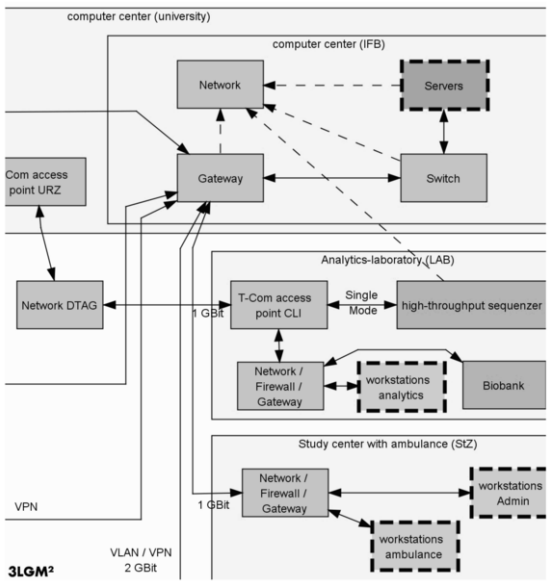

Figure 4 – 3LGM² physical tool layer

Discussion

All models presented here are based on information available at the beginning of this ambitious project. Thus we could not report on an implemented IT-infrastructure but on the models serving as the blueprint for the implementation and on the methods used to achieve the models. Hence this approach is not validated until now.

We are sure that during the implementation of single working packages the models will have to be refined to synchronize them with reality. This is needed to keep track of the work in progress.

Some changes are predictable. The role of the communication server (CS) in the hospital information system (HIS) is an example. At the logical tool layer of the current 3LGM²-model, the CS supports the screening process by processing HL7 messages. This is a possible way but there are other suggestions and ideas to support the screening process like mentioned in this overview [18] or perhaps in a single source approach [22]. So new information system components in logical tool layer could appear, like a data-warehouse which collects medical data of the HIS. Another example is the rollout of the German health insurance card and their underlying IT-infrastructure. This infrastructure could help to connect third party health organizations much easier. But today there is no final date known, when all needed features will be available.

We found, that the model based approach presented here provides effective support in designing a complex IT-infrastructure for translational medicine. Process analyses help to understand the processes which are needed for IFB. A 3LGM²-model proceeds clear functions and object types from the process model and is able to describe the connected application systems, data bases and their communication relations and furthermore network and server hardware which are hosting all components from the logical tool layer.

Conclusion

As shown in this paper, major challenges have to be solved to plan an IT-infrastructure for an Integrated Research and Treatment Center. Especially screening and tagging, integration of information systems and pseudonymization have to be realized.

Screening and tagging are necessary functions to make sure that patient being at risk of adiposity can be identified and both be recruited as attendees for clinical trials and referred to the IFB for treatment. The outlined modifications of the information systems illustrate in multiple views how this could be achieved.

The integration of both the information systems in context of care and the information systems in research context leads to an IT-infrastructure we searched for. This integrated IT-infrastructure is able to support the specified processes.

Especially in healthcare data privacy is one of the most important constraints. So an integrated IT-infrastructure has to implement facilities to ensure this. Besides implementing features of application and network security the use of a pseudonymization service guaranties a reuse of medical data originating from patients' treatment or research and clinical trials without violating patients' privacy.

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The REUSE project: EHR as single datasource for biomedical research

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Abstract

Integrating biomedical research and patient care is a challenging issue requiring interoperability solutions. During a clinical trial, clinical data are captured twice, first in the Electronic Health Record (EHR) and then in the Clinical trials Data Management System (CDMS). The aim of REUSE (Retrieving EHR Useful data for Secondary Exploitation) project is to provide a single source solution for electronic data capture to the investigators of a university hospitals involved in a multi-centric clinical trial. We first investigated the differences between the workflows of patient care and biomedical research to specify the use of EHR for clinical trials. Then we defined a semantic interoperability framework in order to enable the reuse of EHR clinical data and implemented a mediator that transforms CDISC Operational Data Model (ODM) XML into proprietary XML document templates of different EHR solutions and vice-versa. Implementing electronic data capture for biomedical research within EHR eliminates redundant data entry, thus improving data quality and processing speed. Moreover, unlike other initiatives such as IHE integration profile "Retrieve Form for Data Capture" (RFD), the REUSE approach ensures that all clinical data is kept in the EHR whatever the context of data capture is.

Keywords:

HL7, CDISC, ODM, IHE profile, RFD, Electronic health record, Clinical data management system, Biomedical research, Clinical trial, Cardiovascular, Single source.

Introduction

The role that EHR could play in a biomedical research context has been investigated in many recent works. Clinical data in EHR may be useful during the design phase providing a better understanding of real patient population; during the instruction phase, by improving patient recruitment in clinical trials, as well as during the implementation phase by optimizing clinical data entry or adverse event reporting [1-4].

Current information systems for patient care on one hand, and for biomedical research on the other hand, are completely disconnected, even in university hospitals which have the most successful implementations of Electronic Health Records (EHR).

Since, there is evidence for a relevant overlap of routine and research oriented documentation [5,6], interoperability between Electronic Healthcare Record (EHR) and Clinical trials Data Management System (CDMS) for research would be of major advantage. Factors limiting EHR/CDMS interoperability are related to organizational, regulatory and technological issues.

From an organizational point of view, patient care and clinical research processes are very different. Furthermore, the functionalities expected from EHR and CDMS differ significantly in these two contexts. Recent efforts have been made to expand the functionality of EHRs for their use in clinical research.

As an example, the HL7 EHR System Functional Model [7] provides a reference list of over 160 functions that may be present in EHRs. Its functionality has been recently expanded by the global EHR/CR Functional Profile Project [8], a collaborative effort to expand and adapt the functionalities of EHR and associated systems, networks, and processes to support clinical research.

From a regulatory point of view, health data processing is subject to different constraints in patient care and biomedical research. Concerning data security and system validation, requirements for CDMS are also subject to higher constraints than for EHR. In the USA for instance, a system used to manage clinical trials data needs to comply with the FDA [9] Guidance "Computerized Systems Used in Clinical Investigations" (CSUCI) [10].

Finally, from a technical point of view, the standards for archiving and transmitting health data are defined by different organizations. On one hand, in the domain of biomedical research, the CDISC (Clinical Data Interchange Standards Consortium) organization [11] was created in 1997 by a group of individuals from pharmaceutical companies, clinical research organizations and software providers, working closely with the US FDA in order to develop platform-independent standards that support the electronic acquisition, exchange, regulatory submission and archiving of health data.

In 2001, CDISC published the first version of its Operational Data Model (ODM) [12], that defines the different types of information related to clinical trial: clinical trial metadata (definition of protocol and used items), baseline data of the clinical trial (e.g. the normal values of laboratory tests), user's administrative data (access rights and user profiles), patient clinical data and audit trail data (tracking data changes).

On the other hand, for patient care, the efforts of structuring health information and communication systems, are carried out within the European (CEN TC 251) [13] and international (HL7, Health Level 7) [14] committees for standardization. With regards to the EHR, in 2003 the Reference Information Model (RIM) proposed by HL7 became an ISO standard [15], from which are derived the models of both messages and documents (such as Clinical Document Architecture (CDA)) [16]. In order to facilitate the integration of patient care and biomedical research information systems, efforts have been initiated between HL7 and CDISC within the RCRIM (Regulated Clinical Research Information Management) technical committee of HL7, in which NCI (National Cancer Institute) [17] and FDA are actively involved. As part of these efforts, the BRIDG project aims to create a Domain Analysis Model covering the entire field of biomedical research and to develop common semantics for the different actors (hospitals, clinical trials sponsors, health authorities, etc.) [18-20].

We identified some initiatives that propose solutions for integrating information systems for patient care and biomedical research [21,22].

According to the CDISC Electronic Source Data Interchange Initiative [23], we can distinguish three different solutions for EHR/CDMS integration. First in the "*source data extraction and verification"*, part of the source data are extracted from the EHR, the investigator has to verify that the extracted clinical research data from the EHR reflect the source data required for the clinical trial before they are to a separate clinical trial database (CDMS)). In the "*single source"*, source data are all captured into the EHR and the clinical trial data are exported to the CDMS. In "*EHR used as CDMS"*, the source data are all captured into the EHR which is the clinical trial database (CDMS). Many pilot projects have implemented one of these different types of EHR/CDMS integration solutions allowing the reuse of patient care data, but with rare exceptions most examples consist of institution-specific approaches that do not use standards and thus lack the broad interoperability required for multicenter trials

Among "*source data extraction and verification"* solutions, Integrating the Healthcare Enterprise (IHE) published the Retrieve Form for Data-capture (RFD) "integration profile" [24]. Combined with the Clinical Research Content Profile, this integration profile provides a method of data capture within a used application (e.g. an EHR) that meets the requirements of an external system (e.g. a CDMS). An IHE "integration profile" is a real situation describing exchanges of information, called "transactions" of different components of a distributed health information system, called "actors". IHE provides guidelines for implementing these "transactions", using established computer standards such as HL7 or DICOM.

The RFD profile specifies a solution to integrate EHR and CDMS. If an external organization needs to collect clinical data as part of a clinical trial, the RFD profile will allow the EHR user (study investigator, for example) to access to the electronic Case Report Form (eCRF) of the clinical trial without leaving the EHR, and enter the required information so that they are collected by the external agency. However this solution still constrains the clinician to provide and manage two distinct data sources, duplicating data entry from one to another except for only several items described in the Clinical Research Content Profile.

In this context, the objective of REUSE (Retrieve data in EHR Useful for Secondary Exploitation) project is to provide a "single source" integration solution between EHR and CDMS using international IT standards (CDSIC, HL7) and to evaluate it in the hospital context of Assistance Publique-Hôpitaux de Paris (AP-HP).

In this paper, we first describe how we modeled the biomedical research process in a university hospital environment in order to specify the use of EHR in this context. Then we present the design and implementation of the "single source" solution between EHR and CDMS that takes into account the regulatory constraints of biomedical research and addresses semantic interoperability issues. At last we present the experimentation of the REUSE architecture in the context of a multi-centric clinical trial in the cardiovascular domain.

Material and methods

Material and context: AP-HP clinical trial "Arcadia"

The AP-HP is the most important French University Hospital Organization (38 hospitals with about 23,000 beds , 1400 one-day care, 850 capacities of care at home and 1,000,000 hospitalized patients per year; 90,000 employees including 19,000 physicians).

The aim of the New Information System (NIS) project of the AP-HP, is to implement the EHR Orbis ® (AGFA Healthcare ©). However some hospitals such as the Georges Pompidou European Hospital (HEGP) already have an EHR e.g. DxCare® (Medasys©) [25].

In AP-HP, biomedical Research is carried out within 18 Research Institutes; 8 Clinical Investigation Centers (phase I & IIa, Pharmacokinetic/Pharmacodynamic (PK/PD), etc.), 10 Clinical Research Units and 100 INSERM teams. The AP-HP direction of the biomedical research promotes electronic data capture and some experiments are conducted in different hospitals. Within the HEGP Clinical Research Unit several Clinical Data Management Systems (CDMS) are being evaluated such as OpenClinica® (Akaza Research©) or Marvin® (XClinical©) [26].

Arcadia is a biomedical research study conducted at HEGP Clinical Research Unit in the cardiovascular domain that was classified in the "common care" field of French law. The use of EHR as data entry solution was subjected to the favorable opinion of a Committee for the Persons Protection (CPP) [27], which are the French Institutional Review Board (IRB).

Business analysis and design of REUSE

We conducted a series of meetings with the AP-HP managers (from AP-HP direction of the biomedical research), clinicians and researchers (from the Clinical Research Unit (CRU) of HEGP)) in order to carry out the business process models describing the clinical trial implementation activity in a context of institutional sponsorship in France. Then we defined the different stages composing the process which could be simplified and automated thanks to a use of the EHR.

We integrated into the process models elements from the BRIDG dynamic model comprising the use cases and the diagrams activity of clinical trials. We also took into account the CDMS specifications defined in the FDA guidelines "CSUCI" and in the EHR Functional Model, extended to biomedical research.

REUSE implementation

The REUSE architecture implements the “single source” concept so that all data, whether entered in the patient care context or in the biomedical research context, are stored and accessible in the EHR. We developed modules that allow: 1) to import within the EHR a SNOMED encoded electronic case report form (eCRF) of a clinical trial, 2) to align existing clinical data with the eCRF data elements and 3) to export the clinical trial data towards a CDMS.

We used JAVA programming language for its stability, its large selection of library and because it is platform-independent, particularly JDOM Application Program Interface (API) [28] for its simplicity compared to SAX and DOM parser [29] and for the richness of its functionalities.

Results

Process models and functional perimeter of REUSE

We modeled the biomedical research activities of institutional sponsorship in a university hospital and specified the functional perimeter of the EHR within this context.

The activity diagrams made it possible to better analyze the main phases of a clinical trial: the submission phase where the principal investigator and the CRU edit the research protocol and submit it to the sponsor; the instruction phase where the CRU prepares all the tools for the data management and completes the regulatory and financial tasks and the implementation phase during which the patients are included (information of the actors, inclusion lists, patients consents) and the data captured before monitoring and statistic analysis. This analysis made it possible to better identify the role of the main actors at the time of each activity of the clinical trial implementation process (physician-investigator, methodologist, Structure Coordinator, Clinical Trial Coordinator (CTC), statistician, Data-Manager, Clinical trial technician (CTT), Clinical Research assistant (CRA), Administrative and Financial Manager (AFM) and sponsor). The REUSE business process diagram has a hierarchical structure: each modeled phase is made up of several structured activities, themselves made up of sub-activities. In total, it is composed of 15 activity diagrams from which we identified 7 activities and tasks likely to be simplified and automated, thanks to the use of the EHR: "To develop a clinical trial database", "To propose a data-management plan", "To develop eCRF", "To carry over existing data in the EHR", "To modify administrative patients data", "To modify data of clinical research", "To Monitor data» (Figure 1).

Each activity included in the functional perimeter of the EHR is described by a sequence diagram specifying the actors’ interactions using EHR within the REUSE solution.

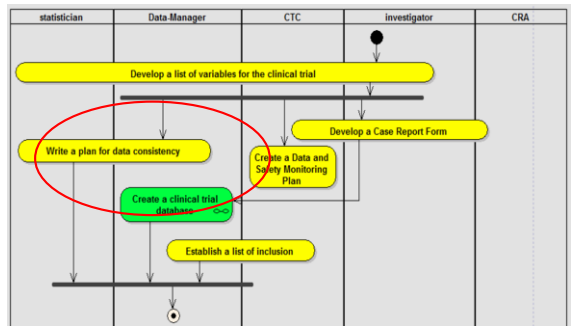

Figure 1- Example of process activities of clinical trial implementation which can benefit from the use of the EHR: "To create a clinical trial database" and "To propose a data-management plan"

REUSE implementation

We defined the “Retrieve & Integrate Form for Data capture” (RIFD) integration profile in order to implement the “single source” concept for the REUSE project (Figure 2).

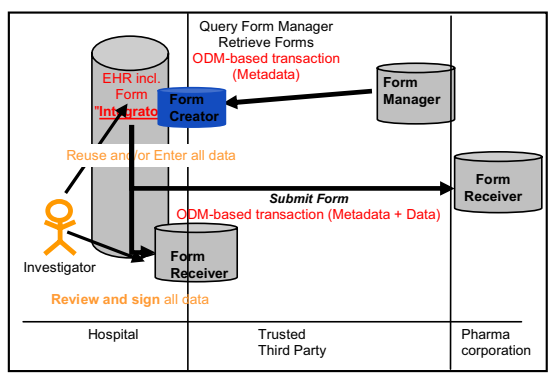

Figure 2- Actors and transactions involved in the "Retrieve & Integrate Form for Data Capture" (RIFD) integration profile proposed

The “Retrieve & Integrate Form for Data capture” (RIFD) integration profile consists in three component or “actors”: “Form Manager”, “Form Creator” and “Form Receiver” and two transactions “Query-Retrieve Form” and “Submit Form”.

The transaction "Query-Retrieve Form"

This transaction consists in importing within the EHR an eCRF of clinical trial provided by the Contract Research Organization (CRO). It relies on an ODM message to transfer the metadata of the eCRF from the "Form Manager" to the "Form Creator". Then, the eCRF is encoded using SNOMED v3.5 VF codes as much as possible and integrated into the EHR. The pre-filling process of the eCRF by pre-existing clinical data in the EHR is achieved through mechanisms specific to the EHR. These mechanisms are based on mappings between clinical items of different forms (used in a patient care as well as in biomedical research context) and SNOMED v3.5 VF used as pivot terminology.

The transaction "Submit Form"

This transaction consists in exporting the data of the clinical trial captured in the EHR towards the CDMS. It relies on an ODM-based transaction between the "Form Filler" and the "Form Receiver". Data validation is done in the CDMS, i.e. in an application which the management depends neither on the investigator nor on the sponsor.

The "Retrieve & Integrate Form for Data capture" (RIFD) integration profile was implemented by the EHR DxCare® (Medasys©) and the CDMS Marvin® (XClinical©).

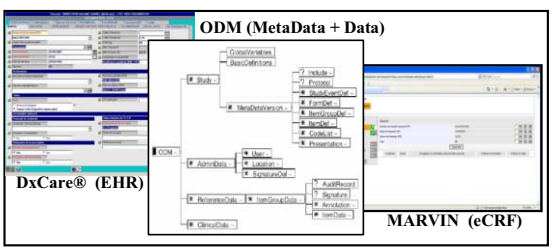

Figure 3- Export of clinical data and meta-data of a clinical trial from the EHR (DxCare, Medasys) to CDMS (MARVIN, XClinical) using the REUSE CDISC ODM mediator.

In HEGP, in the context of the "Arcadia" multi-centric study, figure 3 shows how the CDISC ODM mediator allows transferring data entered into the EHR to the CDMS.

Within the EHR, the ARCADIA study consists of seven forms: Inclusion, initial evaluation, initial abdominal imaging, initial neurovascular imaging, sample, adverse events, and serious adverse events. In using the CDISC ODM mediator, the forms and responses to questions of each patient participating in the clinical trial, have been respectively transformed into Study Event and Subject Data and been generated in the ODM output file with ensuring that the meaning of the data is appropriately preserved, so that the receiving system (ie, researchers) could appropriately use the data.

Discussion and Conclusion

We have modeled the implementation process of clinical trials of institutional sponsorship in a university hospital in order to design, develop and test an integration profile between Electronic Health Record (EHR) and Clinical Data Management System (CDMS) and exploit the EHR clinical data for biomedical research.

The benefits for the health care professionals consist on the economy of a double entry, which is error-prone and time consuming. The benefits for the CRU are to facilitate the data monitoring quality in the electronic Case Report Form. The automatic transfer of data reduces the risk of error, monitoring focuses on data that are not pre-filled from the EHR. Last but not least, due to the "single source" approach that we have adopted, the benefits for the patient are related to the storage in the EHR of all clinical data collected either in a patient care context or a biomedical research context. We believe that considering the EHR as the single source of data may improve patient safety insofar as some of the data collected in a biomedical research setting, such as adverse events of treatment delivered in the clinical trial context, are likely to be useful to support diagnosis and treatment of the patient.

Unlike the RFD IHE profile the "Retrieve & Integrate Form for Data capture" (RIFD) integration profile, that we have implemented in REUSE, not only allows displaying an eCRF within an EHR, but also importing and integrating it in the EHR. This increases the possibilities of pre-filling the electronic Case Report Form (eCRF) compared to what is proposed in the RFD IHE profile. Indeed, even when the RFD profile is completed by the Clinical Research Data capture (CRD) profile [30], the pre-filling of the eCRF is limited to some predefined clinical items. These items are selected from the content modules of IHE Continuity of Care Document (CCD) [31] because they are common to patient care and biomedical research. This set of items, defined generically for every clinical trial, will be by nature limited and therefore, from our point of view, will only slightly address the double entry issue.

An interoperability framework and the use of data standards (HL7 or CDISC "templates" and reference terminologies) are essential for any successful implementation of a data collection system designed to reuse patient data in the context of multi-centric clinical trials. Multicenter trials require data from different sites to be submitted to a central data center, with whom the site's relationship may exist for only a single trial. For reuse of patient care data to be feasible, data collection methods must be easy to implement and use, and must minimize disruption at the clinical site.

Furthermore, successful adoption of IT systems has always been a challenge involving numerous social and organisational factors. The understanding of end user needs and workflow is a key element of the REUSE project. Indeed, these factors must be considered even more carefully when considering a fundamental re-engineering of an enterprise like clinical research enterprise.

Standards have the potential to make this possible by allowing investigational sites to use existing systems without the burden of data transformation.

The main drawback of the "single source" approach is that a new "actor" – "Form Creator" - has to be implemented by the EHR in order to integrate eCRF designed using the CDISC ODM format.The experience gained during the project REUSE should allow us to build an interoperability framework using HL7 and CDISC standards, by developing and implementing the content standards such as a clinical note input templates and eCRF templates derived from protocol specification.

This will facilitate the implementation of Single Source solutions in a European multi-centric context including different vendors, different CROs and different sponsors.

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10 Years Experience with Pioneering Open Access Publishing in Health Informatics: The Journal of Medical Internet Research (JMIR)

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Abstract

Peer-reviewed journals remain important vehicles for knowledge transfer and dissemination in health informatics, yet, their format, processes and business models are changing only slowly. Up to the end of last century, it was common for individual researchers and scientific organizations to leave the business of knowledge transfer to professional publishers, signing away their rights to the works in the process, which in turn impeded wider dissemination. Traditional medical informatics journals are poorly cited and the visibility and uptake of articles beyond the medical informatics community remain limited. In 1999, the Journal of Medical Internet Research (JMIR; http://www.jmir.org) was launched, featuring several innovations including 1) ownership and copyright retained by the authors, 2) electronic-only, "lean" non-for-profit publishing, 3) openly accessible articles with a reversed business model (author pays instead of reader pays), 4) technological innovations such as automatic XML tagging and reference checking, on-the-fly PDF generation from XML, etc., enabling wide distribution in various bibliographic and full-text databases. In the past 10 years, despite limited resources, the journal has emerged as a leading journal in health informatics, and is presently ranked the top journal in the medical informatics and health services research categories by impact factor. The paper summarizes some of the features of the Journal, and uses bibliometric and access data to compare the influence of the Journal on the discipline of medical informatics and other disciplines. While traditional medical informatics journals are primarily cited by other Medical Informatics journals (33%-46% of citations), JMIR papers are to a more often cited by "end-users" (policy, public health, clinical journals), which may be partly attributable to the "open access advantage".

Keywords:

Medical informatics, Publications, Knowledge translation, Medical informatics education, Bibliometrics

Introduction

Between 1987 and 2006, over 77,000 medical informatics articles were published, in 4,644 unique journals [1]. Being a highly interdisciplinary field, it is difficult to determine what constitutes a "medical informatics" journal. In the mid 90ies, several studies independently attempted to identify a core set of medical informatics journals [2-5], based on cocitation analysis and Medical Subject Headings (MeSH) co-occurrences. Another approach to identify "medical informatics" core journals is to consult the Thomson/Reuters Journal Citation Reports (JCR) database, which assigns subjects to journals. Currently, the JCR 2008 (the most recent version as of March 2010) lists 20 journals in the "medical informatics" discipline. Traditional medical informatics journals are poorly cited and the visibility and uptake beyond a relatively small medical informatics community remains limited [6].

At the end of the 90ies, all journals identified as "core medical informatics" journals using the methods above had the following in common: 1) they were published by professional publishers, with authors signing away their copyright as a condition for publication; 2) all had a "paper" counterpart, none of them were "electronic-only" journals; 3) all medical informatics journals were subscription-based journals, none was freely available.

In addition, it became clear that the Internet had a major impact on medicine and public health, as well as on the discipline of medical informatics itself, without any journal covering specifically this field. The *Journal of Medical Internet Research* (JMIR, www.jmir.org) was created to fill this gap [7]. Perhaps even more significant was the fact that the Internet itself as a disruptive technology allowed a change in the publishing model, bypassing traditional intermediaries (publishers), leaving ownership and control of published works in the hands of the scientific community. JMIR was created with these values in mind.

This report chronicles the first 10 years of this ongoing experiment, during which JMIR has risen to the top ranked journal in the Medical Informatics journal, by Thomson/Reuters Impact Factor (IF). While the author recognizes that the Journal Impact Factor is an inadequate and questionable metric of "quality" (in particular if used as proxy for article quality), it is one important metric to compare journals with each other. In this paper, we also go beyond comparing IFs, and look at the origin of the citing articles. One of the underlying hypotheses to be explored is the role of the open access policy for helping the *Journal of Medical Internet Research* to achieve a re-

spected place in the community, without the marketing budget of a large publisher.

Materials and Methods

Journal Details

History

The JMIR editorial board was assembled in 1998 and the first articles were published in August 1999. JMIR was conceived and founded by Gunther Eysenbach, MD, MPH who continues as Editor and Publisher of the journal. At the time JMIR was the first international scientific peer-reviewed journal covering all aspects of research, information and communication in healthcare using Internet and Intranet-related technologies. As a publisher of a journal about the Internet, the founding editor was also dedicated to using and experimenting with the Internet as a communication vehicle [7].

This included making all articles immediately electronically available on the Internet, free of charge for the reader, a model which is now known as "open access" publishing. It should be stressed that while "open access" publishing has now become more prevalent and accepted, at the time of creation, JMIR was an early pioneer of this model. Other open access journals (such as BiomedCentral journals, which launched in 2000, or the PLoS journals, which launched in 2003/2004) as well as other significant developments such as PubMed Central (which launched in 2000) were not existing at the time of the JMIR launch.

Table 1 – JMIR Milestones Timeline

1999: Launch
2001: NLM/Medline indexing
Dec 2002: named Official Journal of IHCC (Internet Health Care Coalition)
Aug 2003: named Official Journal of SIM (Society for Internet in Medicine), abandons *Medical Informatics and the Internet* (Taylor & Francis) as Official Journal
Nov 2003: Use of OJS 1.0
Nov 2004: Major site relaunch: PDFs available, all articles available as XML
2005: ISI begins monitoring JMIR
2006: JMIR in PubMed Central
2007: First Impact Factor (2006) published by ISI: 2.9 (#2/20 in Medical Informatics [MI], #6/56 in Health Care Sciences & Services [HCSS])
2007: Upgrade to OJS 2.0
2007: 30k SSHRC grant for open access journals
2008: Impact Factor (2007): 3.0 (almost the same as the #1 JAMIA: 3.1)
2008: 90k SSHRC grant for 3 years
2009: Founding member of the Open Access Scholarly Publishers Association (with BMC, PLoS, and others)
2009: Impact Factor (2008): 3.6 (now ranked #1 in MI and #2 in HCSS)

Scope

JMIR publishes manuscripts on all aspects of research, information and communication in the healthcare field using Internet and other eHealth technologies. This field overlaps with what is called "consumer health informatics", or – more recently – Medicine 2.0 or Health 2.0 [8] (which is highlighted by the fact that the journal now co-sponsors an annual Medicine 2.0 conference – http://www.medicine20congres.com). The journal also publishes original research on development, evaluation, and application of other (non-Internet) e-technologies in the health care setting (e.g. m-health applications). JMIR targets a broad readership consisting of health professionals, policy makers, consumers, health informaticians, developers, researchers, hospital and health care administrators, and e-health businesses.

As eHealth is a highly interdisciplinary field JMIR invites research papers from a range of disciples including the medical sciences, the computer, behavioral, social and communication sciences, psychology, library sciences, informatics, human-computer interaction studies, and related fields.

Business Model

Open access journals can, by definition, not create revenue through subscriptions. In order to cover the publishing costs, which include professional services such as hosting, copyediting, XML tagging/typesetting etc., novel ways of creating revenue had to be found.

JMIRs business model is unique as it creates its primary revenue streams from personal and institutional memberships, in addition to article processing fees, and sale of PDF reprints. Institutional memberships for departments or institutions such as research centers, universities, and corporations, provide reduced or waived author publication fees for employees, faculty, or students of the institution or department. Many academic medical informatics departments are an institutional member of JMIR. Institutional memberships start at $900 per year, which allows their faculty and students to publish free of charge in JMIR.

While HTML versions of all material in the journal are freely available, PDF versions of individual articles, entire issues and topical article collections ("e-collections") are available for a fee (or freely available for members). An additional revenue stream are a nominal submission fee (currently $90), as well as the optional fast-track fee. The journal also accepts advertisements including Google Adsense on the web site as a source of additional income.

As of September 2009, the journal has almost 400 paying members. As a result, the proportion of funding coming from member contributions is increasing steadily, with over half of the revenue coming from memberships and only 25% from article processing fees. Between 2004 and 2006, JMIR has doubled its total revenue, which now exceeds $100,000 per year.

Review Process

Manuscripts are first reviewed by the Editor who decides whether the manuscript meets the criteria specified in the in-

structions for authors and whether it fits within the scope of the journal. Manuscripts are then sent to an external expert for peer review. Authors are required to suggest at least two peer reviewers. The identity of JMIR reviewers is revealed if the manuscript is published (they are acknowledged in each manuscript), unless requested otherwise by the reviewer, but anonymous during the review process and in case of rejection. Approximately 30-40 percent of unsolicited articles are accepted for publication. The Journal is currently (2010) experimenting with open peer-review models, where submitted articles and their abstracts are listed on the website and any reader can sign up as peer-reviewer (submitting authors can opt-out of this model).

As frustration over traditional turnaround times was one of the original motivations for creating JMIR, editors seek to review and publish manuscripts very quickly. A unique feature is that if authors chose to pay for the journals "fast track" review option, a publication decision is *guaranteed* within 3 weeks and publication within four weeks. Otherwise, the journal attempts to complete the review and publication process as quickly as possible but does not guarantee a specific timeline.

Rights Management

JMIR papers are published under the Creative Commons Attribution License. The license grants others permission to use the content in whole or in part, and insures that the original authors and the journal are properly credited/cited when content is used.

Editorial Board/Governance

The journal has an elected editorial board that has responsibilities such as acting as section editors that oversee the review and editing process for specific sets of manuscripts. The journal also seeks guest editors interested in compiling special theme issues of the journal.

Indexing/archiving

JMIR is indexed or abstracted in a wide variety of bibliographic databases, reference sources, and alert services, including Medline and over 20 other databases. It also deposits full text articles in PubMed Central. A full listing of these can be found on the journal web site, (http://www.webcitation.org/5NwssREcf)

Structure, Content and Formatting

JMIR's article section is organized into yearly volumes and quarterly issues. Open access versions of articles are published in HTML. PDF versions are available for a fee and to individual and institutional members. A variety of manuscript formats are published including editorials, original articles, viewpoints, literature reviews, short papers and letters.

Technical Implementation & Innovations

Automatic XML Production with OrangeX

Since 2002, JMIR is using a LAMP-based (Apache/MySQL/PHP) online manuscript management and publication system, code-named OrangeX, which is a heavily customized and expanded version of the Open Journal System (OJS), an open source journal management system available from the Public Knowledge Project (PKP, 2007). OJS required extensive redevelopment, as it has multiple severe bugs and usability issues, and originally did not support an XML-based publishing workflow. The JMIR development group donated the code and workflows/plugin ideas developed for JMIR as open source to the OJS project. For example, the XML/PDF functionality of OJS and many other plugins have been developed by the JMIR group (MJ Suhonos and Juan Alperin).

The most significant development of the OrangeX modules is a fully OJS-integrated system to generate Pubmed Central-compatible XML documents, from OJS-based metadata and through a conversion of word-documents to XML. OrangeX also automatically checks and corrects cited references against bibliographic databases such as PubMed. Earlier versions of the XML conversion and reference checking software module – which was made available under a GNU license - has formed the basis for the Lemon8-XML software [9], which is a standalone, non-OJS integrated version. OrangeX is not currently released as open source software, but the JMIR group offers hosting of open access journals on the OrangeX platform.

Other Innovations

The journal has been innovative in a number of areas, including: 1) first journal to use screening software to check for plagiarism of material published on the web; 2) development of the WebCite system (www.webcitation.org), which supports permanent archiving of web material cited by authors [10], now adopted by hundreds of other journals; 3) open peer-review models.

Impact Analysis

Analysis of the impact of a journal can come from two sources: Quantitative citation analysis, and qualitative feedback from authors. While we have anecdotal and qualitative evidence from authors reporting on the wide uptake of their works, in this paper we focus on quantitative data based on citation analysis, with benchmarking against other medical informatics journal. We selected 5 benchmarking journals from the Journal Citation Reports database (journals from the medical informatics subject category): Journal of the American Medical Informatics Association (JAMIA), International Journal of Medical Informatics (IJMI), Journal of Biomedical Informatics (JBI), Telemedicine and ehealth Journal, and Methods of Information in Medicine ("Methods").

We used the Web of Science database (Sept 2009) to analyze citations to JMIR and benchmarking journals. In order to determine the subject areas of citing journals, we searched for all articles citing JMIR (or benchmarking journal) articles which were published in 2007-2008. We then tabulated all subject areas of the citing journals and reported those which constitute at least 10% of the citing articles in any of the benchmarking journals. The journal subject areas are assigned by JCR staff. Note that a journal in JCR can belong to multiple subject areas (for example, JMIR belongs to "Medical Informatics" and "Health Sciences and Health Services Research").

Impact factors (defined as the average number of citations to those papers that were published during the two preceding

years) were extracted from the Journal Citation Reports (JCR) database (Thomson/Reuters 2009), searched in October 2009.

Results

Reach and Readership

JMIR has grown to be a very widely read journal with approximately 60.000 pageviews per month (Sept 2009, Google Analytics), and 25-30.000 visits per month. The Alexa Traffic Rank was 440.860 in March 2010 (benchmarked against JAMIA, which is ranked 2,551,028 by traffic). Approximately 24,000 readers subscribe to e-mail notifications of publications (as of Sept 2009).

Impact

The Journal Impact Factor has steadily grown. In 2009, with publication of the 2008 impact factor, JMIR is now the top-ranked journal in the Medical Informatics category (Figure 1), as well as in the Health Sciences and Health Services Research Category (not shown; review journals excluded). While Thomson-Reuters only began publishing an "official" impact factor for JMIR in 2006, previous inofficial impact factors for 2004 and 2005 suggest impact factors of about 2.5 – 3.0.

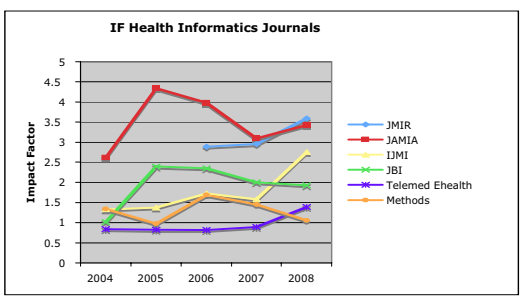

Figure 1- Ranking of Medical Informatics journals by Reuters/Thomson Impact Factor 2004-2008

Citing Journals

In order to explore differences in citation patterns between JMIR and the benchmarking journals we looked at the subject areas of the source journals citing articles from JMIR (or the benchmarking journals). Figure 2 illustrates the subject areas of journals citing articles in JMIR and other medical informatics journals (Note that JBI is also cited by journals from the disciplines "Biochemical Research Methods", "Biotechnology & Applied Microbiology", and "Mathematical & Computational Biology" which are not significant sources of citations for the other journals and which have been omitted from the figure).

As seen in Figure 2, 28% of articles published in 2007/2008 in JMIR were cited in Medical Informatics journals (first vertical bar), a figure which is higher in most other Medical Informatics journals, which tend to be cited primarily by other Medical Informatics journals. In contrast, JMIR is more often cited by "applied" and clinical journals, including those dealing with public health and health services research.

Discussion

Over the course of the last decade, the *Journal of Medical Internet Research (JMIR)* has emerged as an influential and sustainable dissemination tool for health informatics research, despite limited resources and manpower. It is difficult to decide whether the observed quantitative (Figure 1) and qualitative (Figure 2) differences in citation patterns are a result of the open access policy or a result of the editorial policies (or – most likely – a mix of both), but it can be argued that they are – at least partly – attributable to what has been called the "open access advantage" [11]. While the "hard" evidence of an open access citation advantage comes from a citation analysis of articles from a "mixed model" journal (PNAS) [12], these data are complemented by narratives of JMIR authors who often report that their work has been used and taken up by unexpected sources.

Thus, it has been argued that the open access advantage has three components [11]: (1) a citation count advantage (as a metric for knowledge uptake within the scientific community) [12], (2) an end user uptake advantage (end-users being patients, policy makers, clinicians), and (3) a cross-discipline fertilization advantage, meaning that knowledge is more easily discovered and absorbed by scientists from other disciplines. While cross-journal comparisons are always confounded by differences in editorial policies and differences in article selection criteria, data provided in Figure 1 and Figure 2 are consistent with these three hypotheses, showing not only more citations, but also citations coming from a wider area of applied disciplines, instead of just medical informatics, computer and information science journals.

Knowledge users who are not researchers (policy makers, consumers, journalists) do not necessarily read scientific publications. In our 10 years of experience with this journal (JMIR), we have received many anecdotal reports from authors and research users testifying that open access publication can help to bridge this gap. Policy makers and end-users are much more likely to "google" for evidence than to do a formal literature search [13], and even if they come across a subscription-based scientific paper through Google, they are unlikely to actually order it. Only if a publication is open access will end-users skim and eventually read it, or contact the author, after they discovered that it is relevant to the policy (or practical) question at hand. We know that JMIR is used as much by patients and other nonresearchers (eg, policy makers) as it is by eHealth researchers, and we know from our authors that they are often contacted by "atypical" readers (knowledge end-users) who bumped into their article by pure chance, which they would never have done had the article been published in a subscription-based scholarly journal.

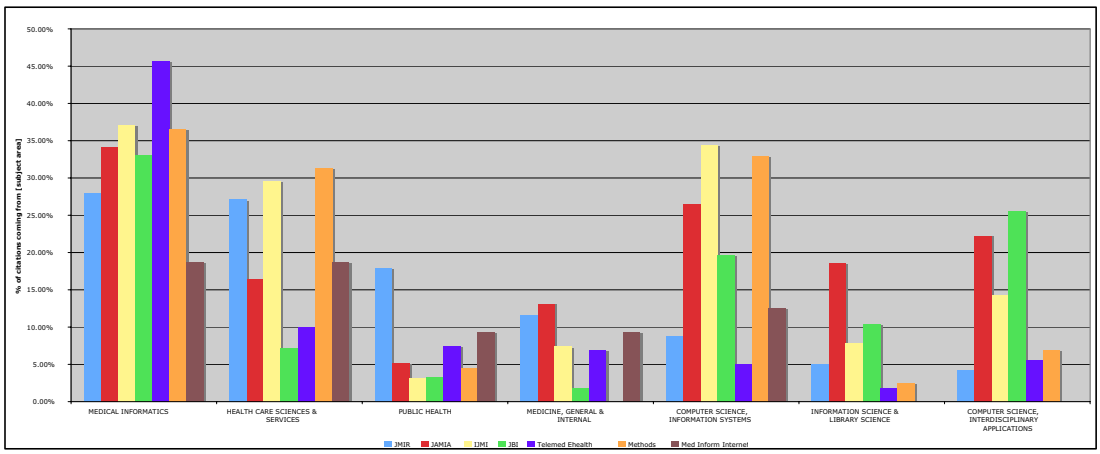

Figure 2 – Subject areas of citing journals

While these findings seem to support the Open Access Advantage, especially in regards to facilitating and broadening the knowledge transfer within and between disciplines, it should be noted that generating revenue with the Open Access model is difficult. As many societies rely on income from their journals, Open Access as a business model is not appealing to them. JMIR has been fortunate to enjoy an increasing circle of institutional support from leading academic medical informatics departments, providing an alternative knowledge dissemination model.

While JMIR has been one of the a pioneer of open access publishing in health informatics (and in medicine at large), other Open Access journals have recently been created in the field (none of which indexed in ISI/JCR yet), using a similar model, e.g. BMC Medical Informatics and Decision Making, Indian Journal of Medical Informatics, Open Medical Informatics Journal (a commercial journal published by Bentham, a publisher who has recently been criticized over quality issues [14]), the Journal of Health Informatics in Developing Countries, The Electronic Journal of Health Informatics (eJHI), an official publication of the Health Informatics Society Australia. JAMIA, also has (in 2010) started to offer an open access option for authors, where they can pay $2000 to make the article open access.

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The IT-Infrastructure of a Biobank for an Academic Medical Center

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Abstract

For high quality research in biomedicine an operable biobank is essential. In order to make optimal use of the material and the huge amount of data a sustainable IT-infrastructure is indispensable. Therefore, we developed a concept for the IT-infrastructure of a biobank for an academic medical center. The conclusions for this concept are deduced from our experience with the biobank and IT-infrastructure of a clinical research unit. Our results indicate that the IT-infrastructure plays a pivotal role in successfully establishing a biobank. Several aspects of the IT-infrastructure are similarly found in other areas as, e.g. data protection and storage and quality management. Finally, we conclude that although a research database is not required for operating a biobank, the need for it will definitely emerge, especially with regard to personalized medicine and high-throughput gene expression analysis.

Keywords:

Biomaterial, Biobank, Biobank software, IT-infrastructure, Repository

Introduction

Biomaterial for research

Many medical research projects and clinical trials include endpoints requiring patho-histological reports, biomolecular tests and survival data. Therefore, it is indispensable to sample and store biological material to conduct clinical trials for finding biomarkers, improving existing, or developing new therapies, and to get statistically reliable results. Without enough high quality biomaterial many projects struggle or fail [1]. One solution to prevent the fast disappearance of biomaterial especially after the end of funding or in a follow-up phase, e.g. in a clinical trial, is a sustainable biobank (Fig. 1). Furthermore, providing a biobank with a solid IT-infrastructure increasingly becomes a criterion deciding about whether a grant application is accepted or not. It is worth to mention that in the beginning of a clinical trial the collection of adequate biomaterial is usually progressing slowly (not depicted in Fig. 1). A biobank should provide long-term storage of high quality biomaterial for research purposes. According to a definition of the German Ethics Council a biobank is the connection of a collection of human body materials and person-related data [2]. The biomaterial increases its value in combination with associated clinical patient data (MDAT) of the clinical trial. To administrate this huge amount of data a sustainable IT-infrastructure is indispensable.

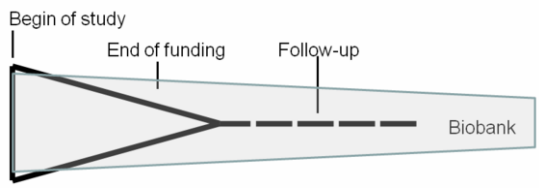

Figure 1- Availability of biomaterial during a clinical trial in comparison with a biobank

The biobank of the clinical research unit 179

In Goettingen the clinical research unit (KFO) 179 funded by the German Research Foundation (DFG) has the goal to develop an individualized therapy for the treatment of locally advanced rectal cancer. The standard treatment currently involves a preoperative radio-chemotherapy (RT/CT) followed by surgery, and an adjuvant chemotherapy. Beside the reduction of tumor size the striking advantage of preoperative RT/CT is the highly significant decrease of local recurrence [3]. Unfortunately, tumors respond very differently to the therapy ranging from complete response to resistance resulting in a survival benefit for only a subset of preoperatively treated patients [4]. Additionally, some patients suffer from severe side effects. For accomplishing their goal of a personalized medicine, the scientists perform experiments, like gene expression analysis, and promoter methylation analysis. For all these experiments they need high quality biomaterial of rectal cancer patients (normal and tumor tissue, as well as blood) that is taken at the initial staging examination of the tumor before

preoperative therapy is given. Moreover, blood samples are drawn during the therapy and of course, the resected cancer is formalin fixed and paraffin embedded to assess the response of the tumor to the neoadjuvant therapy and to finally determine the TNM staging. Thus, the biomaterial collected from rectal cancer patients within the KFO 179 is in the first line used to examine the biological basis of the individual tumor response in patients with rectal cancer. The material is then enclosed into the biobank and can be used by the researchers of the different sub-projects to answer their individual scientific questions. Having the administration data of the biomaterial and the MDAT in validated databases that are included in a sustainable IT-infrastructure has the advantage for the researchers to have an overview about the available material of each patient and the data that were already collected with this material.

Aspects to be considered when establishing a biobank

Although, biobanks are a good idea to counteract shortage of biomaterial, their establishment and maintenance should not be underestimated. There are a lot of aspects which need to be considered besides the storage of biomaterial. The most important aspects when establishing a biobank are in a chronological order:

1. the patient informed consent
2. ethical aspects
3. classification of the biomaterial by one single observer to avoid interobserver-variability
4. data security and protection
5. storage of biomaterial and its quality management
6. rules how to treat specimens with a different purpose of use
7. rules for the transfer of biomaterial to third parties

At the moment there are no biobank-specific laws in Germany, thus the work group biobanks of the telematic platform for research networks (TMF), consisting of scientists and researchers operating biobanks themselves, evolves guidelines, check lists, and privacy models for biobanks [5, 6].

Objectives

A medical center wide biobank would have the advantage that scientists with a specific research question requiring rare samples have a bigger chance to find sufficient samples to answer their question. Therefore, we want to develop a biobank concept with a focus on the IT-infrastructure for a whole academic medical center.

Materials and Methods

Approaching a biobank solution for an academic hospital

The concept for a biobank solution for an academic medical center is mainly based on our experience with the evolution of the biobank software from a remote data entry (RDE)-system for the KFO 179 biobank and supplemented by a literature research analyzing the requirements for larger biobank IT-infrastructures.

Developing a remote data entry system into a biobank software

Since 2007 several existing research projects affiliated with the Department of Medical Informatics at the University Medical Center in Goettingen recognized the need for a professional IT-support for their biomaterial collections. As a first effort, we developed a prototype system for the German Competence Network for Dementia based upon the existing remote data entry (RDE)-system (secuTrial). This product had several advantages over buying specific software, or completely developing software ourselves. Some of the advantages were: our RDE-system was validated in accordance with AMG/GCP, FDA 21 CFR Part11, good clinical practice (ICH-GCP), and TMF privacy models, the adaptation did not cause extra costs, and we were already experienced in setting-up clinical trials.

In 2007 the KFO 179 was founded. Due to its multitude of biomaterials to collect and several sub-projects involved, a web-based biobank software was needed. The continuation of the RDE approach allowed a role-based, audit trail equipped solution, despite the low IT budget of the project.

The KFO 179 biobank software in detail

Whereas the setup of the electronic case report forms for the clinical trials was a standard procedure, several challenges occurred setting up the biobank software. The existing functions of the RDE-system were improved according to the needs of the laboratory staff and a sample-oriented IT-based administration of biomaterial was developed, meaning that the data entry is barcode driven. The setup of the system required multiple redesign phases. Now, the system fully enables the monitoring of biomaterial quality in detail, documenting the storage, and capturing and documenting the respective usage. The basic data of the patients (IDAT) are stored in the study center. As the biomaterial collection does not only contain material and data from patients being treated in the University Medical Center, certain restrictions apply to the design of the IT-infrastructure. In order to fulfill the TMF privacy model, two separate software installations are required for the biobank [5]. One for the administration of the data of the biomaterial (BDAT) gained in the surgery and pathology departments and one installation for the pseudonymized MDAT, which are partially annotated by information from the hospital information system. Via an unambiguous barcode biomaterial specimens of patients can be linked with the information in the biomaterial database. The pseudonym of the patient can be linked to the MDAT in the second database only via an additional list, storing the pseudonym from the biomaterial database in connection with the pseudonym of the MDAT database. Both, BDAT and MDAT can be joined for research aspects via a mapping table. All results should finally be stored with a different pseudonym in a research database. De-identification of a patient is just possible in the study center keeping the IDAT.

The insights gained during this evolutionary process are very valuable for the design of a concept for larger biobanks.

Literature research for larger biobank IT-infrastructures

To identify the demands on biobank software for serving the purpose and fulfilling the TMF privacy model, a literature

research of requirements for biobank IT-infrastructures was performed by analyzing scientific literature and product information from providers of biobank information systems. Key words for the search in PubMed and google scholar were: biobank, biobanking, biorepository, IT-infrastructure, biobank software, biobanking software, BIMS, biorepository software.

Results

In our development process along with the literature research, we found the following points to be most crucial for an IT-infrastructure for a biobank.

Quality assurance

Quality assurance for biobanks has to take place on different levels: from monitoring of the samples to complete annotations during data entry into the database to Standard Operating Procedures (SOPs) describing what to do in case of a power failure.

Within the central laboratory of the KFO 179 the temperature of the samples is monitored manually. The temperature could also be manually entered into the RDE-system, but a direct communication between freezer and biobank software is not possible due to a lack of the necessary interface. That the temperature should be monitored was demonstrated in a study showing that a cyclic (5 times) temperature change from -196 to -150 °C reduces the viability of embryonic neurotissue cells to 50 % [7]. Having the appropriate interface, monitoring of single samples covering the temperature profile and freeze-thaw cycles over the whole life-span of a samples is possible[1].

In the KFO 179 data are entered into the RDE-system by the laboratory personnel for each single sample comprising two entry steps. In a first step, the barcode, the name of the person taking the sample, the date when the sample was taken, the patient`s pseudonym, and the sample`s origin are entered. After the isolation of e.g. RNA from this sample and its quality assessment (taking place just in the central laboratory), the RIN (RNA integrity number) describing the degradation state of the RNA [8], and other quality parameters are entered into the respective form in the RDE-system. Moreover, the storage location, the description of the type of isolated material, and the exact amount and concentration are documented. If a scientist wants to use the same sample for research, the RIN gives information, whether the sample could be used for a certain research purpose. The workflow of the KFO 179 is in accordance with literature mentioning that before samples are included into the biobank, a quality assessment should take place to determine the purity and degradation of e.g. tissue samples [9].

The RDE-system used by the KFO 179 is equipped with an audit trail and a role-based access control. On the data level a check for plausibility such as defined ranges for distinct values exists. Due to the structure of the software (originally designed for clinical trials) based on visit plans, it is not possible to determine whether a single storage location for biomaterial is entered twice, neither to allocate free storage places nor to give an overview about the storage places and their capacities. An identification of duplicates can just be performed after the export of the data and an analysis with statistical analysis system (SAS). In comparison to the literature, the RDE approach has some disadvantages[1].

In addition to high quality biomaterial, high quality annotations are also required. It must be documented what type of biomaterial is stored (using, e.g. the ICD classification), when and with which method it was extracted, purified, and preserved, and how the material was stored during its life-cycle.

In the central laboratory of the KFO 179 an alarm system is installed. In case of a power failure the laboratory personnel follows an emergency plan including a defined workflow for saving samples. This KFO 179 concept is in accordance with literature describing the need to set up a concept in the form of SOPs describing what to do in events of power failure or broken freezer systems [10].

Document and workflow management

The KFO 179 uses a web-based portal system run by the Department of Medical Informatics to save essential documents like study protocols or SOPs. These documents are stored in distinct folders for each sub-project. In addition, the portal offers access to several applications so that the progress can be monitored and collaborations can be fostered. It is described that certain laboratory information management systems (LIMS) are able to directly provide such document storage services without the need for an additional portal[1].

Search functions

In order to allow long-term sample scheduling, researchers need a permanent overview of samples present in the biobank.

Within secuTrial it is possible to get overviews of the biomaterial present in the biobank including a sorting function. For more complex queries, the data needs to be exported and analyzed with SAS. The same applies to the statistical analysis after the end of the study. Some LIMS[1,2] allow a detailed query to work with the biomaterial in the biobank.

Sample request and distribution

One function of biobanks is the storage of biomaterial. Therefore, an essential aspect is how to deal with sample requests and how to serve them.

Within the KFO 179 a transfer of biomaterial to the single subprojects works as follows: A scientist asks for biomaterial in the central laboratory and gets it and the transfer is manually recorded in the RDE-system. The access to MDAT is controlled by a data management and safety committee (DMSC). A transfer of biomaterial to third parties is not planned so far. Our literature analysis revealed that a biobank should offer a web-based possibility to request, and if possible, also to search for samples [10]. In this way, the whole process could be documented at the same time. To minimize errors in issuing samples to third parties and to be in agreement with data protection laws, an IT-supported identification method like RFID

[1] See: http://www.starlims.com/Biobanking_Brochure_final.pdf
[2] See: http://www.biofortis.com/products/labmatrix

tubes or the more common barcode tags should be used on each sample instead of identifying data of the patient. The transfer of MDAT and biomaterial to third parties should just take place in anonymized form [5].

Development of a concept for an IT-infrastructure for an academic medical center wide biobank

Covering the aspects to be considered when establishing a biobank (see introduction), we can deduce the following concept for an academic medical center considering the KFO 179 solution and the literature research:

(1.) The usage and transfer of samples have to be described very detailed in the patient informed consent. The patient has to be informed, whether the sample and the generated data are used only in a specific scientific area, e.g. cancer research, or generally for research purposes. Moreover, it must be possible for the patient to withdraw the consent at any time.

(2.) Ethical aspects: A DMSC must be installed to preserve the safety of patients. In addition, it secures the reliability of the data, which has to be guaranteed, and the transparency of the working processes within the projects.

(3.) To avoid interobserver-variability, all observers have to synchronize their classification methods. Within a clinical trial there should be only one single observer examining the biomaterial and for example staging it. A central image-bank could be one solution to solve this problem.

(4.) Data security and protection: Role-based access control, encrypted transfer of data into the RDE-system, separate storage of MDAT, IDAT, and BDAT, and pseudonymization of the data must be given. The IT-infrastructure must be setup according to data protection laws, TMF guidelines [5], and requirements of the ethic committee of the respective academic medical center.

(5.) Quality assurance must take place on all levels. Especially for a larger biobank it is necessary to ensure high quality biomaterial as well as very detailed annotations. The temperature profile of each sample should be monitored. Thus, an increase in temperature due to a defect or a power failure could directly lead to a warning message to the responsible persons and counteractions could be taken immediately. Unless one directly uses room-temperature sample storage for DNA or RNA obviating the need for freezers [11]. The entry of data into the biobank software must be controlled by a role-based access control and the values added into the fields of the forms should have plausibility checks also for duplicates of barcodes or storage locations. The data entry into a biobank software depends on the state of automation of the biobank, i.e. whether robots are used for storage locations or making aliquots of samples [12].

(6.) It is necessary to store biomaterial of clinical trials for a long time. The progress of research is very fast and therefore it is important that researchers can use datasets of former trials e.g. to establish and validate new methods. In the KFO 179 such an older comparable dataset is used for examination aspects in order to reproduce the results. In case of different results it might be helpful to generate data of older samples again using the current technology. For reducing the problem of treating specimens stored with a different purpose and to label them and determine their content, it is necessary to anonymize them. Nevertheless, for a complete new biobank we recommend to first setup a functional IT-infrastructure including machines for reading samples, labeling, and storing them. Just upon the complete existence of the framework a biobank should start collecting samples.

(7.) A web-based tool for third parties to enquire biomaterial is essential. For the transfer of biomaterial to third parties a DMSC is required, controlling the giving away and required measures like anonymization. An interesting solution is practiced at the biobank of the Medical University in Graz, Austria. There, third parties are supported by the biobank to write research proposals. The biobank determines the availability of the required samples and performs all experiments within core facilities of the Medical University. Only the research result is given away to the third party upon payment[3]. Thus, valuable samples are not given away and a quality loss of the specimen caused by an interference of the cold chain can be excluded.

Finally, it is indispensable to avoid parallel solutions meaning that per academic medical center just one biobank should exist. Most importantly we recommend a new biobank software for an academic medical center, as the secuTrial approach has too many limitations and is not sufficient anymore.

Discussion

Our experience showed that around younger scientists there is a big acceptance of new ideas, whereas senior laboratory personnel tend to generally dislike changes. Nevertheless, existing skepticism is quickly released when the personnel realizes the simplifications, which such new ideas bring with them for the daily workflow.

On the one hand, compared to a distributed storage approach one central biobank has the advantage of saving costs regarding cooling facilities, alarm, and power back-up systems [10]. Optimally, the biobank should be linked to the central laboratory for health care to take over otherwise discarded samples. On the other hand, room must be created for many samples and it requires an elaborate workflow to secure continuous cooling of the specimens from the place of retrieval to the biobank freezers. Moreover, property issues and data sharing issues can easily inhibit the central approach. Therefore, a mature biobank software should not be depending on local issues.

The financial aspect of the biobank depends on the state of automation, e.g. machines for aliquoting, refractioning of blood, storage of samples, labeling of samples, but also on the software for the IT-infrastructure and the number of employees for the biobank.

An academic medical center wide biobank offers advantages and disadvantages to its scientists, although the advantages prevail. The main advantage is that scientists can revert to a larger selection of samples for their research. The fact that

[3] See: www.meduni-graz.at/1449

physicians would need to hand in all their samples gained from patients not used for medical examination into the biobank might be a disadvantage on the first sight. In reality this is an advantage, as it allows the blinding of the physician, who might have a double-role as clinician treating patients and scientist working with their material.

In the KFO 179 an emerging need for an easy-to-use research database (RDB) came up recently. So far, this lies beyond the possibilities of an RDE system. A suggestion for an IT-infrastructure for an academic medical center including a RDB is described in figure 2 [13].

The MDAT stored in the study database (SDB) are encrypted with a person identifier (PID), as well as the IDAT which are stored in a separate list. The BDAT in the biomaterial database (BDB) are organized via a laboratory identifier (LabID) and have a different patient pseudonym. Before researchers can start working with their data, e.g. combining gene expression results with MDAT, a mapping of the identifiers must take place preferably by IT. A RDB into which the matched datasets from SDB and BDB and genetic data could be imported via several interfaces could be searched by a query tool like i2b2 (informatics for integrating biology and the bedside)[4] [14, 15].

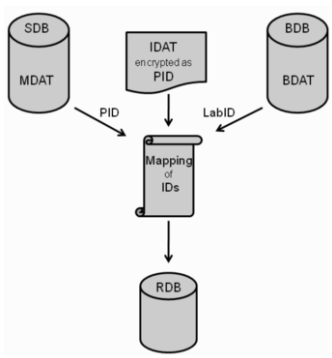

Figure 2- IT-infrastructure for an academic medical center in accordance with German data protection laws

Conclusion

A biobank for an academic medical center should be developed for every university paying special attention to the IT-infrastructure. The choice of software for the single components (Fig. 2) should be well-thought of as the IT plays a pivotal role. The need for a RDB will just slowly arise during operating the biobank, but the person in charge should at an early stage decide how a product could fit best into the existing IT landscape.

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[4] See: https://www.i2b2.org

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Reaching for the Cloud: On the Lessons Learned from Grid Computing Technology Transfer Process to the Biomedical Community

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Abstract

Natural scientists such as physicists pioneered the sharing of computing resources, which led to the creation of the Grid. The inter domain transfer process of this technology has hitherto been an intuitive process without in depth analysis. Some difficulties facing the life science community in this transfer can be understood using the Bozeman's "Effectiveness Model of Technology Transfer". Bozeman's and classical technology transfer approaches deal with technologies which have achieved certain stability. Grid and Cloud solutions are technologies, which are still in flux. We show how Grid computing creates new difficulties in the transfer process that are not considered in Bozeman's model. We show why the success of healthgrids should be measured by the qualified scientific human capital and the opportunities created, and not primarily by the market impact. We conclude with recommendations that can help improve the adoption of Grid and Cloud solutions into the biomedical community. These results give a more concise explanation of the difficulties many life science IT projects are facing in the late funding periods, and show leveraging steps that can help overcoming the "vale of tears".

Keywords:
Healthgrid, Grid computing, Technology transfer.

Introduction

The Argon National Laboratory and CERN played leading roles in the breakthrough of Grid computing. Both institutes share a history in performing basic research in IT and providing IT services for users from the natural and applied sciences – mainly physics. In contrast, developing Grid services for life scientists has been carried out by numerous healthgrid initiatives. We use the term "healthgrid" to refer to the different initiatives developing Grid e-science services for the biomedical community, like caBIG, WISDOM, the French Medigrid and the German MediGRID. These initiatives are transferring the Grid computing technology into the life sciences [1].

"Technology transfer" is a concept which first appeared in literature in 1960s [2]. The term "technology transfer" is widely used to refer to transferring the technology developed in universities and governmental laboratories to the industry. Inter domain technology transfer was also addressed in several studies. We distinguish between knowledge transfer and technology transfer. According to Gilbert and Cordeyhayes [3], knowledge transfer refers to the ''scientific knowledge used by scientists to further science''. Technology transfer refers to the ''scientific knowledge used by scientists and others in new applications''. Healthgrid initiatives are conducting both.

The Grid computing technology transfer process is being carried out by academia and facilitated by government funding agencies. This has been an intuitive process using an exploratory approach. Some difficulties facing the biomedical community during this transfer can be understood through the Bozeman "Effectiveness Model of Technology Transfer" [4], which summarizes the research work on technology transfer. Grid and the emerging Cloud computing technologies are still in flux and thus their inter domain transfer process is subject to problems which are not considered in classical technology transfer models. Taking these differences into account, we can better understand some difficulties facing the transfer of Grid and Cloud technologies. In this paper we show to which degree the principles of technology transfer apply to building an e-science infrastructure for the biomedical community and make recommendations for an improved transfer process.

Materials and Methods

Dynamic-technology transfer

A common view of "technology" is to consider it as a physical entity, a "tool", which is the outcome of a production process and which can be transferred easily (for example by moving it to the target setting) [4]. In contrast, Sahal and Bozeman [4, 5] consider technology as the product as well as the knowledge and methodology to use this product. In our case, the Grid knowledge transfer is not separable from the Grid technology transfer process. Alike Sahal and Bozeman anyhow, we do not consider the applications of the (Grid) technology a part of the technology transferred. The biomedical use cases follow different goals than applications in physics or astronomy. The latter are foremost data grids. Biomedical Grid computing applications are combinations of three types of Grid: data Grid, knowledge Grid, and compute Grid (see Figure 1).

Technologies in development are critical for the transfer process. This was questioned by Bozeman but not incorporated

into his model: "a technology is changed because there is an active attempt by its users or creators to change it. In other cases, the technology is changed by characteristics of its use or by changes in the physical and social setting within which the technology exists. When the functions and application environment changes, does that affect the meaning of the technology or its transfer?" [4]. We believe this question is crucial in our case, as the Grid and Cloud technology is designed to be extendable from the beginning. Known technology transfer methodologies, including Bozeman's model consider static technologies. Technologies under development are dynamic and require different methods. In the discussion, we present our experience and lessons learned with such transfer.

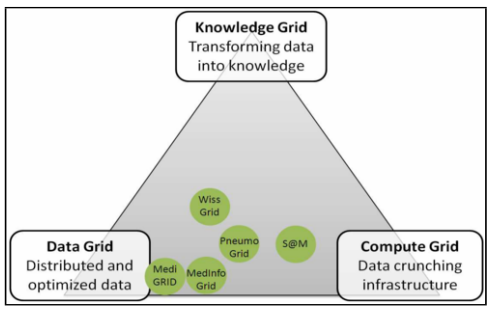

Figure 1- The three generic applications of biomedical Grid computing. A healthgrid is a combination of compute, data, and knowledge grids. MediGRID represents the first phase in transferring the Grid technology to the biomedical community in Germany. Services@MediGRID (S@M), PneumoGrid and MedInfoGrid are successors of MediGRID. WissGrid (Science Grid) is a third phase D-Grid project and involves different communities including life sciences.

The effectiveness model of technology transfer

Bozeman provided a "Contingent Effectiveness Technology Transfer Model'' to summarize the research work on technology transfer. "The model focuses on effectiveness, a perspective well-matched to a literature so often motivated by the search for what works" [4]. With the "what works" approach it is meant how to measure success in a technology transfer process. Five dimensions determine the effectiveness: the transfer agent, the transfer media, the transfer object, the demand environment, and the transfer recipient. The interaction between these dimensions determines the effectiveness of the transfer process. Therefore, the impact of technology transfer should be understood in terms of who is doing the transfer, how they are doing it, what is being transferred and to whom. The novel thing here is that there is no single notion of impact of a technology transfer process. We need to understand the effectiveness in terms of different dimensions, i.e. the goals of one participating party is not necessarily the same (sometimes even contra effective) for other parties. The effectiveness of the transfer can be classified in six deferent criteria: ''Out-the-Door'', Market Impact, Economic Development, Political Reward, Opportunity Costs, and Scientific and Technical Human Capital. Table 1 describes the dimensions of the effectiveness model and Table 2 describes the effectiveness criteria. More details about the model can be found in [4]. We focus on the special case of having Grid computing as the transfer object with the recipient being the biomedical community.

Technology transfer research agenda

Bozeman divided the political agenda to perform technology research into three paradigms:

The market failure technology policy paradigm assumes the free market "will lead to optimal rates of science production, technical change and economic growth" [4]. The government role is to remove barriers to the market, e.g. by providing regulations for intellectual property. The duty of universities is education and providing public domain research.

The mission technology paradigm premise is that the government supports research and development activities "in service of well-specified missions, in which there is a national interest"[4]. Examples are funded R&D from governments for national security, energy production and conservation, medicine and public health. This paradigm has expanded the role of universities to builders of the national technological interests.

The cooperative technology policy paradigm presumes that government's and universities' role is to perform research and to supply applied technology to society and industry. The cooperative technology paradigm emphasizes cooperation among industry, government, and university in the development of new and infrastructure technologies.

D-Grid and MediGRID

The D-Grid Initiative aims to assemble, set-up and operate a Grid infrastructure in Germany in three stages. D-Grid-I, 2005-08, was launched to design and develop Grid services for scientists. D-Grid-II, 2007-10, is designated to design IT services for scientists, industry, and business. D-Grid- III, 2009-11, extends the infrastructure with a knowledge management layer. The aim of MediGRID is to develop a Grid infrastructure for biomedical research. The MediGRID consortium is organized in modules distributed on academic departments and governmental laboratories. The D-Grid/MediGRID funding began following the mission paradigm and looking for a "market pull" of the technology. Unfortunately, the dissemination of the technology was difficult. Especially in life sciences, the requirement for high security and data protection standards proved to be a hindrance [6]. This resulted in a delay in creating a critical mass of users for the infrastructure. In order to enforce a market oriented infrastructure, the funding agency changed the paradigm later to a cooperative technology transfer approach. In the discussion, we show why this shift was early and not ideally suitable for healthgrids in Germany.

Results

The transfer agent – academia and healthgrid initiatives

The technology paradigm is the leading aspect in choosing the right transfer agent, whether it is a university, a governmental laboratory, or an industry partner. D-Grid started with a mission paradigm; it was natural to involve universities as the leading transfer entity. After the shift to the cooperative paradigm, the transfer agent continued to be the universities. Uni-

versities are basically sittings for research and education. The enforced technology policy forced them to take new responsibility in the technology development. In our case, MediGRID started as a research initiative from a department of Medical Informatics at the University of Goettingen. Academic medical informatics departments usually carry out interdisciplinary research in the intersection of computer science and life sciences. They are capable of importing new IT technology in an inter-domain technology transfer process. But they are not necessarily market oriented institutions. Whether academia succeeded in developing a market oriented infrastructure is still an open question. Nevertheless, MediGRID was able to attract some users from industry in its second phase.

The transfer media of Grid computing

This includes objects, like software and literature, and human activities, like meetings and workshops. ***Software:*** Grid middlewares were primarily developed for physicists, who mainly required storage capacity and job farming capabilities. There are three common Grid middleware: Globus, gLite, and Unicore. All are open source, which makes it easier to deploy, modify and adapt them, however this means they are in flux and are not stable technologies. An organizational framework, e.g. Service Level Agreements, is also still missing. ***Science Park:*** MediGRID consolidated the Grid computing activities in Goettingen campus to establish a Grid computing Science Park. Scientists from multiple disciplines formed the GoeGrid, in which physics, bioinformatics, humanities, libraries, computer science, and medical informatics are represented. Participants established an interdisciplinary academic course, in which discussions, demonstrations, and invited talks enriched the understanding of the technology. ***Literature:*** the available literature on Grid computing is vague and complex. The middleware documentations are not complete and contain mistakes. A solid experience with Linux and software development is a requisite to be able to work through the documentations. This has been a major hindrance in the transfer process.

The transfer object – e-science using Grid computing

The goal of building a healthgrid is to perform e-science in biomedicine. While this is a scientific aim, one enduring focus of technology transfer is whether the transferred technology has commercial potential [4]. The question in our case is rather whether Grid computing for medical application is currently ready to be commercialized (we offer our opinion in the Discussion). The second and third phase of Grid computing funding in Germany focused on developing business models for the use of the Grid. This was meant to enforce economical sustainability in a highly dynamic system that is still under development. While the fundamental research in Grid computing is more or less finalized, the methodology of importing life sciences IT applications, from the closed local environments into the open Grid environment, is still under development. Organized and focused interaction with industry is a prerequisite for technology transfer from basic research [4, 7]. Therefore, it is important to cooperate with and engage the life sciences industry to gain trust in the transfer object, before hard commercial criteria are used to evaluate the end objective. This is being tackled currently by Services@MediGRID.

The demand environment

The critical mass of demand for the technology is a major factor in determining the success of technology transfer, especially in life sciences [8]. We faced different difficulties in introducing the Grid technology to the life sciences community: the technology was new to the market and missing ready-to-use applications, the overhead to import existing IT-solutions into the Grid was high, and using the Grid for low level services (like data storage) demanded new skills of the user. This was led to a low acceptance of the technology. To overcome this, MediGRID moved to a market push policy in its second phase by building contacts to the biomedical firms and offering the needed support to import the application into the Grid.

Characteristics of the transfer recipient

The traditional recipients of healthgrids technology are researchers in academia, i.e. non-profit organizations. They depend mainly on public funding, which makes it challenging to develop an economically sustainable infrastructure similar to what e.g. engineering grids do - selling services to industries. The market push policy should help to reach a wider user group in industry and academia.

Table 1- Dimensions of the Contingent Effectiveness Model with corresponding in healthgrid initiatives.

Dimension	Focus [4]	Examples [4]	In Healthgrids
Transfer Agent	The institutions seeking to transfer the technology.	Government agency, university, industry and their characteristics	Mainly academia
Transfer Medium	"The vehicle", by which the technology is transferred	License, copyright, person-to-person, formal literature	Literature, Grid computing software, workshops
Transfer Object	The content and form of what is transferred	Scientific knowledge, technological device, know-how, and specific characteristics of each	The methodology of performing e-science using the Grid technology
Transfer Recipient	The organization or institution receiving the transfer object	Firm, consumer, group, institution, and associated characteristics	Biomedical/healthcare professionals, researchers, and companies
Demand environment	Factors (market and non-market) pertaining to the need for the transferred object	Price for technology, substitutability, relation to technologies now used, market shelters	New tools for physicians, E-marketplace for medical service providers, collaboration concept for researchers, new possibility for knowledge management [1]

Discussion

We show that the answer to whether the Grid technology transfer process was successful or not is multi-layered. Our experience shows that the Grid computing is mainly being evaluated according to market-oriented criteria. This is not suitable for measuring the success of healthgrids. Healthgrids should be evaluated according to the produced scientific and technical capital as well the new created research opportunities. Hence, the mission paradigm is more suitable for starting healthgrids. Especially for technologies under development like Grid or Cloud computing, funding in the mission paradigm shall last until a clear political reward is reached. This will pave the way for a market impact and the move to a cooperative funding paradigm (see Table 2 and Figure 2).

''Out-the-door'' criterion in healthgrids

The assumption here is that "transfer itself equates with success" [4]. As D-Grid-I followed this criterion, the technology was not ready to fulfill the needs of life scientists. Security extensions, information privacy concepts, and workflow extensions were missing. Therefore, MediGRID followed its own course, which was different from other D-Grid community projects, including physics, engineering, and astronomy. MediGRID put emphasis on analyzing the middleware, providing concepts for data protection, and building prototypes applications. In other communities' projects, scientists used "out-the-door" approach and were ready to use of-the-shelf Grid technology. Thus, "out-the-door" is a success criterion for most Grid technology transfer projects, but not for healthgrids.

Why do life science grids not have a market impact, yet?

Market Impact measures the effectiveness of the transfer process according to the commercial success of the technology in the new environment. In our case, the question is not whether the success of a healthgrid can be measured in terms of the market impact, rather when to do so in general. Whether a technology is ready for the market depends largely on the acceptance by the transfer recipient. In MediGRID one major factor influencing the acceptance was simplicity of access, thus, in MediGRID a main emphasis was put on having a web portal as main gate to the Grid resources. Portals for other D-Grid community projects were not an issue, since their users possessed enough IT skills to operate the resources on the command line. That physicists are willing to pay for Grids accessed via the Linux shell, does not mean life scientists will do the same. In technology transfer, it is wrong to put the technology in the market before it is ready. We believe the enforced change from the mission to cooperative paradigm in the German D-Grid was early for MediGRID. Not being ready for the market means little market results, and thus a false negative result. "… technology transfer with little market result has no place in the [cooperative technology policy] paradigm" [4].

Why is the political reward still minimal?

Receiving further funding is the main result of a political reward. Although healthgrids in Germany received further funding from the Federal Ministry of Education and Research, the funding was strategically dedicated towards commercializing the infrastructure. Despite of the involvement of users from industry in the second phase of MediGRID, we are still far from economical sustainability. The necessary political reward would be further funding from the Federal Ministry of Health or from partners from the biomedical industry, due to their roles in healthcare and life sciences. This is not yet reached.

Which opportunities do healthgrids establish?

Each transfer process yields alternative local benefits beside the intended goals of the transfer itself. Examples are the researchers who receive PhDs while working for a technology transfer project, using the received funds for a better internal evaluation of the institute, or changing the profile of the transfer agent. This is common in technology transfer projects. This criterion overrides the common concept of success to provide the effectiveness from the transfer agent's point of view. The various opportunities offered by D-Grid included PhD research, establishing new specialized research groups, starting follow-up projects, and offering infrastructure for academic courses. We believe that more emphasis should be put on considering and supporting such opportunities as a strategic goal in the future. Because Grid computing in life sciences is a young inter-disciplinarily field, the dissemination and establishing the field is an important part of the transfer process.

Table 2- technology transfer effectiveness criteria [4] with corresponding in healthgrid initiatives.

Criterion [4]	**Focus** [4]	**Relation to practice** [4]	**In healthgrids**
''Out-the-Door''	One organization receives the technology provided by another, no consideration of its impact	Common in practice	Uncommon
Market Impact	Has the transfer resulted in a commercial impact, a product, profit or market share change?	Pervasive in practice	Not yet reached
Economic Development	Similar to Market Impact but on a regional or national economy rather than a single firm or industry	Pervasive in practice	Not yet reached
Political Reward	Based on the political reward flowing from participation in technology transfer (e.g. increased funding)	Pervasive in practice	Minimal
Opportunity Costs	Examines alternative uses of resources and possible impacts on other missions of the transfer agent/recipient	A concern among practitioners, rarely considered	Common
Scientific and Technical Human Capital	Considers the impacts of transfer on the enhanced scientific and technical skills, technically-relevant social capital, and infrastructures (e.g. networks, users groups)	A concern among practitioners, rarely considered	Common

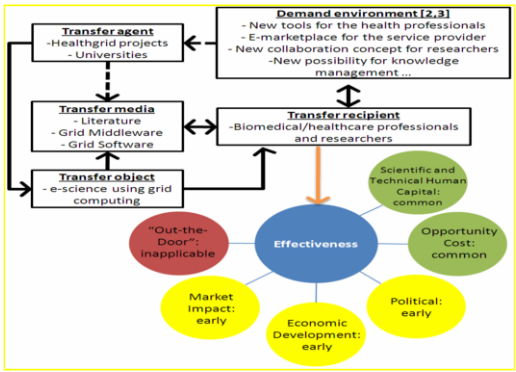

Figure 2- Contingent Effectiveness Model applied on the Grid technology transfer to the biomedical domain.

Scientific and technical human capital in healthgrids

Building up human scientific and technical capacity is as important as producing specific impact from a project [9]. Similar to Bozeman et al., we believe that scientific and technical human capital is a neglected criterion for measuring the technology transfer effectiveness in general [9], and in healthgrids in particular. An important mission of the technology transfer process is to increase the scientific human capital. Such capacities could be within a geographic area, a scientific and technical field, or an institution [4]. D-Grid/MediGRID was a vehicle to reach achievements in these three categories. Within Goettingen campus MediGRID initiated a Grid science park: the GoeGrid. Healthgrid started in Germany 2005 with one project; by 2009 four follow up projects are funded from the federal government. The department of Medical Informatics at Goettingen increased the number of scientific assistances and publications during this period. The "network-based concept of effectiveness" is another important concept [4], which couple the evaluation of technology transfer with impacts on interconnected scientific and commercial actors. The ongoing relations among networks of technology partners are more important to transfer effectiveness than the market factors [10]. MediGRID established in 2008 the "Grid Forum" to coordinate German Grid computing activities in the fields of medicine, medical research and life sciences. These achievements are not the defined goals of the intended technology transfer, but they are a significant and vital part.

Conclusion

Unlike classical Grid users, life scientists are not yet used to sharing computing resources. The government funded three step cross-pollination achieved interesting results, but fell short in some aspects. During the first funding periods it is accepted that the Grid platforms still suffer from stability and sustainability issues. According to the Bozeman-approach it was timely to reinforce industry involvement in the follow up funding periods in order to foster the market impact. However, different organizational and stability issues have hindered a broad market penetration. So the vale of tears still has to be stridden for life science Grids. This is about how collaborative work will be organized in the life sciences in the foreseeable future. Technology labels like Grid or Cloud do not make any difference in the subjacent problem. The problem lies in transferring a dynamic technology using the models and experiences of static technology transfer. In absence of well established models for dynamic technology transfer, we proposed a three steps strategy based on our experience with MediGRID/D-Grid: 1- building a strong scientific and technical human capital, 2- reaching a clear political reward while in the mission funding phase, 3- reaching out to the market and gradually ascent toward a market cooperative paradigm.

Acknowledgment

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A Mobile Phone Based Telemonitoring Concept for the Simultanous Acquisition of Biosignals and Physiological Parameters

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Abstract

Congestive Heart Failure (CHF) is a common chronic heart disease with high socioeconomic impact. Conventional treatment of CHF is often ineffective and inefficient, since self-management is complex and patients are insufficiently involved in therapy management. With telemedical concepts, continuous monitoring of the health status can be ensured, and consequently therapy management can be adapted to the individual requirements of every individual patient. Therefore, a mobile phone based patient terminal for the concurrent acquisition of biosignals (e.g. ECG) and bioparameters (e.g. blood pressure) for patients with CHF has been developed and prototypically implemented. Usability and interoperability aspects were especially considered by using Bluetooth and Near Field Communication (NFC) technology for data acquisition and standardized data formats for transmission of the data to a central monitoring centre. Results indicated that even complicated measurements like the acquisition of ECG signals could be accomplished autonomously by the patients in an intuitive and easy-to-use way. Through the usage of IHE conform HL7 messages, self-measured data could easily be integrated into a higher-ranking eHealth infrastructure.

Keywords:

Near field communication, eHealth, Telemedicine, Mobile communication, ECG, Congestive heart failure, Interoperability

Introduction

Motivation for Telemonitoring of Congestive Heart Failure

Congestive Heart Failure (CHF) is defined as *"a complex clinical syndrome that can result from any structural or functional cardiac disorder that impairs the ability of the ventricle to fill with or eject blood."* Since self-management of CHF is complex and since patients are insufficiently involved in the state-of-the-art therapy process, patients' compliance to the given therapy management is often poor – resulting in a high rate of re-hospitalizations within six months after discharge and in poor quality of life [1].

Telemonitoring for patients with CHF provides advantages for not only the patients but also the healthcare system. The attending physician can carefully watch the overall health status of his patients by the monitoring of various health parameters, namely ECG, weight, blood pressure, heart rate, medication, and well-being. This enables the physician to adapt the therapy in due time – avoiding readmissions to the hospital, emergency cases and extraordinary treatment costs [1].

State of the art

In the last years, several systematic reviews concerning the benefit of telemonitoring in the management of CHF have been conducted. Chaudhry et al. state that telemonitoring may be an effective strategy for disease management in high-risk CHF patients [2]. Clark et al. conclude that telemonitoring programs have a positive effect on clinical outcomes in community dwelling patients with CHF [3]. Louis et al. [4] conclude that telemonitoring might have an important role as part of a strategy for effective CHF management. Seto et al. [5] deal with the cost-effectiveness of telemonitoring in the management of CHF. The results of the aforementioned systematic review suggest that although CHF telemonitoring will require an initial financial investment it will reduce costs in the long run. The cost reduction is particularly caused by the decrease in readmissions and travel costs.

Most of the aforementioned studies used rather complex patient terminals, which could not be used intuitively or were too expensive for a widespread usage. A success factor for the implementation of telemonitoring in the healthcare system is to provide the patients with an easy to use patient terminal for intuitive data acquisition at low cost.

The mobile phone as patient terminal

Mobile phones have already been used as patient terminals in several existing telemonitoring systems for the management of e.g. obesity [6], psoriasis [7], diabetes [8], asthma [9], and CHF [1]. Most of the mentioned systems have used mobile phones with numeric keypads for data entry and mobile Internet technology for the transmission of the data to a central monitoring centre. However, manual data entry often overburdens (elderly) patients, especially if they are not familiar with handling mobile phones.

While the acquisition of an ECG could be helpful in CHF therapy management, it also opens new challenges for the development of a mobile phone based patient terminal. In [10-13], systems for the acquisition of ECG signals in a telemonitoring scenario were introduced. All systems used mobile phones as patient terminals and Bluetooth for the communication between the ECG recorder and the mobile phone. None of these solutions has been evaluated in the course of a clinical study with respect to usability for the given group of patients. Most of the systems required the application of adhesive electrodes to the chest in order to record an ECG. The quality of the ECG strongly depended on the ability of the patients to apply the electrodes correctly, which may pose a problem for daily usage in a telemonitoring scenario. Furthermore, the presented ECG recorders seemed to be too complicated to be used by the patients autonomously.

Aim of the present work

It has been the aim of the present work to develop a patient terminal, which supports

1. an easy-to-use interface for acquiring bioparameters (e.g. blood pressure) and biosignals (e.g. ECG) and
2. the smooth integration of the patient terminal into existing eHealth platforms and hospital information systems.

The patient terminal should prototypically be implemented for the acquisition of home-monitoring data acquired by the patients themselves in the course of CHF therapy.

Materials and Methods

Wherever possible, standards were used for developing a prototype implementation of a telemonitoring system for CHF. These standards are shortly described in the following.

Communication protocols

One way for sending data from a measurement device to the mobile phone is Bluetooth. Therefore, prior to transmitting data in between the devices, the devices need to be paired using a PIN the user has to enter to the mobile phone. Bluetooth pairing is not an intuitive procedure and it may overstrain especially elderly patients. Therefore, an alternative easy-to-use method was demanded.

Near Field Communication (NFC) is an intuitive communication technique, allowing wireless data transmission over short distances. In the case of mobile phones, the maximum distance in between sender and receiver is about 1 cm. Data can either be exchanged between two active devices or in between an active device and a passive NFC tag. In the second case, information can be written on a tag (e.g. an identification number) and later on be read out by an active NFC device (e.g. mobile phone). Unfortunately, communication via NFC is rather slow and it is disconnected as soon as the devices are separated by more than about 1 cm. Therefore, transmission of large data such as a whole ECG file from a measurement device to a mobile phone via NFC is not possible in a reliable way.

Device Enterprise Communication (DEC)

The *Device Enterprise Communication* (DEC) profile as described in the IHE *Patient Care Device Technical Framework* [14] was used for developing the prototype. The DEC profile describes three actors: The *"Device Observation Reporter"* receives the data from the measurement devices, including these based on proprietary formats, and maps the received data into an HL7 *"Observation Result"* message. The reporter forwards the HL7 result message to the *"Device Observation Consumer"*. Additionally, a *"Device Observation Filter"* can be put in between the reporter and the consumer, transmitting only data that the consumer is expecting to receive [15].

Annotated ECG

ECG signals were encoded using the *annotated ECG* (aECG) data format. aECG is an HL7v3 message that has been developed by the HL7 Regulated Clinical Research Information Management Technical Committee. It is intended for the submission of annotated ECG waveforms by the sponsor of a clinical trial to the United States Food and Drug Administration (FDA) [16]. Like the DEC profile, aECG is based on the "Point of Care medical device communication (MDC) Nomenclature" of the ISO/IEEE X73 standard [17].

Backend server

All data acquired with the developed patient terminal were sent to an existing backend infrastructure including identity management, database, web-server, feedback service, interfaces to hospital information services etc.

Results

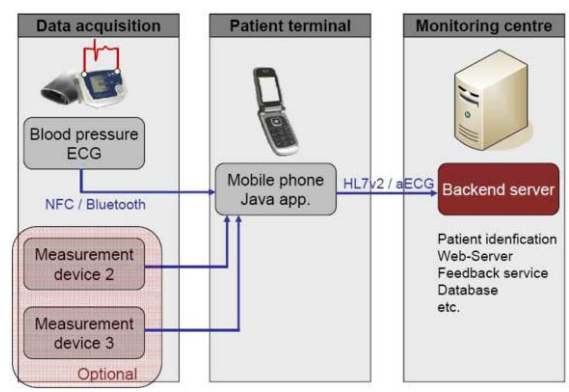

Figure 1- System architecture. A mobile phone based patient terminal collects data of several data acquisition devices and transfers them to a backend server via a standardized interface based on HL7v2 and annotated ECG (aECG).

A framework for acquiring bioparameters (e.g. blood pressure) and biosignals (e.g. ECG) has been prototypically implemented and integrated into an existing eHealth infrastructure.

A schematic representation of the system architecture is shown in Figure 1. The architecture is based on the *Device Enterprise Communication* (DEC). A J2ME based software application running on the patient terminal served as *Device Observation Reporter*. The backend server was used as *Device Observation Consumer*. As the *Device Observation Filter* is an optional part of the DEC profile, it has been omitted for the prototypical implementation.

Patient terminal – Mobile phone

A commercial mobile phone featuring wireless communication via Bluetooth and NFC (Nokia 6212 Classic, Nokia, Espoo, Finland) served as a patient terminal. A Java 2 Micro Edition (J2ME) based software application was implemented on the mobile phone. We used the Java Specification Request (JSR) 82 for implementing the Bluetooth protocol and the JSR 257 for NFC communication implementation.

Data acquisition – Measurement device

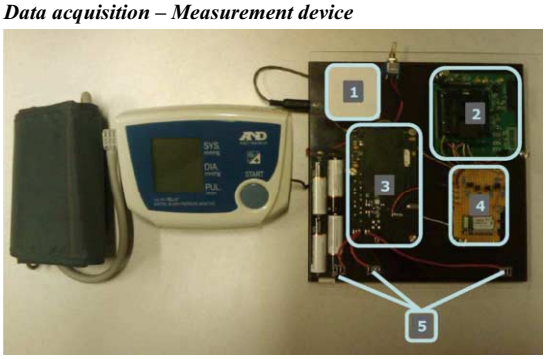

Figure 2- Prototype of the adapted blood pressure meter. 1) NFC Tag, 2) controller unit, 3) ECG module,4) Bluetooth module, 5) electrodes

In order to simultaneously acquire the ECG (Einthoven I), systolic and diastolic blood pressure, mean arterial pressure, and heart rate, an off-the-shelf blood pressure meter (UA-767 Plus BT, A&D, Tokyo, Japan) was used and extended.

An 8-bit single-channel 125 Hz ECG recording module (AIT Austrian Institute of Technology GmbH, Vienna, Austria) was added. For the prototype, the additional hardware was installed on a separate device connected to the blood pressure meter via cables. Three metal electrodes (left arm, right arm, driven right leg) were attached to the casing. These electrodes were to be touched by the fingers of the left and right hand.

Finally, a controller unit (MSP430F2410, Texas Instruments, Dallas, Texas, USA) was installed.

The system was equipped with an NFC tag (Mifare Standard 1K, NXP Semiconductors, Eindhoven, Netherlands) and a Bluetooth module (BNC4, Amber Wireless, Köln, Germany) enabling communication with the mobile phone. Figure 2 shows the hardware prototype of the adapted blood pressure meter.

Data transfer from measurement device to patient terminal

We combined the advantages of NFC and Bluetooth to develop an easy-to-use and reliable interface in between measurement device and mobile phone. The service ID of the Bluetooth module was written on the NFC tag on the adapted blood pressure meter and the Bluetooth connection was established by reading out this ID – without the need of any manual pairing procedure.

Data transmission from the blood pressure meter to the mobile phone was done in a proprietary data format. On the mobile phone, measured values were converted using an extensible mapping scheme. Every value and the corresponding unit were coded according to the MDC nomenclature of the ISO/IEEE X73 standard. For sending the data from the mobile phone to the backend server, the HL7v2 and the aECG standard were used.

Workflow

For data acquisition, the NFC tag on the blood pressure meter had to be touched with the mobile phone. The J2ME application started automatically read out the Bluetooth service ID from the tag and asked the user to take on the cuff of the blood pressure meter and to touch the ECG electrodes with his fingers. Next, the J2ME application sent a trigger impulse to the blood pressure meter, starting the inflation of the cuff. Thereafter, blood pressure measurement and ECG recording were done simultaneously.

The data were transmitted to the mobile phone via Bluetooth – using the service id stored on the NFC tag. The J2ME application analyzed the ECG signal and displayed a graphical representation of the current signal quality.

As soon as blood pressure data and ECG signals were available in sufficient quality, the data were automatically transmitted to the backend-system via UMTS. A device ID was added to the request, which was used to map the transmitted data to the patient.

The J2ME application guided the patient through this workflow, using a visual and acoustic interface – telling the patient, which step he had to take next.

Several measurements and processing cycles were performed successfully in various healthy volunteers.

Discussion

Usability

Effective and efficient treatment of CHF is one of the major challenges for healthcare systems and telemonitoring has been shown to be a useful tool for patients and physicians, increasing the overall therapy outcome. For telemonitoring, it is essential to provide the patient with an easy-to-use patient terminal for intuitive data acquisition. The advantage of mobile phones compared to other patient terminal technologies are their ubiquitous availability at low costs and their mobility. Limited resources concerning memory capacity and processing power, as well the small keypad and display are the main dis-

advantages of mobile phones. In the present work, the usage of NFC and Bluetooth technology completely eliminates the need to use the mobile phone's keypad for data entry. However, the limitation concerning the small display still is valid, even though much (but not all) information was provided to the patients visually and acoustically.

Manual inspection and automated detection of the ECG signals transmitted to the backend indicated that the signal quality would be sufficient for QRS detection and ventricular rhythm analysis. However, up to now no clinical validation of the system has been done. In a future study the usability of the system for CHF patients and the clinical benefit of recording ECG signals (additional to bioparameters as used for up-to-date CHF telemonitoring) will be evaluated.

Standardization and expandability

Initially, standardized data transmission throughout the whole system was intended. However, the adapted blood pressure meter used a proprietary data format. Therefore, standardizing the communication from the device to the mobile phone according to the (currently developing) Continua Health Alliance interoperability standard [18] is planned for the future.

In the management of CHF, it is important to monitor different parameters (ECG, weight, blood pressure, heart rate, medication, and wellbeing) in order to get a complete view on the health status of the patients. The DEC profile only supports physiological parameters (weight, blood pressure, heart rate). Parameters like medication or well-being are not in the scope of the current version of the profile. Additionally, as the current version of the profile does not define the standardized handling of biosignals like ECG, a concept for additional integration of biosignals was needed and has been implemented on the basis of the aECG standard.

Currently, the use case described only supports the acquisition of ECG and blood pressure data (systolic, diastolic and mean blood pressure, heart rate). For clinical usage, additional parameters (weight, medication, subjective parameters) have to be included in order to get a complete view on the health status of the patients. However, because of the modular architecture of the software and due to the use of standards, modules for the acquisition of further parameters could easily be integrated into the developed software.

Safety and security considerations

Up to now, the Bluetooth connection in between measurement device and mobile phone established via NFC by the use of the device's Bluetooth service address is un-authenticated and unencrypted. Therefore, in a clinical setting, an alternative way of establishing the Bluetooth connection via NFC may be required.

In 2007, the Bluetooth Special Interest Group (SIG) announced the new version of the Bluetooth core specification, namely Bluetooth 2.1. Among others, with Bluetooth 2.1 and through the usage of NFC, the initiation of this simplified pairing process can be automated. The only user action required for pairing is holding one device closely to the other. NFC handles the initiation of the pairing without further user interaction.

Unfortunately, Bluetooth pairing via NFC is an optional feature of Bluetooth 2.1, and mobile phones currently available only support this feature for sending images to electronic picture frames or printers. However, it is expected that in future devices this feature will be implemented for all Bluetooth devices.

Security issues are explicitly excluded from the DEC profile. As it is primarily intended for the usage in an encapsulated network (e.g. within a hospital network) data security methods are disregarded. For the use in a telemonitoring scenario, the profile has to be embedded into an additional "Security Framework" in order to ensure a secure end-to-end transmission of the acquired data and to be compliant with data protection regulations. For the development of the prototype, security aspects were also disregarded in the first step. Hence, further developments of the software will focus on the development of a security layer including an encrypted Bluetooth connection form the device to the patient terminal and encrypted data transmission over the Internet form the patient terminal to the backend server using HTTPs.

Identity management of personalized data (i.e. the assignment of a data set to a patient) is one of the big opportunities in future telemonitoring scenarios. Today entering username and password is the golden standard for personalizing data on the Internet. For elderly patients it may be hard to keep the username and password in mind and additionally entering data using the alphanumeric keypad is rather difficult. Identity management issues are also disregarded by the DEC profile. We chose to use a device ID, which was explicitly mapped to a patient ID, for assigning the data received from the patient terminal to a patient. Alternatively, NFC smart cards with personal patient IDs could be handed out to the patients and identification could be made by simply touching this ID whenever transmitting data.

Conclusion

An interoperable mobile phone based patient terminal for the intuitive acquisition of biosignals and physiological parameters was developed and implemented prototypically. Via the use of Bluetooth combined with NFC technology, an easy-to-use interface in between measurement device and mobile phone could be developed. Due to standardized transmission protocols, architectures and data formats, smooth integration of the patient terminal into existing eHealth structures was achieved.

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Chapter 20.

Posters

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A. Translational Bioinformatics

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The Role of the Electronic Health Record in Support of Genomic Research

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Electronic health records (EHR) are a source of information which could be used to better understand the chronological evolution of disease for optimising and innovating treatment. In parallel, translational research focuses on the analysis of gene expression signatures (GES) with the aim to diagnose subtypes of diseases in order to predict clinical outcome. The combination of genomic and clinical information is opening the opportunity to explore the concept of clinical phenotype. Here we present the first step of an overall informatics architecture for exploiting phenotyping information from an EHR for genomic research purposes. This work, developed in studies of gene expression for ovarian cancer, describes the use of EHR data to document specimen quality and clinical context with significant impact on the selection of specimens for genomic studies.

Keywords:
Electronic health record (EHR), Data warehouse, Translational research, Clinical phenotype, Gene expression signature (GES), Ovarian cancer, Specimen quality.

Quality of Electronic Nursing Documentation in Australia Aged Care: Approaches to Evaluation

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Electronic nursing documentation (END) systems are increasingly deployed across aged care organizations in Australia and require evaluation to determine their effect on the quality of service. This presentation describes the development of approaches to the evaluation of END systems in aged care, and considers issues to be taken into account in the evaluation of service quality. Following the establishment of three evaluation goals, a nursing documentation audit instrument was constructed, using approaches derived from three information sources. The focus of the instrument was on documentation structure, format, process and content. The content validity of the instrument was tested by staff at an aged care facility and a high level of consensus was obtained. The audit instrument and related approaches will be used in a research project to evaluate the quality of electronic nursing documentation systems in aged care facilities.

Keywords:
Electronic nursing documentation, Evaluation, Quality, Nursing care, Patient outcomes, Aged care

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Predicting Outcome Measures in Active Learning

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Text classification requires labeled data which is generally scarce and creating additional labeled data requires manual annotation which is an expensive and time consuming task. In our recent work with medical text classification we adopted an iterative labeling process where physicians label instances in batches. Each batch is incrementally added to the training set and changes in outcome measures, such as area under receiver operating characteristics curve (AUC) and accuracy, are calculated. We realized that being able to predict the outcome at a given sample size would be useful and can inform our decisions to terminate labeling and/or learning. In this paper, we describe one such method based on non-linear curve fitting.

Keywords:
Active learning, Non-linear regression, Curve fitting

DISCOCLINI: a system for Biomarkers Discovery in Medical Functional Genomics data

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One of the difficult problems of data interpretation in the analysis of cDNA chips is that the number of expression levels per chip is very high compared to the number of chips. Our method, DISCOCLINI, consists in calculating all correlations in data and reformulating them to easily visualize variation patterns.

Keywords:
Gene expression, Biological and clinical data, Data mining, Knowledge discovery, Correlation, Visualization.

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Towards a web-based environment which assists physicians in guiding ARV resistance treatment

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The aim of this study is the development of a web-based environment that offers various bioinformatics tools to assist physicians in determining the optimal highly active anti-retroviral therapy for individual antiretroviral resistant patients. The clinical environment will facilitate the analysis of the collated output from different interpretation gold standards and predicting the future resistance profile of a patient.

Keywords:
Forecasting, Artificial intelligence, HIV, Drug resistance

Enterprise Data Translational Architecture (EDTA)

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The future of clinical and translational research depends on the ability to gather, store, retrieve and analyze vast quantities and different kinds of data rapidly. These data sets consist of data ranging from genes and molecules to clinical parameters of individuals and characteristics of entire populations. Their acquisition, curation and comprehensive analyses will form the basis of modern medical practice, occupying a central place in the development of translational research and personalized medicine. The architecture employs standard Ontologies to provide a consistent and common data infrastructure for all clinical data at Mount Sinai. The Enterprise Data Translational Architecture (EDTA) is designed as a service oriented architecture (SOA) to provide researchers with optimal access to clinical genomic datasets in support of translational research and personalized medicine.

Keywords:
Translational research, Personalized medicine, Enterprise Data Translational Architecture (EDTA)

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An Integrated Information Platform for a Biomedical Research Network: Concept and First Experiences

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In biomedical research a variety of data like clinical, genetic and proteomic data are processed to gain new insights in diseases and therapies. In a transregional research network (TRN) different projects work together with data in different resources and in different formats. Providing an IT infrastructure that integrates these data enables cross-project analyses and provides an overview of available data and resources (blood, tissue etc.). For a German TRN on liver cancer we develop an integrated information platform for research data of 22 projects. Data will be stored together with meta-data to enable a generic approach. Major challenges are harmonization efforts on procedures and data structures as well as security issues.

Keywords:
Biomedical research, Information platform, Data standards and ontologies

Mutation Operator and its Effects on Protein Structure Prediction in Genetic Algorithms

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We have used Genetic Algorithms (GAs) for the Protein Structure Prediction (PSP) problem, which utilise two main search operators: crossover, and mutation. However, in this paper, we have focused particularly on identifying optimal mutation that can be used to avoid local minima effectively. This is done by altering the chromosomes randomly within the identified range of rotational degree of freedom to provide better diversity to the search algorithms. We have identified the optimal range of rotational moves by empirically analyzing the instantiates of the conformational effects using the mutation operator applied on couple of proteins from the PDB.

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Application of Biomedical Informatics to facilitate clinical use of gene expression microarrays in colon cancer

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Biomedical informatics plays a key role in extracting meaningful information and knowledge from microarray experiments that could be used in clinical settings. In this work we show an example of how biomedical informatics tools can be applied with the aim of facilitating the integration and analysis of different information levels in a microarray-based colon cancer gene expression study although there remain challenges to be addressed toward clinical use of gene expression microarrays. The main result of these analyses show that phenotypic characterization based on "Duke stages" does not match to different molecular entities.

Keywords:
Gene expression, Microarray, Biomedical informatics, Genomics

Sharing paths of exploration to support collaborative reasoning in genomic data analysis

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A significant proportion of data analysis of modern large-scale genomic data sets takes place in an investigative, exploratory mode of working that helps to refine hypotheses. This typically proceeds by reviewing annotation meta-data associated with statistical results, with a view to using the annotation data to suggest refinements to the statistical models used. The researcher's exploratory path through the annotations also represents part of the overall evidence chain, and as such should be captured. We identify three distinct main aspects to the capture problem, i) automated capture of the images and meta-data of the viewed annotations, ii) replay of the captured images and meta-data, iii) a record of insights with discoveries shared with collaborators. We report a prototype capture tool, built around a Workbench for the analysis of large-scale genetic data sets that uses Rich Internet Application technologies to visually replay the captured exploratory paths taken.

Keywords:
Genome-wide association studies, Case-control studies

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Approaching the Nanomedicine field from Biomedical Informatics

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The new discipline of Nanoinformatics represent a solution to manage the new information arising from the fields of nanotechnology and nanomedicine. It aims at integrating it with existing biomedical informatics data, tools and methods. We present here an overview of several activities which have been carried out by our group to approach this new domain. For this purpose we have initiated the analysis of existing information resources in nanomedicine and developed a general framework and a catalogue to organise them. We have also adapted a knowledge management system to integrate nanomedicine available through the Web 2.0. Finally we are participating in several research projects (ActionGrid, NanoSost, Ibero-NBIC) and in standardization initiatives in this field (ISO Technical Committee 229 – Nanotechnologies. Joint Working Group1: Terminology and Nomenclature).

Keywords:
Biomedical informatics, Nanoinformatics, Nanomedicine, Nanotechnology.

Stakeholder Analysis for Digital Preservation in Biomedical Research

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This poster describes the implications of digital preservation on biomedical research from a national perspective. Preserving digital research data for long-term durations is an issue for every area of contemporary science. Looking for recommendations for a digital preservation infrastructure for research sites in Germany a stakeholder analysis was conducted. A stakeholder analysis describes the relevant environment aspects of a contemplated object: biomedical research extended by a digital preservation infrastructure. The results are prepared as an UML use case diagram and reflect requirements for biomedical research. These results are fundamental for a national solution for digital preservation. Legal requirements regarding privacy, retention times, and contractual relationships are of major concern. However, a concrete implementation is presently not available.

Keywords:
Digital preservation, Biomedical research, Stakeholder analysis, Confidentiality, Data privacy protection.

B. Health Information Systems Design and Architecture

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Hospital Information Disaster Recovery System and Simulation Drills

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Comprehensive and integrated Hospital information system has many advantages and can enhance clinical processes. Clinical data and application systems are critical properties of hospitals. Any problems causing unintended information service failure can result in disastrous consequences to clinical environment. Disaster recovery system (DRS) was developed for continuous information service even in disaster situation, medical record protection from hardware or data server failure, and seamless information service during primary server upgrade operation. Real-time updated and physical DR system was developed with Oracle Data guard solution. 13 times DR simulations were performed. Role transition times were 17.0±6.4 minutes. DRS showed short interruption time and it was very useful for primary system upgrade. Hospital disaster plan with DRS and regular drills are needed for real disaster situation.

Keywords:
Disaster recovery, Hospital information system, Electronic medical records

Demography, Biometry and Monetary Influences – A Health Economic Evaluation of the Potentials of Short Cycle Monitoring for Elderly Cardiovascular Patients with Help of Tailored Telemedical Services

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The approach presented in this paper defines a framework of new telemedical services for homely aftercare: The integration of all involved medical service providers (MSP) enables a media break free information flow and therefore offers a swift response in the case of an impending decompensation of the monitored patient. The collected data is locally independent and context rich accessible to all MSPs and supports a short cycle adaption within the rehab process. Incorporating the usability specifications required for elderly and retarded users, a cost efficient and adequate access to medical services in poorly developed regions becomes possible. Additionally, the quality of life itself is being raised with individualized value added services which offer a universal access to products and services that is also locally independent. This concept helps to engage the financial burden to the medical health system caused by the demographic change and actively reduces it. The medical support throughout the anastasis is systematically improved as well as the previously mentioned quality of life.

Keywords:
Telemedicine, Age distribution, Man-machine system, Computer communication network

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Quantitative Evaluation Trial for Functions Embedded in Currently Available Electronic Clinical Pathways Products

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No quantitative method is available to evaluate the functions of electronic clinical pathways (eCP) embedded in electronic medical records. Therefore, we developed new evaluation sheets in which the standard functions of eCP published in 2007 were modified to facilitate their quantification, and in which functions requested at Kawasaki Medical School Hospital were added when electronic medical records were introduced. eCP products by four vendors were evaluated quantitatively and each function was given a weight according to its importance. Moreover, we compared this quantitative evaluation to the subjective evaluation of four staff from the Committee of Clinical Pathways. The results indicated that the implementation of many functions differed among the four vendors, and the quantitative evaluations were comparable. The weights of each function may differ among hospitals due to differences in their medical background, and further studies regarding weighting are necessary. However, the method described in this study will be useful for quantitative evaluation of eCP functions.

Keywords:
Clinical pathways, Evaluation method, Electronic medical records, Standard functions, Quantification

ProSeniis: multi-parameter remote monitoring system for the elderly

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Prevention and rehabilitation efficiency can greatly benefit from the application of intelligent, 24 hour tele-diagnostics and tele-care information systems. Tele-monitoring also supports a new level of medical supervision over the patient's lifestyle. In this paper we briefly present the aims and first results of the ProSeniis remote monitoring system. The novelty of the system is the unified and flexible processing of various signals retrieved from modern, body-worn devices in an efficient signal abstraction framework. The signals include motion sensors that record patient movement in the home, physiological signals and patient responses in tests performed on the GUI of the central home unit (Home Hub). We are currently testing the prototype system; public experiments will begin early 2010 involving volunteers with neurologic degenerative diseases as well as healthy elderly.

Keywords:
Home monitoring, Intelligent signal processing, Neurologic degenerative diseases, Rehabilitation.

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Supporting Teamwork Along the Dynamic Multi-disciplinary Care Pathway

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Teamwork, collaboration and coordination are key aspects of the patient-centric approach taken by modern healthcare. Adequate support for these aspects has yet to be achieved. This paper proposes using associations between patients, practitioners, care teams, professional roles, and the integrated care pathway to provide improved support for practitioners as individuals and as members of integrated care teams. It proposes context-based access to patient information, automated notifications and alerts, and change management support as the patient passes along the care pathway.

Keywords:
ICP, Medical records systems, Patient care team, WFMS

Transinstitutional Health Information System Architectures – a Literature Review

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Two approaches are widely discussed in the discipline of medical informatics as concepts to cope with the negative consequences out of the ongoing demographic change: health enabling technologies and transinstitutional health information system architectures. To realize their full potential, we feel that both technologies should be integrated to sensor-enhanced transinstitutional health information systems. Fundament of such integration is knowledge of the variables characterizing these innovative technologies. While assessing health enabling technologies elsewhere, in our work we present an overview of important dimensions of transinstitutional health information system architectures. Based on a systematic literature review of publications listed in PubMed, we identified relevant (1) user-groups, (2) operation and coordination concepts, (3) the functionality of current transinstitutional architectures in health care and analyzed (4) the basic information flow supported by them.

Keywords:
Information systems, Hospital information systems, Integrated delivery of health care, Transinstitutional, Architecture, Review

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How could we improve Health Care with Enterprise Resource Planning Systems? – A Literature Review

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The use of information systems in healthcare has increased rapidly during the last few years. These information systems are, however, stand-alone, independent and communicate poorly with each other. At the same time, healthcare operations are increasingly migrating towards process-based models. These kind of work flows need information systems that support decision making at different levels of the organization to improve the overall performance. Industry has used enterprise resource planning (ERP) in running and controlling processes. The question arises: could we use ERP also in health care - and if we could - in what way? Although there is a lot of evidence of the benefits of ERP systems in production industry, very limited evidence exists on the role of these systems in healthcare. We present a systematic literature review in order to analyze how ERP systems have been adopted in healthcare, and how these systems can improve healthcare.

Keywords:
Healthcare, Enterprise Resource Planning systems, Systematic review

Virtual Scenarios for diagnosis and rehabilitation of mentally disordered offenders and for men sentenced for domestic violence

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Assessment and rehabilitation of mentally disordered offenders (MDOs) and of men prosecuted for domestic violence is performed in constrained settings, where social and cultural factors are missing. We have developed a simulation system, where scenarios in which violence might occur, can be realistically visualized. The system called Reactions on Display (RoD) allows the offender to choose from different scenarios, make decisions in certain situations, choose actions, see the reactions from victims and others and subsequently learn how to avoid violence. Results from two pilot studies have showed that RoD's interface and design were well received by offenders and professionals.

Keywords:
Virtual encounters, Simulation, Forensic psychiatry, Risk assessment, Violence

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Physicians interrupted by mobile devices – relations between devices, roles and duties

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A common denominator for modern hospitals is variety of communication problems. In particular, interruptions from mobile communication devices are a big concern for many physicians. This study adheres to an interpretive research approach. 11 physicians were observed for a total of 135 hours during May and June 2009, and shows in which degree physicians are interrupted by mobile devices in their daily work, and in which situations they are interrupted. This study contributes to knowledge that could help us in designing and developing an interruption management system for mobile communication in hospitals.

Keywords:
Mobile communication, Context-aware systems, Pagers, Wireless phones, CSCW, HCI

MEDIS: An Italian Registry of Clinical Investigations on Medical Devices

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Clinical Investigations (CI) on Medical Devices (MD) are one of the most important means of demonstrating MDs safety and efficacy under normal condition of use. In Europe the approval of CIs is carried out by each National Competent Authority (NCA) following European Directives, whose aim is to facilitate MD manufacturers to perform nationwide investigations and improve information exchange among NCAs that evaluate CI proposals and monitor their performance. An European registry that gathers information on CIs is at its initial developing stage within the wider context of the European Database on Medical Devices (EUDAMED), while only few countries have developed their own information system to monitor CIs. The development of these information systems at both local and European level facilitates the communication among different stakeholders ranging from NCAs and CI applicants to clinicians and general public.

In Italy the National Research Council is carrying out a project supported by Ministry of Health aiming to develop an information system (MEDIS, Medical Device Information System) that manages CI proposals and monitors CIs.

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Clinician Transformation has to be Clinician Driven

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A clinician who had diversified into software development teamed up with a highly experienced Rheumatologist to create a standalone EMR for rheumatology services. This incorporates existing as well as evolving disease activity standards for an included CDSS. E-Prescriptions, Investigation reports as well as other hard copies which the patient can keep for his information are integrated. The application was launched in July 2007 after over two years of joint effort. Constant innovation and enhancement is still continuing. Use of the application has resulted in a transformation of our clinical workspace with faster patient turnover, efficient disease management, coordination between team members as well as better and extremely fast research output. This application is now being adopted for use by other Rheumatologists. We believe that this successful implementation – an actual clinical transformation - was related to the deep involvement and understanding of the processes required by the users i.e. the clinicians themselves. Luck, willingness to innovate and preexisting IT based environment were other factors helpful for success. The methodology used can be adopted by other specialties to produce relevant world class applications for such their fields. Similar to this example, we have been working in other specialties with albeit less success as the involvement of the relevant clinician is less so.

Keywords:
EMR, Medical records systems, Clinical transformation, Organizational innovation, Time factors

Using an Electronic Health Record to estimate the prevalence of overweight and obesity in children and adolescents and frequency of these diagnoses by physicians

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Growth and nutrition assessment is an essential component of pediatric healthcare and a fundamental tool for the early detection of childhood obesity. We estimated the prevalence of overweight and obesity using anthropometric data from an EHR and compared it to the frequency of overweight and obesity diagnoses registered by primary care physicians. From 14743 patients aged 2- 19 years, 22.1% were overweight and 12.4% were obese. In contrast, the registry of the diagnosis of overweight in the EHR was 3.3% and 1.1% for obesity. Despite the use of more sensible references for screening obesity, a large number of patients remain undiagnosed. An EHR provides quick and easy access to anthropometric data and growth charts in the clinical setting for monitoring growth and early detection of children at nutritional risk. The objective of this paper is to estimate the prevalence of overweight and obesity in a pediatric population based on BMI data in contrast to the frequency of recorded diagnosis by primary care physicians, their referral to specialists and laboratory tests ordering using an EHR.

Keywords:
Computerized medical record system, Overweight, Obesity, Prevalence, Body Mass Index, Child, Adolescent

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Implementing the WHO Child Growth Standards in an Electronic Health Record in Argentina

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Assessing growth and development is a central component of pediatric care. The WHO Multicentre Growth Reference Study (MGRS) provides standards of growth of children living under favorable conditions in breastfed children up to 5 years. The web-based outpatient EHR has offered the possibility of entering growth measurements and chart the data entered on a matrix of XY coordinates. The chart is generated automatically by the EHR with a connected plot for each percentile curve. When Argentina adopted the WHO growth values as the national standard for children younger than 5 years old, these charts were implemented in the EHR. The graphic output was developed using a Java API that allowed creating interactive graphs with no limit in the amount of points helping in the quick implementation of the new standards. The aim of this paper is to describe the implementation of the weight and length/height charts from the WHO Child Growth Standards in an EHR to support pediatric growth monitoring.

Keywords:
Computerized medical records systems, Growth and development, Child, Pediatrics, World Health Organization

Automated method to identify patients eligible for quality measures using an EHR: feasibility and accuracy

Christoph U. Lehmann, David Bundy, Harry Caughey, Sue Weimer, Lilly Engineer, Sean Berenholtz, Marlene Miller, David Silver

The US National Quality Forum (NQF) identifies and endorses measures that evaluate patient outcomes of healthcare. One family of NQF measures addresses whether patients using medications for which annual laboratory monitoring is recommended receive such monitoring. Identifying eligible patients by manually probing an electronic health record (EHR) is time consuming. We hypothesized that an automatic query would perform as well as manual reviewers in identifying eligible patients.

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MedLAB1(ML1); a Software Defined Health Informatics Messaging Protocol for Medical Laboratory Technology

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Electronic Hospital Records (EHR) are usually designed so that records from different vendors can exchange all data according to public standards. Health Level 7(HL7) for instance, is a voluntary consensus standard for electronic data exchange in health care environments. It defines standard message formats for sending or receiving data on patient admissions, registration, discharge or transfer, queries, orders, results, clinical observations and billing. However, in this work, we designed and implemented a proprietary messaging protocol suite for medical laboratory tests called MedLAB1 (ML1). ML1 is implemented in software and it contains medical laboratory records acquisition, retrieval and communication protocols which can interoperate seamlessly with HL7. Various medical laboratory tests that could be handled by ML1 are; chemistry test, culture diagnosis, heamatology, hormonal assay, urine analysis, urine microscopy diagnosis, acid fast bacilli, widal analysis and stool analysis.

Keywords:
EHR, HL7, ML1, Health informatics, Diagnosis, Messaging protocols.

Age of Consent: Contentions with a Seamless Health Record

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The intent of this poster is to explore, within a Canadian context, the opportunities, challenges and complexities of applying informed consent procedures within the context of a seamless electronic health record environment that serves as a forward-looking decision support system, rather than the more traditional retrospective view of the data subject's health experience.

Keywords:
Informed consent, Seamless electronic health record

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Experiences integrating RIS/PACS into personal electronic health records

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The University Hospital Heidelberg is implementing a personal electronic health record (PEHR), to improve the information exchange between other hospitals, primary care givers and the patient itself. This article describes the concept of the automated transfer of clinical imaging data to the PEHR. On the basis of an ideal conceptual model a goal model was developed considering the local conditions. The common basis is a centralized pull model. Local primary systems are connected via HL7 and DICOM interfaces to the record. This integration concept is characterized by a highly complex message interaction involving several components and depends exceedingly on the local conditions. Thus, the solution is not as generic as originally intended. Not only the connection of additional partners can be complex and difficult but also a loss of functionality has to be taken. Nevertheless the integration of workflows can be supported better than traditional teleradiology may do. As a result pictures can be directly transferred into the record referenced to the case and to the patient.

Keywords:
RIS, PACS, PHR, EHR, eHealth

Development of Monitoring System for Outcome Assessment in Off-Pump Coronary Artery Bypass(OPCAB)

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Introduction: The coronary artery bypass graft surgery was performed 4,000 cases annually in Korea and was rapidly increasing. Moreover, the Off-Pump Coronary Bypass (OPCAB) was one of the important clinical indicators in evaluating quality of care. Objectives: In order to monitor and manage the outcome of the OPCAB, we developed the EMR, CDW based monitoring system. Methods: It consisted of 4 systems; the mortality predicting system, the specified medical record, the warning pop-up and the Clinical Data Warehouse. Results: The monitoring systems were available in predicting the risk of the operation, explaining to patients, preventing the miss of the medical services and records, assessing the outcomes of the OPCAB. Conclusion: Our monitoring systems were useful in managing the quality of care in the OPCAB.

Keywords:
Outcome assessment, Off–Pump Coronary Artery Bypass, Hospital mortality, Risk adjustment

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Ingest and Integration of Medical Data in a World with very little DICOM

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The Digital Imaging and Communications in Medicine (DICOM) standard has held and continues to hold promise for the transformation of the healthcare systems landscape. The promise is that of rich documents from arbitrary medical devices, with lots of helpful metadata, that enables the distribution, sharing, seamless viewing and automated analysis of different facets of a patient. Unfortunately, this vision has been slow to materialize in the marketplace for a number of reasons. However, there is still a critical need to construct longitudinal and complete views of a patient. In this paper, we describe how novel and reusable ingest and integration technology can be used to bridge the current chasm.

Keywords:
Systems integration, Data systems

Collaboration of an Electronic Medical Record system and Data Warehouse in HIS

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A large scale Hospital Information system (HIS) generally consists of two parts, the On-Line Transaction Processing (OLTP) system and the On-Line Analytical Processing (OLAP) system. The electronic medical record (EMR) system is a main element of the OLTP system, and the data warehouse (DWH) system not only assumes many important roles as the OLAP system but serves as the backbone for keeping medical care of the institution in high level by providing the best practice cases to the EMR system. This paper will discuss the following points: the reason why OLTP and OLAP are necessary, and the roles of the DWH system.

Keywords:
HIS, EMR, Data warehouse

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Lessons learned from migrating reports with IHE XDS

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We have experienced the migration of the medical information system of Ehime University hospital at May 2009. As there were many variations of implementations for reporting system, the migration of report documents to the new system had many work-hour requirements. Under the migration process, the quality of data decreased by losing the data granularity and deformation. Developing the standard framework for document archiving is a critical component for everlasting document archive with keeping data quality high. Currently there is no standard of enterprise content management system for healthcare. This paper describes how we tried to apply IHE XDS based repository as the enterprise content management system in healthcare.

Keywords:
IHE XDS, EHR, Data migration, Repository, Registry, Enterprise content management

A Regional Model for Healthcare Information Sharing in China

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The regional model for information sharing has been under national discussion in many countries. China also has a great demand on information sharing in healthcare. This paper describes a regional information sharing model for the Chinese healthcare system. It is a stepwise implementation of integrated regional healthcare services to create a virtually borderless healthcare organization.

Keywords:
Electronic health record, Regional information sharing, China

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The use of a Social Network Analysis for a Physician Engagement Model for CPOE

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The use of Social Network Analysis can help us identify key physician communication patterns that form a physician engagement model with CPOE Adoption.

Keywords:
CPOE, Social network analysis

Development Journey for New Clinical Management System III for HKSAR of 7 million population

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For the past 15 years, the Hospital Authority of Hong Kong Special Administration Region (HKSAR) has developed and implemented a corporate application system named as "Clinical Management System (CMS)" for all 40+ public hospitals (28,000 beds), 40+ Specialist Outpatient Clinics, 70+ General Outpatient Clinics, associated Diagnostic Radiology Centers, associated Pathology Laboratory Centers and associated Pharmacies. At present, more than 35,000 clinical users including doctors, nurses, ward clerks, radiologists, radiographers, pathologists and pharmacists are using the CMS on a regular daily basis for carrying out the patient care delivery process via 17,000+ clinical workstations installed at every corner of the Hospital Authority. In terms of its workload, the current CMS has to take care the huge annual clinical activities for about 1 million admissions, 2 million emergency attendances, 14 million out-patient attendances, 15 million laboratory specimen tests, 51 million drug items dispensing & 3.6 million radiological examinations for 7 million citizens in Hong Kong.

Keywords:
Electronic health record, Electronic medical record, Electronic patient record

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Architecture Development for Interoperable EHR in Korea

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In major advanced nations, EHR introduction guaranteed by mutual management is being activated. In proportion to this trend, domestic market is also developing EHR architecture for effective EHR establishment. Accordingly this study is to suggest architecture development-business architecture and its application architecture based on such demand-in accordance with domestic treatment information. Henceforth this architecture model is supposed to support not only international sharing of information but also inter-hospital sharing.

Keywords:
Electronic health record, Architecture, Interoperability

Integrating Clinical Endoscopic Images into Electronic Patient Record - Pathway to Clinical and Technical Success

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This paper described a new function for capturing and sharing of non Digital Imaging and Communications in Medicine (DICOM) clinical images in a regional scale Clinical Management System (CMS) and Electronic Patient Record (ePR). Non DICOM Clinical images and photos were valuable clinical information supporting clinical decision-making and communication. Huge amount of clinical photos were taken using various modalities in clinical practices without effective capturing and sharing. A generic way of identifying patients, capturing and archiving images, sharing on a common platform and integrating into a longitudinal multimedia-enabled electronic patient record is therefore essential and of great value. The architectural framework and workflow integration of image capturing and sharing were designed and piloted for endoscopy image. Post implementation review on user feedback and system usefulness was done. Utilization rate, system performance and clinician feedback were encouraging. With the successful pilot, further roll out of the endoscopy image capture function was planned after enhancement of system performance.

Keywords:
Endoscopy, DICOM, Electronic patient record

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Conflicts between terminology and EHR information models as obstacles to semantic interoperability: a scientific review

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A focus on sharing knowledge is essential for ubiquitous care. Several terminological approaches can be taken to meet the challenge, when terminology models are used to provide a bridge across a range of standardized EHRs information models. Developments in standardized information models as presented by CEN EN 13606 and HL7 have strived for an intrinsic extensibility based on an ad-hoc methodology. We will address the role of terminology systems and EHR information models in achieving semantic interoperability and highlights issues that arise when combining these two domains. A review of scientific literature on information models and terminology systems is conducted with a purpose to categorize research and on obstacles concerned with combining terminology systems and EHRs information models. The majority of the papers analyzed in our review highlight that issues exists, however only a minority contains extensive discussions on these issues. Findings show that ambiguity is key and one attempt to solve this issue is to use terminology binding.

Keywords:
Medical informatics, Semantics

Ontological Approach to Clinical Recording and Form Generation: A proof of concept

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We have designed a generic event ontology, clinical event ontology, and user interface ontology. And we propose a Clinical Record Form Generation Architecture which exploits proposed ontologies. With the proposed form generation architecture we can support EMR system developers in creating clinical record forms and interfaces. This architecture will increase usability and foster convenience for EMR users.

Keywords:
Medical records, Terminologies, Forms and records control

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Semantic interoperability: A method using LOINC and an EAI component for the LIMS integration

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Clinical information systems through their service-oriented architecture are composed of heterogeneous and complex systems. Semantic interoperability based on terminologies allows these systems to combine their informations and process them automatically and relevantly. This paper presents a solution to interoperability in healthcare based on the use of the Enterprise Application Integration (EAI) and LOINC terminology.

Keywords:
Semantic interoperability, Loinc, mediator

Usage of the IHE-Patient Identifier Cross-Reference Profile in a Telemedicine Platform for Cardiac Rhythm Management

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This work explores the usage of the IHE-Patient Identifier Cross-Reference Profile in a telemedicine platform for cardiac rhythm management at the pivotal point between clinical research and routine. It is shown how patients can be uniquely identified in a distributed eHealth environment by usage of electronic health records and devices attached to them.

Keywords:
eHealth, Record linkage, Patient identity management, Cardiac rhythm management, Telemedicine

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Integrating clinical data to foster a comprehensive eHealth record

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To meet the highly specialized clinical requirements in different clinical departments, best-of-breed Clinical Information Systems (CIS) provided by different healthcare solution suppliers are introduced in Hong Kong Hospital Authority (HKHA). Clinical data is captured and stored in different CIS in a scattered manner. In order to eliminate manual data input, prevent transcription error, improve operational efficiency and clinical effectiveness, bi-directional exchange of clinical data was enabled of contributing a comprehensive electronic health record that facilitates clinician to give clinical care at the point-of-care at right time.

Keywords:
Clinical data integration, eHealth record, Point-of-care access, Messaging standard, Quality.

The importance of data audit control when creating an Enterprise Master Patient Index

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Unambiguous identification of patients is the Achilles heel of Health Information Systems, especially electronic medical records. The Enterprise Master Patient Index (EMPI) solves the problem of maintaining a single list of patients and clinical records across multiple hospitals or health systems. This paper aims to describe how Megasalud, the largest integrated ambulatory healthcare network in Chile created a person identification validation service (PIVS) integrating their legacy patient database, and implemented an audit trail system.

Keywords:
Master Patient Index, Computerized medical records systems

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Non English Characters Representation for Patient Safety in the Electronic Health Record Systems – an International Issue

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Accurate patient identification is an essential component in providing both safe and effective diagnostic and therapeutic services. The name borne by individual patient is often the key to identify patients. Globally there is at least 20% of the population who bear names with Chinese characters only. It is therefore important to have the correct Chinese characters represented accurately in the Electronic Health Record. However, Chinese characters differ from the typical Western alphabet set in that there are multiple variants in the strokes in the Character Set. Up to 5% of all patients in Hong Kong bear names which are not listed in the ISO 10646 code lists. Therefore, it is imperative that an international common standard in the Standard Non-English Character Sets and Variants be instituted in order to allow correct representation and registration in a health registration system, Patient Master Index (PMI). This should be done in a consistent and unambiguous manner so as to achieve an accurate patient identification and to match with patient's associated artifacts.

Keywords:
Patient identification, Patient safety, Chinese characters

Enhancing Patient Privacy and Security Via Complex Event Processing (CEP) and Legitimate Relationships Service (LRS)

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We present a solution and a methodology that enhances patient's privacy and security in cross-organizational, regional and national healthcare provisioning models. The research was accomplished in the context of the Legitimate Relationship Service that is part of the United Kingdom's National Programme for IT (NPfIT). The solution monitors access requests issued by clinicians to patient information clinicians from multiple different organizations and issues alerts and notifications based on modeled event patterns. The solution employs Complex Event Processing (CEP) which stems from Event-driven SOA. HL7 messages are used are canonical event model and CDA documents as canonical Entities. We describe the solution in form of a logical view as a Reference Architecture(1) that can be reused in independent of the implementation and technologies. The reference implementation utilized hl7:QUPA_IN010000UK01 message as input basic event.

Keywords:
Hospital information systems, Multihospital information systems, Automated pattern recognition, Service Oriented Architecture (SOA).

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Using electronic health records in a rural setting (Uganda)

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Quality and usage of medical data captured in rural settings typical of developing countries is an ongoing challenge. This research investigates the influence of continuous monitoring, evaluation and improvement of technical and non-technical aspects surrounding an electronic health records (EHR) system covering all critical hospital processes. Staff feedback and compliance with international EHR standards is used for continuous improvement, monitored through weekly meetings, integrated quality indicators and continuous observation. EHRs can be sustainably used in rural settings, if challenges encountered (technical and non-technical) are continuously addressed.

Keywords:
Computerized medical records systems, Quality assurance, Health care, Rural health services

Utilising Open Source Medical Systems to Develop a Virtual Health Care Referral System in Kenya

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Health systems in Kenya and Africa are faced with challenges of lack of access to technology for accurate diagnosis and treatment. The labor force does not meet demands of a growing population with increasing health needs. Health specialists are few and prefer to remain working in urban areas thus limiting their consultations from rural areas to a minimum. Referral systems are limited by delays in access to care because of a poor road network and poor infrastructure. This poster describes the use of an open source medical records system (OpenMRS) to develop a referral system in such a situation for pathology specimens. This involves actual system development and implementation. This is done remotely and clinicians with internet access can view slides and comment on result aiding in diagnosis and referral.

Keywords*:*
Health informatics, Virtual referral, Kenya, Pathology, OpenMRS

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NefroCard for Dialysis

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This work proposes the implementation of a system for management of patient data in nephrology and dialysis based on smart cards.

Keywords:
Smart cards, EHR, Data mining, Dialysis.

Assessing information integration among discharge summaries and case report forms in an Electronic Health Record

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Formerly in health systems, the case report forms (CRF) were held in parallel with the medical record without integration and with fragmentation of information. This increased the risk of losing important data. With the integration of these CRF with the medical record using the model of structured registry forms this problem seemed to be solved. Structured registry forms allows incorporating information quickly, systematic and with appropriate terminology controls. In the current health information system at Hospital Italiano de Buenos Aires, the information of the CRF are added to the electronic health record integrating the information. It was performed a retrospective, descriptive, cross-sectional study with review of secondary databases. We took two integrated processes (discharge summary registry and CRF registry), The objective of this study was to assess the contribution of these two different sources of data to the completeness of patient morbid history, using as indicators two highly prevalent comorbidities (arterial hypertension and diabetes) and acute clinical diagnosis (hyponatremia). We conclude that, information integration helps to maintain and/or complete the morbid burden of the patients.

Keywords:
Electronic health record, Case report forms, Hospital information system.

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The Clinical Information System response to an epidemic Influenza A H1N1

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In early June 2009, the influenza A H1N1 epidemic had been dispersed around Buenos Aires. The Hospital Italiano created a system for identification and monitoring patients in the H1N1 pandemic. This study evaluates the temporal correlation between the fully implementation of the system and the evolution of the epidemic of influenza A. Materials and Methods: The system was integrated to the HIS and consisted of: 1) A portal for use by members of the committee created for the pandemic. 2) A Web page for institutional recommendations. 3) A website for the community. 4) A system for updating of administrative and medical information and 5) A system for patients identification and follow up. This study evaluates the temporal correlation between the epidemic curve and hospital Information Systems (HIS) applications during the swine flu epidemic time period from May 24th to July 11th, 2009.

Keywords:
Health information system, Hospital information system, Influenza A H1N1

Using Electronic Medical Records to Measure Guideline Adherence in Low-Resource Settings

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The objectives of this study are to a) to evaluate the feasibility-of-use of structured outpatient EMR data to measure guideline adherence for treatment of AIDS in a low-resource setting, and b) to describe the characteristics of available EMR data that could be used to generate performance feedback for healthcare workers in a low-resource setting.

Keywords:
Electronic medical records, Audit and feedback, Clinical practice guidelines, Developing countries

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High-Level Query Language Support for EHRs Databases - Multi-step QBE Approach

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Large scale adoption of electronic healthcare applications requires semantic interoperability. The new proposals propose an advanced (multi-level) DBMS architecture for common repository services for health records of patients. These also require query interfaces at multiple levels and at the level of semi-skilled users. In this regard, a high level user interface for querying the new form of Electronic Health Records (EHRs) has been examined in this study. Its aim is to decrease user effort and communication ambiguities, and increase user friendliness.

Keywords:
Electronic health records (EHRs), Archetype-based EHRs, Query language support.

Personal Health Records functionalities reported in the literature

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The Personal Health Records are seen as a powerful tool to empower patient, but there is no standard or specification on the functionalities that these systems should contain or in better words what it is and what services should offer. Due to the versatility of the various options of what Personal Health Record should provide and based on this problem, the objective of this paper is to analyze the functions of the Personal Health Record that have been published. This paper explores all types of Personal Heath Records and reviews the published articles that explain the different features of them. Also gives a brief resume of the experience of having and implementing a Personal Health Record in the Hospital Italiano of Buenos Aires.

Keywords:
Personal health record, Functional model, Computerized medical records systems

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The Medical Ecosystem – Personalised Event-based Surveillance

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Early detection and early response is a strategy for circumventing devastating public health events. Traditional systems for identification of potential health threats can be used to recognise long-term trends, but mostly fail in urgent cases and are of less use for unknown diseases. In this paper, the Medical Ecosystem (M-Eco) is presented, which is a framework that integrates processing resources for unofficial sources such as user generated content and traditional sources for the early detection of emerging health threats. M-Eco will emphasize adaptivity and personalised filtering so that relevant signals can be detected for targeting the needs of public health officials who have to synthesize facts, assess risks and react to public health threats.

Keywords:
Epidemic intelligence, Medicine 2.0, Public health event detection

Automatic recognition of health problems through the movement analysis

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Due to aging of population, less people are capable of taking care for elderly. We propose an intelligent and ubiquitous care system for monitoring elderly in order to recognize a few of the most common and important health problems, observable through the movement. Movement is captured with wearable infra-red motion capture system, whose outputs are positions of tags at each moment. According to our approach positions of tags are transformed into specific features, relevant to the observed health problems, making the modeling of the health problems patterns more accurate. For the modeling, Support Vector Machines (SVM) machine learning algorithm is used, which classifies walking of user into walking with hemiplegia, Parkinson's disease, pain in the back, pain in the leg or nothing of those. The obtained classification accuracy is 85-95%. Also, the study of the impact of tag placement and noise level on the accuracy of detection of health problems is presented, as a guidance for future research.

Keywords:
Health problems recognition, Machine learning, Motion capture

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How to Build a Corporate e-Pain Form and Pain Terminology?

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Pain has become the universal disorder and around 10,000 pain patients are treated in Hong Kong (HK) public hospitals annually. Pain management data are along scattered or manually captured and difficult to be studied. This paper describes how to develop a patient-event based problem-oriented electronic pain management form to improve data collection, clinical documentation and information sharing through electronic patient record (ePR) system in Hong Kong. A working group with multi-disciplines is set up to address the various and complex requirements. The framework of the pain form is confined to 5 major components: 1) pain survey by patient, 2) pain site & intensity, 3) pain diagnosis, 4) psychological and functional assessments and 5) progress notes. 1,096 pain terms are modified from International Association for the Study of Pain (IASP) chronic pain terminologies and then incorporated into a standardized Hospital Authority Clinical Vocabulary Table (HACVT) for pain diagnosis.

Keywords:
Chronic, Pain, Terminology, Standards, Electronic form

Partnering health service managers to create software that makes a difference: support for HIV and TB programme management at district and facility level

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IN 2002 WHO [1] published a policy framework calling for close collaboration between HIV and TB programme structures and the integration of services in high prevalence settings such as South Africa. In response to this call a task team was established in Cape Town consisting of health service managers and facilitated by an academic institution (University of Western Cape) to develop an evaluation tool to promote integrated HIV/TB services and improve the quality of each programme component. Initially information was managed in Microsoft Excel but this proved to be inefficient, resulting in a need for a purpose-built software tool. Our objectives in this process were to incorporate the expressed information needs of our health service partners, to capture, warehouse and analyse the audit data and to produce automated and customisable reports. The end product was developed using Microsoft Access and Delphi and allows for rapid processing of audit data into useful information. It is generic allowing for widespread application and is compatible with existing health information systems.

Keywords:
HIV and TB programme evaluation, District health information management support, Access database

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A requirement engineering framework for the application of Web 2.0 technology in health care

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Web 2.0 is a concept that provides the potential of more interaction in the web environment. To develop a successful Web 2.0 project it is essential to obtain the needs of its end-users. Traditional requirement engineering models are mostly based on initial development of requirements and consequent continuous management of them, whereas recent advances in web programming has facilitated the opportunity to collect data for requirement management via a prototype platform designed for such systems. Health care systems have special demands which should be considered during the requirement engineering process. The integration of requirement engineering with prototype phase of system can ensure access to requirements of remote-users which are not easy accessible in some of telemedicine projects. This article proposes a step-by-step guide through a framework for this process.

Keywords:
Web 2.0, Requirement engineering, Health

A Co-evolution Design Approach for Implementing Telehealth Homecare Support Systems

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Telehealth homecare support systems are a rapidly growing area for eHealth, but their development has been hindered by their complex nature which makes it difficult to adopt standardized business processes or systems structure characteristics. Here we identify some of those difficulties and advocate the use of a co-evolution design approach. We show how this approach can be used to represent a generalised telehealth homecare support system, for direct implementation.

Keywords:
Systems analysis and design, Telemedicine, Workflow

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Integration and Information Sharing Needs in Cross-organizational Health Care

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Holistic patient care is a cross-organizational issue including information sharing between different health facilities via integrated information systems and other media. Designing the integration often starts with technical descriptions, neglecting broader scopes of study. In this study the results of two case studies, one in Finland and one in China, are combined. The cases were parts of larger technically driven projects, hosted by the local authorities, and aiming at developing computer-based information sharing between the organizations. In our case studies, the research objective was to explore the health professionals' information sharing needs with Activity Driven Needs Analysis and identify the spots for development in information sharing. The research group was partially the same in both cases. In this study, issues impacting the integration design decisions are categorized into four scopes. The results contribute to discussions preceding integration design decisions.

Keywords:

Systems analysis, Systems integration, Healthcare facilities, manpower, and services, Continuity of patient care

Impact of Potential Teratogenic Medication Alert System in the Emergency Department

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It has always been important to prescribe medications for reproductive-age women with considerations of teratogenic effects and potential fetal harm. To help healthcare providers make evidence-based decisions, we developed PLEASE (Pregnant Lady Early Access System for Embryo) in the Emergency Department. We could check whether reproductive-age women were pregnant or not, and also we could confirm whether medications were potential teratogenic or not by using PLEASE system at the appropriate time. After the implementation of PLEASE in the Emergency Department, the average prescription ratio of medications per person has fallen by 10 percent and the average prescription ratio of drugs defined by the FDA category X per person has fallen by 55 percent. Decision support alerts available at the exact moment of prescription for potential teratogenic medications for reproductive-age women could improve the safety in both patients and the healthcare providers by avoiding dangerous exposures to medications with fetal risks.

Keywords:

Alert, Decision support, Patient safety, Emergency, Pregnancy

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Development of a clinical information system in an Underserved Community Clinic: A Community Partnered Participatory Research Approach

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Community Partnered Participatory Research (CPPR) offers a research approach which addresses the barriers to Health Information Technology (HIT) use in medically underserved communities. It advocates for equal community and academic partnership. Here a team of academic informaticians and health care providers from a community health center, serving a mostly uninsured minority patient population, are together using a CPPR approach in order to develop a clinical information system) for improved diabetes disease management.

Keywords:
Clinical information system, Community clinic, Disease registry, Diabetes

An Integrated Architecture for a Customized CDS Service from Heterogeneous CDSSs

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Most clinical decision support systems (CDSS) are built-in subsystems or plug-in commercial software with low flexibility under many constrains. In this study, we proposed a platform-independent CDS service integrating two heterogeneous drug-drug interaction (DDI) CDSSs for a teaching hospital with established built-in Drug Utilization Review (DUR) system by integrating new rules and process of a general-purpose CDSS named 'U-brain': (1) data/service interface was designed between the CDSS and prescription system, (2) DDI decision making were performed by the inner inference engine of U-brain system and (3) an integrated DDI knowledge base was built in the U-brain system through reconstructions of two rule sets at hospital information system (HIS) site. From 4781 prescriptions of randomly selected 499 patients, the new CDS system reported 224 DDI alerts and showed 100% of sensitivity and specificity.

Keywords:
CDSS, DDI, CDSS Integration

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Collaboration in the real world as foundation for health robotics research for aged care

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In many countries longevity is the norm. Healthcare becomes more complex as people age [1], opening up an opportunity for assistive robotic technology. Developing a healthcare robot requires input from a broad range of disciplines and skills – medical, engineering, management, psychology, computer science and health informatics. Interviews, observation and photographs were used to gain insight into how medicines are managed by residents and care givers in an aged care facility. Multiple perspectives were used to produce a medicines management process and a description of its context. Several worldviews were 'bridged' in this research resulting in an alignment of the research project team's efforts in preparing a robot that supports medication management.

Keywords:

Robotics, ehealth, Self-help devices, Medication therapy management, Chronic disease, Geriatrics.

EpiBasket: a prototype information system to support the epidemiological investigation of an emerging infectious disease outbreak

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The epidemiological investigation of an emerging infectious disease outbreak requires a series of different designs, protocols and questionnaires. The de novo development of these protocols and questionnaires deployed upon outbreak alert results in a substantial detrimental delay for the understanding and control of the epidemic. We propose a new web application for facilitating the outbreak investigation. In this prototype of information system, the user is guided to select variables of interest in a proposed dataset based on the analysis of the available literature on previous similar outbreaks, and afterwards, the system provides ready-to-use forms to be used for the data collection of the desired epidemiological investigation. This new tool can save time, standardize the data collected during an outbreak, and facilitate collaboration at a national and international level.

Keywords:

Information systems, Emerging communicable diseases, Disease outbreaks, Epidemiologic studies.

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Patient Trajectories and the Coordination of Work

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The concept of 'patient trajectory' has been proposed in order to address the actual flow of events in clinical reality, as a counterpart of concepts such as 'plan', 'guideline' and 'protocol'. When using the patient trajectory concept for designing computer support for coordination of work, the complexity and ambiguity of the concept is seldom questioned. The patient trajectory is frequently presented as merely 'the sequence of events', a rather *uniform object without much internal structure*. This is less problematic when the focus is on supporting inter-trajectory coordination (coordination of different trajectories), as *coordinating them comes down to balancing overlap in time and pooled interdependencies with respect to the use of shared recourses*. However, it breaks down when the focus is on intra-trajectory coordination (coordination of work within a trajectory) as different actors require different representations of the patient trajectories.

Keywords:
Patient trajectory, Coordination, Design, Awareness.

Development of a Customised Free and Open Source Database for Routinely Assessing Waiting Times of Patients at Health Facilities

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Long waiting times is one of the commonest complaints of people accessing public health care services. Hence decreasing excessively long waiting times would be a highly visible real and perceived improvement in quality of care of public health care service. In order to achieve this one would have to measure the extent of the waiting times, the mix of causes of high waiting times and develop solutions that effectively address the causes of the high waiting time. The difficulties encountered are developing a simple yet robust and standardised methodology, managing large volumes of data, cleaning the data in a standardised manner and producing standardised reports which allow causes of high waiting times to be easily identified. An action research approach to develop a methodology to achieve this, and a database which facilitates easy handling and standardised cleaning of data and produces automated reports, was employed. The database went through several cycles of appraisal and improvement until finally a stable and user-friendly database which met all the above objectives was developed.

Keywords:
Waiting time, Database, User-friendly, Standardised cleaning, Automated reports, Open source.

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What if "business process" is the wrong metaphor? Exploring the potential of Value Based Requirements Engineering for clinical software

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Low satisfaction of clinical software users suggests to challenge the prevailing "business process" metaphor underlying most present clinical software. We outline why Value Based Requirements Engineering, a new direction in software engineering, has the potential for better accepted software and how an empirical approach can lay the foundations for exploring that direction. Relations between value inventories and software properties are target of the present project phase.

Keywords:
Clinical software, Value based requirements engineering

Re-engineering of Prescribing Process in Computerized Physician Ordering System

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In 2007, the director general of the Health Policy Bureau of Japan issued a government notice to promote role-sharing by healthcare providers. The notice recommended that co-medicals such as nurses, and clerks should expand their roles to enable sharing of roles between them and physicians. For example, nurses would be authorized to "adjust amount of medication" and clerks to "write prescriptions" under physician's guidance. We aimed to discuss how to redesign the business process, especially the prescribing process, rather than how to share physicians' work with co-medicals. However, arguments in this topic are rarely based on business process reengineering. The purpose of this study is to clarify and analyze the current prescribing process and suggest a solution that will promote sharing of roles.

Keywords:
Medical order entry systems, Electronic prescribing, Medical secretaries

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Validation of a knowledge base for advanced CPOE systems based on test cases

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Medication errors and resulting Adverse Drug Events (ADEs) are an important issue of global healthcare, and CPOE systems are promoted to prevent them. Within the European PSIP project (http://www.psip-project.eu), contextualized decision support modules being part of CPOE systems and aiming at preventing ADEs are being developed. The objective of this paper is to describe the methodology used for their validation and to present first results.

Keywords:
Validation studies, Medical order entry systems, Medication error, Adverse drug event, Clinical decision support

Creating Usable Health IT for Physicians - The Smart Point of Care system

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The major objective of health IT should be to subtract work, not to add work or make our work harder. Most health professionals do not use available health IT systems because current systems fail to offer value. The recent National Academy of Science study concluded that the current health IT efforts may even set back the vision of 21st century health care [2]. Here we describe features of a point of care architecture that supports patient care.

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Implementation and Evaluation of an On-line Prescription Check System using a Database of Drug Indications

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Medical incidents related the drugs, which have similar names but different effects, are occasionally reported in Japan. Thus we develop an on-line prescription check system using a database of drug indications. After implementation, we surveyed the rate of alerts and physicians' responses. 38,780 prescriptions were checked by our system in 1 month. The rate of alerts is 5% of total prescriptions and PPV is 65%.. 44 prescriptions were revised or canceled by physicians after alerting. It may prevent medication error. We concluded that On-line prescription check system using a database of drug indications is potentially effective in prevention of medication error.

Keywords:
Clinical decision support systems, Medical order entry systems, Medication errors, Prescriptions, Drug

Information security assessment tool for digital hospitals

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Information technology security is usually a complex issue, involving international standards to allow public recognition. In healthcare, it gains complexity due the complex nature of operations and also dues country regulations that demand additional controls and accountability for the organizations Information Security Management System. But since the use of Electronic Medical Records and Hospital Information Systems is increasing, the organizations are pushed to face this challenge. This poster shows that we have developed a Web based tool to assess the current status of digital healthcare information security management in a hospital comparing to the recognized standards considering the business processes for confidentiality, integrity, availability and also the software features to provide protection of medical data. With this tool, hospital's IT (Information Technology) managers have a first report to start developing it's Information Security Management System (ISMS) or to check de adherence of the existing one to the standards on this subject.

Keywords:
Health informatics, Information management, Health information security

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An individualized web-based information supply system for home oxygen therapy patients

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The number of patients who require home oxygen therapy (HOT) is increasing in JAPAN. According to patient static data, there are large numbers of HOT patients in the patient who receives medical treatment at home. It is easy for them to repeat hospitalization and release. It is thought that the reason for one of the causes is that knowledge and coping process have not adhered to the body so that it is possible to correspond to an acute exacerbation appropriately. There are many systems that provide information to HOT patients, but they do not provide suitable information for patient's needs. The purpose of this study is to design an information supply system tailored to meet the specific needs of patients based on their individual conditions. From the perspective of evidence-based medicine, we built an information infrastructure to provide relevant information corresponding to data on individual patients. The system provides information in 11 categories and immediately displays suitable coping procedures for individual situations. The system also calculates Body Mass Index (BMI) and the quantity of oxygen they require, as well as determining the degree of urgency and the coping procedure.

Keywords:

Individualized information, Home oxygen therapy patients, Evidence-based medicine, Electronic health record, Personal health record

An Intelligent Platform for Personalized Remote Monitoring of the CIED Patients

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Over the last decade, we have witnessed exponential growth in the number of Cardiovascular Implantable Electronic Devices (CIEDs) and their electronic and software complexity widening their function and application. However, due to limited processing capabilities restricted by size and power considerations, CIEDs need to be supported by standalone software running on data centers for remote monitoring. The objective of this work is to introduce the high level architecture of iCARDEA, an intelligent platform to semi-automate the follow-up of CIED patients through context-aware adaptable computer interpretable guideline models. CIED data and legacy Electronic Health Record (EHR) data are exposed through standard interfaces so that information about a patient's medical history can be used in the clinical follow-up workflow. An adaptive care planner employing clinical guidelines automates risk assessment generating alarms as appropriate. CIED patients are empowered with integrated Personal Health Records (PHRs) that enable informed and responsible participation in their health care and education. In this way, they may feel more secure and in control of their life.

Keywords:

Remote monitoring, Interoperability, EHR, PHR, CIED

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Scanning strategy for transition to an Electronic Health Record

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The Hospital Italiano of Buenos Aires (HIBA) is a non-profit health care academic center. In 1998 HIBA began the implementation of a Healthcare Information System (HIS). Currently the inpatient electronic health record allows viewing the patient administrative data, order for further studies and visualize their results, referral request and display information from the patient's outpatient record and the scanned notes relating to the attention of the health team that are still on paper. The digitization project was initiated as a transition strategy for the inpatient electronic record. An Indexing Model was developed in order to result in a full migration to an electronic record. The aim of this paper is to describe our experience in this project, the creation of an ad hoc ontology of documents and stress the need for a multidisciplinary team working on projects of this magnitude.

Keywords:
Terminology, Nomenclature, Hospital information systems, Abstracting and indexing, Information storage and retrieval.

Ruby implementation of the openEHR specifications

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The openEHR project has developed the specification for future-proof interoperable electronic health record (EHR) systems. This project provides the specification and implementation on which the ISO/CEN 13606 standard is based. The implementation has been formally described in Eiffel, C# and Java, but not in scripting languages. A team from Japan has implemented this specification using the Ruby language for the efficient development of new healthcare computing environments and for investigation of the universal applicability of the openEHR specification.

Keywords:
Electronic health records, openEHR, ISO/CEN 13606, Ruby, Open-source software.

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C. E-Health Infrastructures

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Application Service Provider System for Healthcare with Data Mining Function

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An application service provider system for healthcare with a data mining function has been developed. The system provides computer-based healthcare services over the Internet to advise customers on how to improve their lifestyles on the basis of association rules relevant to their health and lifestyle data. These association rules can be automatically extracted using a data mining technology on the server computer on the basis of customers' stored time-series health and lifestyle data that are transferred through their mobile phones or PCs. The healthcare adviser can send comments made up of the rules to the customers over the Internet.

Keywords:
ASP system for healthcare, Data-mining, Time-series data.

Deriving User Semantics from XML-Based Biomedical Warehouse

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Maintaining a data and knowledge warehouse, built on a rich data model, is a major challenge to achieving semantic interoperability in the field of biomedical informatics. Promoting the adoption of worldwide accepted information standards, along with common terminologies, is a suitable path to achieving this goal. Once data from diverse data sources is integrated into the warehouse, the semantic richness of the warehouse model enables the sharing of data among information silos. However, the same richness and complexity of the data model poses a challenge for data consumers such as healthcare applications and analytics. These consumers eventually use a much more focused data model that is tailored to their semantics when accessing the underlying data. We describe a unique approach for addressing the tension between the wide warehouse model and the data consumer model, by introducing a framework for generating data marts, derived by the consumer's model and terminology.

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The Development of Telemedicine in China and Our Recent Achievement

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In this article, we reveal that telemedicine is developing very fast in our country, and we show our recent achievement in this paper, which is called Regional Collaborative Medical Service (RCMS).

Keywords:
Telemedicine, RCMS, China, Medinfo 2010.

Feasibility of Integrating Dental School Electronic Health Record Data to Facilitate Oral Health Research

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There is a critical need or high quality data sources that can enable research, evidenced-based dentistry and improve patient care. In this project we determined the feasibility of integrating data from 3 dental school EHRs. The results suggest that dental EHR data may be a viable source for creating a large oral health dataset suitable for research.

Keywords:
Dental informatics, Data integrations, Electronic health records

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Development of a Teleradiology web portal for the exchange of medical data using DICOM e-mail

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The Teleradiology/Emergency Medicine Network (TEN) in the Metropolitan Rhine-Neckar Region (Germany) enables the exchange of medical data [1]. However, the inclusion is difficult for technical and financial reasons for some partners like general practitioners (GPs). For that reason a web portal for the exchange of medical data within the TEN is under development. The DICOM e-mail standard [2] offers the base for the data exchange. The portal itself will be developed by Java Server Pages (JSPs) and Java Servlets. The data will be saved in a MySQL-database and a LDAP-server. The DocCheck service will be also integrated into the web portal. The concept has been finished and the portal is under development. The concept foresees that the web server is located in the demilitarized zone (DMZ) of the Heidelberg University Hospital and the database as well as the LDAP-server are running within the clinical network. The client server architecture will be realised by Servlets and JSPs. The portal offers the possibility to use the TEN for free.

Keywords:
Teleradiology, DICOM e-mail, Telemedicine, Portals

Registers for networked medical research in Germany: Situation and prospects

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Disease specific registers are important means of networked medical research. A study of the Telematikplattform für Medizinische Forschungsnetze (TMF), an umbrella organization of research networks in Germany, revealed a typical setting of "research registers". Based on this study, the TMF compiled recommendations concerning the organizational architecture as well as the development of research registers. Research registers mainly support clinical research through the generation of hypotheses, the identification of eligible patients, and the interfacing of clinical trials. Best practice in register organization differentiates five levels: executive, operations, IT-management, software, hardware. Development and organization oriented to best practice are a prerequisite for a successful and sustainable implementation of registers.

Keywords:
Competence networks, Documentation, Registers

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Using ICT & Electronics Technologies for an Effective Chronic Disease Management Model in Latin America

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Policy makers across the world increasingly recognize that chronic disease management (CDM), is one of the most important challenges that health systems face. As a consequence, Telehealth Remote Monitoring emerges as a new e-enablement technology to further improve treatment and lower costs. Based on an integrated platform of microelectronic devices, telecommunication carriers and IT clinical systems, in previous uncontrolled patients treated with oral medications in a clinical practice setting were monitored. First results showed a good level of acceptance and a significant improvement of their physiological parameters.

Keywords:
Telehealth, Telemonitoring, Chronic diseases

Improvement of Patients' Privacy and Security in Seoul National University Hospital EMR system

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As the EMR (Electronic Medical Record) system has been utilized, privacy and security of patient information has been highlighted as one of the most important issues in the EMR system. Therefore, Seoul National University Hospital (SNUH) surveyed current weak points in need of improvement in the SNUH EMR system, and made improvements to EMR in four aspects, including medical records access control, hospitalization privacy, privacy & security guidelines, and user policies. Consequently, SNUH received ISO 27001 information security management system certification for its EMR system.

Keywords:
Patient data privacy, Data security

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Study on a Safety Management Method and Location Detection using Centralized Controlled Wireless LAN System

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Recently medical information systems at patient's bed side are well-practiced using handy terminals or notebook computers via wireless network. For the stable operation of these wireless systems, network administrators need to keep the wireless network system healthy. In the management operation, the main task is to confirm the absence of unauthorized accesses via uncontrolled computers and the absence of unauthorized wireless devices that effects the operation of medical information systems. For the reduction of risks by such unauthorized devices, it is useful to establish an effective monitoring method of unauthorized devices on the wireless network.

Keywords:
Safety management, Wireless LAN, Location detection

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Surveillance of ENT diseases in children during winter

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Acute ear, nose, and throat (ENT) diseases in children mainly occur during the winter season and are the main sources of consultation. These pathologies are very frequent but their epidemiological surveillance is almost inexistent. In this context, we set up a national observatory. A cumulative number of 369,258 consultations was collected during the last 2 winter seasons. The incidence rate of the observed diseases was estimated. Time-space results were provided online by interactive and direct access, or by newsletters including weekly national and regional reports. This study demonstrates the feasibility of setting up each winter such a surveillance system, based on a new generator of a real time platform of surveillance that we developed. It is a support for better understanding winter spread of ENT diseases in children as well as a tool for public health decision making.

Keywords:
Communicable diseases, ENT diseases, Information, Public health, Informatics.

D. Health Informatics Evaluation

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Analysis of the Use of Social Media for Adequacy Evaluation of Health Related Websites Based on Health on Net Code

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The use of Web 2.0 technologies has increased. The use of these technologies for health related websites adequacy criteria is extremely relevant. This study shows that 90% of participants think that health related websites content assessment is important and 95% believe that Web 2.0 technologies are good to perform these evaluations. It is extremely important to spread through social media the ratings of health related content websites. This study is an evaluation of the use of Web 2.0 to verify the adequacy of health related websites according to criteria based on the Health On Net Code (HON).

Keywords:
Internet, Social network, Web 2.0, Technology assessment.

Assessing the attitude of healthcare professionals towards the use of a mandatory Hospital Information system: An empirical investigation

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The Unified Theory of Acceptance and Use of Technology (UTAUT) as proposed by Venkatesh et al. was applied, together with other research works in order to empirically assess the acceptance of technology in one of the largest and technology-aware hospitals in Greece. Forty nine participants provided feedback regarding the mandatory information system. Data analysis was conducted using a structural equation model, specifically partial least squares. Results indicate the important effect of facilitating conditions to performance and effort expectancy along with the very strong effect of performance expectancy to attitude towards use of technology and behavioral intention.

Keywords*:*
Technology assessment, Evaluation, Hospital information system

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Computerized Physician Order Entry System: Physicians' Comments and Satisfaction Survey in Taiwan

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This survey includes interface design, operational functions, effectiveness of usage, interface usability and satisfaction with CPOE (computerized physician order entry).

Keywords:
Computerized physician order entry, Usability, Satisfaction, Interface design

User Perception of the Effect of the e-Chasqui Laboratory Information System on Patient Care, Reducing Lost Results, and Nation-Wide Impact

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There are limited data on the effects of laboratory information systems in resource-poor settings. The e-Chasqui laboratory information system was implemented in 12 of 34 health centers in two health districts of Lima, Peru. 3 years after implementation, personnel from the 34 health centers were given a written survey. The overall response rate was 93%. Though e-Chasqui users were more satisfied with the paper system than control HC users (p=0.005), they still preferred e-Chasqui (p=0.009). 70% of clinical users reported at least 1 in 10 patients expressing an unsolicited, positive opinion. A majority of those interviewed were missing at least 10% of results, while 70% of e-Chasqui users found results in e-Chasqui that were not on paper. All e-Chasqui users thought implementing e-Chasqui nation-wide would improve patient care.

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Standardized terminology using SNOMED CT

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The needs for communicating clinical data between different health care practitioners are increasing, within as well as across national borders. To secure patient safety it is important that the context and content are not lost in the communication process. To explore the possibilities of SNOMED CT as a reference terminology for the Swedish health care system we compared the concepts and terms in a standard care plan for revision of hip replacement with concepts and terms in SNOMED CT. 82 % of the concepts of the standard care plan had a complete match in SNOMED CT. This study has shown that the use of SNOMED CT could be helpful for the retrieval and reuse of clinical data across organizational boundaries.

Keywords:
Terminology, SNOMED CT, Mapping, Standard care plans

Evaluation of medical safety in an e-Health information system through incident reports management system

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A new e-Health information system was introduced to Nagasaki University Hospital in June 2008. In this paper, the effect of medical safety by introducing new system is evaluated through incident reports management system. Although total number of incident reports increased after the new incident report management system was started in 2007, the number of reports with keywords of medication and drug injection decreased from 413 (21.2%) to 357 (17.0%) ($p<0.001$) and from 289 (14.8%) to 277 (13.2%) ($p=0.132$) after e-Health information system was updated respectively. The number of reports with more severe level of over "3a" which had keywords of medication or drug injection decreased, too. These results show the new e-Health information system was effective for medical safety at least on the medication and drug injection process.

Keywords:
Incident report, EHR, Medical safety

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Evaluation of migration to EHR with assistance of Document Imaging system

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Currently many healthcare institutions try aggressive EHR introduction, it is far from achieving the complete paper-less stage. Document imaging system is useful for termination of paper-based clinical document. In this study we have developed the document imaging system cooperated with EHR to compensate the weakness of EHR. Analyze of document image system's log shows that EHR still has a critical defect in the user interface so that some physicians avoid adapting to routine usage of EHR. The result suggests that the harmonization of clinical workflow with paper document is the critical component of successful EHR introduction.

Keywords:
Document imaging system, EHR, Clinical document

A Comparison between the EMR Adoption Model[SM] and CMMI®

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This study analyzes similarities and differences between the EMR Adoption Model[SM] with the Capability Maturity Model Integration for Services (CMMI), which is a worldwide standard for process and quality improvement. EMR Adoption Model is a static standard for evaluating hospital's adoption of electronic medical record system. CMMI is not only is a standard, but it also a framework to guide organizations how to improve their levels within the framework.

Keywords:
EMR adoption model, CMMI.

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Mobility in Intensive Care: Pre-Implementation Evaluation

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Mobile point-of-care solutions could help improve health care in areas where technology-based, high volume data are generated as in intensive care units, by enhancing possible ways to retrieve information anywhere and anytime. The purpose of this study is to explore clinicians' perceptions regarding mobile technology prior to implementation of mobile technology systems in a university hospital intensive care unit. Data about physicians' and nurses' perceptions regarding mobile technology were gathered by the questionnaire developed by the researchers. The participants are 27 physicians and 15 nurses. More than 90% of respondents said that computers had a potential to provide large benefits for clinical care, also 75% of respondents thought that use of computers would be enhanced with mobile technologies in the ward. Most doctors and nurses have positive opinion about usefulness and ease of use of wireless technology.

Keywords:
Mobile technologies, Ease of use, Usefulness, Intensive care

Evaluating the Use of an Electronic Dispensing Program for Antiretroviral Treatment at Two Public Health Facilities in KwaZulu-Natal, South Africa

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Reproductive Health and HIV Research Unit (RHRU) has implemented iDART, a dispensing software program at two public health facilities in KwaZulu Natal. This electronic dispensing system for capturing patient information of ART clients was seen as improving drug dispensation time as well improving reporting and the tracking of patients. An operational tool was developed to evaluate the utilization of the program and determine its effectiveness. As a result of the software, sites saw an increase in drug dispensation, health care workers proficiency in using an electronic patient management system and several other system improvements were noted.

Keywords:
Electronic dispensing system, Patient information, Evaluate

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Routine use of OncoDoc2, a guideline-based decision support system for breast cancer: categorization and quantification of cases of non adherence with guidelines

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Despite "multidisciplinary staff meetings" (MSMs) and the publication of clinical practice guidelines (CPGs), actual cancer management may still vary from CPG recommendations. Clinical decision support systems (CDSSs) are considered appropriate tools to promote adherence with CPGs. At the Tenon hospital (Paris, France), breast cancer MSMs occur once a week and local guidelines (CancerEst) were developed for breast cancer management. OncoDoc2 is a therapeutic CDSS that implements CancerEst CPGs. In 2005-2006, a before/after intervention study has been performed with OncoDoc2 in Tenon's MSMs. The adherence rate of MSM decisions with CancerEst CPGs significantly increased from 79.2% to 93.4% when the system was used. Since then, OncoDoc2 has been routinely used in a quality management process. We propose a categorization of non-adherent decisions.

Keywords:

Clinical decision support system, Quality assurance, Health care, Guideline adherence, Breast cancer management.

Physician's Usage of Mobile Clinical Applications in a Community Hospital

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We analyze twenty-two months of usage data of mobile clinical applications by approximately 200 physicians in a community hospital in southwestern Pennsylvania in the United States. Applying a novel, semi-parametric, group-based, statistical methodology, we obtain developmental trajectories depicting how usage evolves from initial 'trial' adoption to long-term institutionalization. The analysis of trajectories of physician usage patterns indicate that physicians who began using the system within the first three months of deployment were heavier and more stable, routine users. Voluntariness of use and the availability of multiple channels of access to clinical information may also have impacted adoption of the technology.

Keywords:

Mobile, PDA, Developmental trajectory analysis

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A Scientometric Study of Medinfo Conferences Meeting Abstracts

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Medinfo conference as the main presentation point of research done in the filed of health and biomedical informatics has been setup first in 1974. In the present research, we studied all the meeting abstracts of Medinfo indexed in the ISI Web of Science and evaluated them using scientometric indicators. The results showed that USA, Japan, France, Germany and England ranked accordingly based on the most ISI indexed abstracts of Medinfo conferences. The citation per paper average of Medinfo abstracts is 1.1 and its h-index is 14 which show the Medinfo abstracts usage and validity.

Keywords:
Scientometric indicators, Medinfo conference, Citation analysis.

Development and application of the RFID system for patient safety

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Radio Frequency Identification (RFID) has been considered as an innovative technology to advance patient safety in the hospital. In order to improve medical accidents related to information mishandling of surgical patients, blood transfusions, and anti-cancer medication, we developed an RFID system that can be used in general hospitals. Our survey on the RFID system with 63 nurses and 20 patients who actually experienced the RFID system revealed a high level of satisfaction in terms of reinforcing the patient's safety in medical environments. Nurses surveyed had intention to utilize the RFID system for managing hospital assets and tracking patients later. For the full scale application of RFID system in hospitals, it is important to ensure information system stability, including the network system, and quantitative analysis of the effects of the system.

Keywords:
RFID system, Patient safety, Medical error.

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Do Electronic Information Systems Facilitate Errors in Medication Management?

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Human error is common when information management is conducted manually. Sometimes errors correct themselves; however, in the hospital context, if they lead to adverse drug events (ADEs), the consequences can be serious. This retrospective study aimed to identify types of ADEs related to information management via electronic information systems. The research questions were as follows: 1) What kind of ADEs have occurred? 2) What are the causes of these errors? The results of this study confirm previous studies indicating that accurate patient data has a major role in safe practices.

Keywords:
Information management, Medical errors, Information systems

Evaluation of innovative health IT applications: importance of usability studies in hospital settings

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This poster addresses the problem of the necessary evaluation of innovative Information Technology applications to ensure their safe transfer to the actual care providing environment. It focuses more specifically on the usability dimensions of such an evaluation. It describes at a national institutional level the installation of new centers for innovative technologies in charge of designing and applying proper evaluation methodologies to health IT applications.

Keywords:
Usability, Medical informatics applications, Evaluation, Certification

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Validity Insurance of Telemetric ECG Measurements

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The insurance of measurement validity has a primary importance in home care measurements. In this paper the possible impact of ECG electrode misplacements and the different body positions on the signals transmitted has been analyzed, based on a large database of body surface potential maps. According to our results in the course of self-measurements considerable, diagnostically meaningful errors might be expected in the precordial leads, which might be even emphasized if the chest position of the patient is not defined properly.

Keywords:

Home care, ECG, Electrode displacement error, Positional differences

WTC Medical Monitoring and Treatment Program Clinical Studies Data Management System: A Usability Evaluation

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This poster describes a process for analyzing and recommending improvements for the WTC Medical Monitoring and Treatment Program regarding its clinical and operational workflow as well as the user interface of its data management system, a customized version of TrialDB. Heuristic evaluation and workflow analysis were performed to identify problems and improve the overall system. Two biomedical informatics researchers used seventy-four heuristic evaluation questions categorized in ten principles in order to understand the capability features of the TrialDB user interface. Workflow analysis was undertaken with discussions with the Deputy Director and a system architect of the WTC Medical Monitoring and Treatment Program to determine the redesign of data collection procedures. Overall, the evaluation methods were instrumental in identifying the problems that need to be resolved and recommending features that need to be integrated into the system, and the methods of analysis are applicable to the evaluation of other HIT systems.

Keywords:

Usability engineering, Human factor engineering, User experiences, Heuristic evaluation, Workflow analysis, Clinical studies data management system, Medical monitoring and treatment program, World Trade Center.

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Quality of human-computer-interaction – Results of a national usability survey of Hospital-IT in Germany

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Due to the increasing functionality of medical informatics it is hard to imagine day to day work in hospitals without IT support. Therefore, the design of dialogues between humans and information systems is one of the most important issues to enable IT in health care. This survey presents an analysis of the current quality level of human-computer interaction of healthcare-IT in German hospitals.

Keywords:
Hospital Information Systems, Usability, Human-computer interaction, Human factors of software systems

Do machine translations increase the usefulness of summaries of MEDLINE abstracts? An interface evaluation with medical students and physicians in Peru

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Searching and reading MEDLINE citations and abstracts can be challenging for non-native English speakers. The objective of this paper is to evaluate the usefulness of an interface that incorporated an automatic machine translation of MEDLINE citations, short "bottom line" summaries and abstract from English into Spanish. Twenty one participants (5 physicians and 16 medical students) from a Peruvian medical school evaluated the perceived usefulness of the translations. Overall, Spanish translations were rated as "useful" to "very useful" (3.7/5, mode=4). We also found that more than a half of the participants (62%) and most of the suggestions were related to interface improvement (33.3%) already underway. Improving the search boxes and the translation were also suggested. A usability evaluation study with more participants and with special measurement instruments designed for web interfaces is planned.

Keywords:
MEDLINE, PubMed, TBL, Machine translation, Interface, Spanish, Peru.

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Impact of Alert Specifications on Clinician Adherence: a Systematic Review

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More than half of the alerts integrated into health care information systems are overridden by clinicians. A systematic review on studies evaluating alert specifications, such as alert type, design and message content, and their impact on clinicians' alert adherence was done. Use of colors and icons in alerts of varying severity and the presentation of alerts in an interruptive fashion based on their severity increased clinicians' adherence. Lack of clinical importance and correctness of alert information resulted in alert non-adherence. The amount of evidence generated on the impact of alert specifications on clinicians' alert adherence is limited. However, this review shows that a relation is apparent between alert specifications and clinicians' alert adherence.

Keywords:
User-computer interface, Hospital information systems, Alert, Reminder systems, Clinicians adherence

A Scientometric Study on Health and Medical Informatics Literature

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Few researches evaluated medical and health informatics literature. All published papers on medical or health informatics indexed by ISI Web of Science databases including Science Citation Index Expanded, Social Sciences Citation Index, Conference Proceedings Citation Index- Science, and Conference Proceedings Citation Index- Social Science & Humanities from the beginning of 1985 until the end of 2008 were retrieved. The results indicated that total 3123 papers on medical or health informatics have been indexed by ISI Web of Sciences which received 16630 citations between 1990 and 2008. The average citations per year were about 5 times. The language of the most papers was English. USA, England and Germany respectively published more papers than other countries. According to the results, running more researches in this field seems to be necessary.

Keywords:
Health informatics, Medical informatics, Scientometric indicators, Health information management.

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Comparing Two Protocols for Head and Neck Cancer: a Cost-Effectiveness Analysis

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A decision analytic model has been developed to perform a cost-effectiveness analysis on the addition of docetaxel to the standard treatment for Head and Neck Cancer (HNC). The point of view of the analysis is the Italian National Healthcare Service (NHS). The new therapeutic opportunity, while more or less doubling the cost, has been shown to significantly improve survival in two recent clinical trials. They evaluated the use of docetaxel in two slightly different protocols, i.e. ChemoTherapy + RadioTherapy (CT+RT) and ChemoTherapy + ChemoRadioTherapy (CT+CRT), respectively. To represent the disease progress, Markov processes have been included in the model. Data have been derived mostly from the two trials and, where not available, from literature and expert panel. Adding docetaxel is cost-effective leading to a cost of € 12,880 and € 8,820 per life year saved for the two protocols, respectively. The robustness of the results has been tested with a probabilistic sensitivity analysis.

Keywords:
Cost-effectiveness, Markov model, Head and neck cancer.

Obesity and Web 2.0: Psycho-educative Groups

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We present a pilot research, that is in progress, by the Maugeri Foundation of Pavia, in collaboration with Department of Psychology of the University of Pavia. The purpose of this study is to investigate the effectiveness of applying the Information and Communication Technology (ICT) in the treatment of patients with obesity. In particular we want to compare the effects that two different way of treatments product on the patients: on one hand psycho-educational group face-to-face and, on the other hand, the association between a psycho-educational group face-to-face with psycho-educational group on line.

Keywords:
Web 2.0, Obesity, Adherence evaluation.

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Transfer In and Out of Stroke Care Units: A Preliminary Study Using Bayesian Networks

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Some reports have questioned the cost effectiveness of SCUs. Therefore the focus was to compare episodes treated by teaching hospitals with and without SCUs that experience ongoing care or transfers. The transfer-patients are often high users of the system; with an associated high cost. As a proof-of-concept Bayesian Network (BN) was applied to routinely collected public-hospital administrative data. The results demonstrated that SCUs mainly treat Subarachnoid haemorrhages whereas the non-SCUs the Cerebral infarctions. There were differences in the mix of admission types, care types, the hospitals transferred from and transfer destinations. Although the teaching hospitals with SCUs achieved shorter LOS, they treated younger patients with lower overall complexity than non-SCU teaching hospitals. This preliminary study demonstrated the value of BN to explore in an ad hoc manner the caseload, trajectory and outcomes recorded in hospital-administrative data. Studies such as this are important for gathering information on the current practices and creating opportunities for benchmarking and improving care.

Keywords:
Health services research, Bayesian networks, Administrative data, Stroke units.

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E. Education and Building Health Informatics Capacity

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Development and implementation of the Cyber Education Program for Quality management and patient safety

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As the importance of quality management in a hospital is increasing continuously, Seoul National University Hospital tried to find an effective way to educate staffs for quality improvement and patient safety. The web-based training program provided meaningful results. The objectives of the project are to develop education programs for quality improvement and patient safety for a hospital and to carry out the programs to all staffs in the hospital. The project was developed in three steps which are 1) writing manuscripts, 2) making storyboards and 3) programming. By and large, four programs were completed from the project. The researchers implement the project four times hospital-wide. More specific programs will be developed considering various types of jobs and roles. In addition, a way to evaluate the effectiveness and efficiency will be figured out in further research.

Keywords:

Healthcare quality assurance, Risk management, Computer-assisted instruction, Staff development, Education

Medical education in the third millennium: interactive 2D and 3D computer simulations

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We present different on-line interactive multimedia resources that have been developed from original two- and three-dimensional multiscale simulators born out of mathematical qualitative and quantitative models. The increasing content of this freely accessible virtual campus will allow medical students to gain a complete understanding and an integrative view of many physiopathological mechanisms.

Keywords:

Computer simulation, Physiology, Virtual reality.

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Impact of Computer-Assisted Education about Psychiatric Stigma on Medical Students

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Stigma of psychiatric disorders among medical students may both preclude them from using mental health services and may affect their future professional lives. We assessed the impact of computer-assisted educational program about psychiatric stigma in 51 medical students attending large state university in Russia. The study results showed significant impact of the educational program on psychiatric stigma and knowledge about psychiatric disorders and stigma. The anti-stigma program was very well accepted by students. We concluded that computer-assisted anti-stigma interventions are useful and effective in medical students.

Keywords:
Psychiatric stigma, Medical students, Computer-assisted education.

Factors Related to Learning Outcomes in New Healthcare Staff with the e-learning Orientation Program

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The purpose of this study was to explore the factors associated with learning outcomes in new healthcare staff receiving the e-learning orientation program. The data analysis contained 154 valid questionnaires, and 13 staff s' interview contents. New staff in this study had a positive attitude toward e-learning system. Perceived ease of use and perceived usefulness were critical factors for new staffs' satisfaction and continued intention to use the orientation program. In addition, four major themes emerged regarding the e-learning program: acknowledgement of the training program, benefit of e-learning, usability concern, and content suggestion. Therefore, understanding users' barriers and difficulties could improve learning outcome and further orientation program design.

Keywords:
E-learning, New healthcare staff, Orientation programs, Learning outcome, Users' experiences.

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Web 2.0 based Educational Intervention for Adolescents with Type 1 Diabetes: Design of a randomized controlled Trial

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Web 2.0 can be a very good technology to build a framework for diabetes education and consequent evaluation of this education. Objective - The objective of the study is to evaluate the effectiveness of a web 2.0-based educational intervention, on glycemic control in adolescents with type 1 diabetes. Methods - A randomized controlled trial design will be used. 300 adolescents diagnosed with type 1 diabetes will be randomized into 3 groups: Web 2.0-based Intervention; Web Intervention and Control group. The evaluation of the educational program will be given by the following variables and instruments: HbA1c (Test Lab); Social Support, Resilience, Quality of Life and Knowledge about diabetes (Questionnaires). Discussion - Web 2.0 applications are emerging with educational potential. Following this trend, the present study design provides an innovative contribution to integrate and evaluate the web 2.0 resources into an educational intervention for adolescents diagnosed with diabetes.

Keywords:
Internet, Web 2.0, Web-based intervention, Diabetes, Resilience, Distance education

Establishment of an Education System for Working Graduate School Students Using a Distance Education System

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In Japan, the demand for practical educational programs for healthcare professionals with full-time jobs is now increasing. However, students face a variety of difficulties in continuing their jobs at hospitals in order to attend graduate school, and hospitals may lose valuable staff members who choose to study rather than work. Therefore, it is important to prepare a graduate school environment that is compatible with the lives of working people. In April 2008, a Clinical Information Analyst Course for working Health Information Managers (HIMs) was established as a 2-year master's degree program at the International University of Health and Welfare Graduate School. In this course, we train HIMs to become clinical information analysts capable of analyzing clinical data using knowledge from a wide range of topics, including information technology, medical business and cancer registration. The objectives of the present study are to explain the approach of this course and to obtain knowledge about the establishment of an education system for working graduate school students. This course is a part of the Ministry of Education, Culture, Sports, Science and Technology (MEXT) project "Training Plan of Cancer Professionals".

Keywords:
Distance education, Graduate education, Medical record administrator.

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Drop-out Causes in an E-Learning CME Course with High Retention Rate

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E-learning efficiency regarding Continuing Medical Education (CME) has been proved but drop-out rate is quite high. The aim of the present work is to investigate the drop-out causes focusing on a course for nurses and physiotherapists (7811 users). An email was sent to 1393 drop-out users (17.8%) to investigate the possible causes of abandon that can be classified in 4 major areas: 1) lack of a real interest to attend; 2) presence of real interest but abandon due to reasons independent from the will i.e. lack of time or lost website address; 3) technical or usability problems; 4) disagreement with the educational model. About 18% of the users replied to the email within the following 2 weeks assessing lack of time as the first abandon cause (41.6%), maybe related to difficulties in considering e-learning education as a working activity.

Keywords:
E-learning, CME, Drop-out.

Health Informatics Building Blocks (HIBBs) For Distance Learning in Low Resource Settings

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The Health Informatics Building Blocks (HIBBs) project seeks to facilitate the acquisition of informatics and associated management skills by health care workers and leaders in local communities and health systems in low resource settings to improve their ability to use eHealth solutions (e.g., electronic health record systems) to strengthen clinical care and public health services. The HIBBs project, funded by the Rockefeller Foundation and managed by the American Medical Informatics Association, is initially focusing its efforts in Sub-Saharan Africa (SSA). A hallmark of the project is to develop ongoing collaboration with organizations in SSA that are providing clinical, research, and/or health informatics training to ensure the application of a locally-based, community-focused approach to the development and dissemination of HIBBs.

Keywords:
Informatics training, Low resource settings

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Inter-university clinical informatics education program for co-medical students*

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In order to promote the utilization of digital clinical information among co-medical staff, seven universities in Japan have planned to introduce the Electronic Health Record (EHR) system for education on the virtual private inter-university network (VPN) and to develop materials involving fictitious model patients used for learning team medicine via EHR. The EHR system and the associated educational materials have been evaluated by these seven universities. The materials for fictitious patients, including medical records, study results, and medical images, were added to a database developed for EHR education. This program was evaluated using a questionnaire administered to students and the administrators of hospitals employing students who have graduated.

Keywords:

EHR, Education program, Co-medical staff, Clinical record

Establishing a Core Medical Informatics PhD Program Curriculum in China

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The lack of medical informatics education and research infrastructure in China remains a major barrier both to the development of medical informatics as a discipline and high level medical informatics education. This paper introduces a core medical informatics PhD program curriculum in China, which will foster knowledge, skills, and abilities needed by current and future medical informatics leaders in professional applications. The PhD program will also minimize background differences from students with different professional training.

Keywords*:*

Medical informatics, Interdisciplinary, Education, Core curriculum.

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Health Informatics Education: Are we Building Capacity?

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Workforce development and associated professionalism are essential for leveraging the benefits of technology to improve healthcare delivery [1]. However there is limited knowledge about how health informatics education contributes to workforce capacity. This study reports the findings of a small online questionnaire of graduates to investigate why people choose to study Health Informatics and the impact of studying on their career. While the sample size is too small to provide generalisability it does offer a snapshot of Health Informatics graduates. The results indicate that they are mid career, from diverse backgrounds, with differing motivations for studying Health Informatics. While there is evidence of a positive impact on current roles and movement to Health Informatics roles, the amount of time spent on Health Informatics activities is not particularly high (52% spend less than 20%). Membership of a Health Informatics professional body is also low. These results mirror other studies highlighting the need for further information about the workforce [2,3].

Keywords:

Medical informatics, Health manpower, Health personnel-education

Biomedical Informatics Doctoral Programme and Lifelong Education

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Educational programmes in the area that we nowadays refer to as biomedical informatics cover topics from the field of medical informatics, healthcare informatics and bioinforma-tics. The conceptual roots of such programmes lead back more than thirty years and the programmes are well esta-blished in many countries. New approaches and e-learning tools applied to doctoral programme in biomedical informa-tics running at Charles University in Prague and lifelong education are introduced and discussed.

Keywords*:*

Biomedical informatics, Education, e-learning, Communication, Information technologies

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The questionnaire analysis about the urgency and necessity of biomedical informatics education in a medical school

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Although the number of medical schools which give a biomedical informatics education has been increasing in Korea, but there is no guideline for medical school students, yet. The result of this research analyzing perception of clinicians and biomedical informaticians could be foundational data for establishing a guideline. The questionnaire consisted of 32 questions related to detailed fields of biomedical informatics. On each question, respondents were asked whether it is urgent and necessary as curriculum for medical school student or not. The questions answered it's not only 'necessary' but also 'urgent' were 'Electronic medical record', 'Medical information system', 'Office programs', 'Graphic programs', 'Evidence based document research', 'Data back-up', and 'Arrangement of references'. These contents should be considered when the curriculum of biomedical informatics is made up.

Keywords:
Biomedical informatics, Curriculum, Questionnaire analysis

Using Social Networking Sites When Hiring Informatics Job Candidates: A Preliminary Study

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Employers and job seekers are using the Internet to find job candidates and opportunities, respectively. However, little is known about the use and attitudes towards social networking websites that supposedly support personnel selection. A preliminary study asked employers about their attitudes towards the use of online social networking sites. Surprisingly only a slight majority of respondents reported value in using online profiles in addition to traditional resumes and vitas when searching for a job candidate. Additional study and analysis is required to better understand how social networking sites can enhance personnel selection. Efficient and effective personnel selection is important given the worldwide lack of a sufficient informatics workforce.

Keywords:
Personnel selection, Job application, Computer communication networks

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Ancestry Estimation in a Web-based, Searchable Database of Orthodontic Case Files for Patient Care, Education, and Research

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In 2005, the Maxwell Museum of Anthropology accepted a donation of orthodontic patient records from an orthodontist who has been practicing in the Albuquerque area since the early 1970's. This collection represents a diversity of patients not often encountered in orthodontic training in the United States. A virtual, de-identified, web-based version of a subset of the collection is now being developed. Users can search for cases with particular characteristics of interest (e.g., patient ancestry, extraction patterns, diagnoses, and cephalometric parameters), then review sequential intra-oral and X-ray images to observe treatment outcomes. An innovative feature of the database is that it records multiple ancestry estimations, made at multiple points in time by multiple raters, along with a list of ancestry indicators on which the estimations are made (e.g., skin color, hair form and color, facial shape, name, and locality). This poster describes how the database can be used to overcome the limited diversity in the patient populations available to most orthodontics trainees. When this project concludes, the database will contain approximately 400,000 digitized images from 5650 individual cases.

Keywords:

Dentistry, Orthodontics, Medical informatics applications, Internet, Anthropology.

From Strategy to Implementation: A Progress Report on AMIA's Global Partnership Program to Build eHealth Capacity in Low Resource Countries

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Shortcomings in the health information systems of low resource countries limit the availability of reliable clinical data for diagnosis, treatment, and public health. AMIA's Global Partnership Program (GPP) seeks to improve health care delivery systems and outcomes by increasing regional eHealth capacity in low resource countries. AMIA and its partners are leading a team of experts in developing scalable approaches to eHealth training to help address the need for a global informatics workforce and scholarly network. Planned activities include bidirectional movement of local multidisciplinary leaders and teams to build collaborative relationships among partnering institutional stakeholders, mobilizing support from decision makers and beneficiaries, and facilitating organizational change to introduce electronic health record (EHR) systems and to sustain their continued use. The GPP experience will offer valuable "lessons learned" in training and education for capacity building and managing high-quality, low-cost health care in low resource countries.

Keywords:

Public-private partnerships, Sub-Saharan Africa, Education, Training, Electronic health records, Systems integration, Community networks, Outcome assessment (health care).

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User Training of Patient Information System-Longitudinal Study in Central Finland

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Health care professionals require versatile user training when adopting information systems. The first study was completed in November 2006 (n=290) and the second in June 2009 (n=420). The respondents were generally satisfied with the classroom teaching. Almost half of them had practised the use of information systems after the teaching in the training environment. The second study reveals training independently at work was in particular appreciated. Good learning results were obtained when practising with personal guidance after classroom training.

Keywords:
Health services, Information systems, Computer user training (MeSH)

Usability of PDAs to Deliver Multi-Language Health Worker Training and Patient Behavioral Assessment in Kenya

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To assess the utility of PDAs to deliver health provider training and HIV patient assessment in Kenya, we conducted usability testing with 15 people living with HIV/AIDS (PLHA), and 15 nurses providing HIV care, in Nairobi. We found that PDA content in both English and Kiswahili was acceptable and usable by both highly-educated nurses, and PLHA who had no previous computer experience.

Keywords:
PDA, HIV, Adherence, Nurses, Patients, Kenya.

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Public Health Informatics Capacity Gaps in Low Resource Countries

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The emergence of new, complex public health challenges in the 21st century demands that the public health informatics field strengthen its capacity to respond. The Health Metrics Network (HMN) and the US Centers for Disease Control and Prevention (CDC) and their partners are vital to collaboratively improve the global public health informatics infrastructure. This study represents an exploratory effort to assess public health informatics gaps in low resource countries. A review of the HMN assessments in 54 low resource countries notes the need for human resource capacity building in public health informatics. Findings suggest increasing level of awareness to support the training, deployment, and career development of public health informatics professionals. Investments from different public and private sources are required as part of a major intervention in the area of public health informatics capacity building. These data provide a foundation for future research and can be used to inform policy decisions regarding the design and implementation of public health informatics trainings in low resource countries.

Keywords:
Public health informatics, Needs assessment, Training support, Human resources, International cooperation, Partnership

Lifelong Learning – A Challenge for Education in Health Informatics

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The health informatics field becomes more challenging as the technology advances. Health care professionals, with understanding of modern technologies, are expected to improve the quality and efficiency of health care. In health care effective use of information and communication technology sets needs for lifelong learning. Especially, improved knowledge and skills in implementation of health informatics is of high importance. To meet these needs the continuing educational program (40 ECTS) has existed since 1997. The aim of this study is to explore the success of learning and pedagogical methods, as well as to analyse the contents of the education modules. The education is based on the use of activity theory. The outcome measures of the program analyzed in January 2010 and feedback from the participants has been largely positive.

Keywords:
Education, informatics, professional

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Data Capturer Internship Program at Health Facility Level, South Africa

Hlengiwe Ngcobo

The Health Information System for Data Capturers (HISDC) Project, an initiative by the National Department of Health (NDoH) aims to address both the inadequate opportunities for career development in the public sector as well as to build national capacity for data management at the level where health data is collected i.e. facility level. This project which is mapped to be implemented over a period of three years is in its second year of implementation. The project is implemented by a consortium comprising the Continuing Education at the University of Pretoria Trust, Health Systems Trust and the Health Information System Programme.

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F. Consumer Health Informatics

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Mobile Social Networks: Students solving their own health problems

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This paper describes research in progress. A survey was carried out to determine if Gen Y users are utilizing text messaging as a means of sharing health information with their family and friends. Survey was sent to 5000 students with a response rate of thirty eight percent. (n=1900) Results show that this cohort uses the text message function of their phones to share health information in differing degrees with family and friends and is also affected by the types of condition they are communicating about.

Keywords:
Generation-Y, mhealth, Health sharing

Identifying with other people suffering from alcoholism in an e-mediated and cross-cultural venue

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To reach a common ground for identification is regarded as one of the most important success factors for self-help groups. The members should be able to relate to each others' experiences so that they feel that they are part of the "we-ness". In this study we explored two Alcoholics Anonymous Internet groups with an international membership. The objective was to explore the members' experiences of participating in an international AA self-help group. The research questions are: How does using e-meetings, e-mail lists and electronic bulletin boards with an international and cross-cultural membership influence on the process of identifying and thus on the members' rehabilitation processes? Are they able to find a common ground of identification? Data were obtained over the course of one year by means of participant observation in two online AA groups and e-mail interviews with 11 online AA members. Results suggest that members can easily identify with each other. Two things seem to bridge the potential gap between members from different countries and cultures: The AA members' view of alcoholism as a global disease with similar symptoms, and the experience of AA`s conceptual framework as a universal language.

Keywords:
Internet, Self-help groups, Alcoholics Anonymous

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Comparing Diabetes Search Engines: HON vs Google

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Google search engine is one of the tools most used by consumers searching for health information on the world wide web. Several studies have examined the quality of information returned from Google and other public domain search engines, but none have compared a single disease focused search engine delivering certified content, and the rules clinicians apply to decide on website quality. We compare a general Google search engine with a customized Health on The Net (HON) search engine specifically designed to pre-filter HON certified websites for diabetes content. Across three stratified groups including primary care practitioners, informaticians, and diabetologists, we address quality as a response to the question " Which of these websites are you most likely to recommend to your patients ?". We then assess the rules clinicians apply to website decision making. Our in-progress pilot study suggests a preference for HON certified websites, with the dominant selection rules being 1. An absence of blogs or personal experiences, and 2. Pre-existing familiarity with the website. This poster will compare search results for Google and HON, and the selection rules clinicians apply across primary care practitioners, informaticians, and diabetologists.

Keywords:
Internet search

An ontology for automatic generation of computer-based cognitive exercises

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Cognitive rehabilitation may take advantage of computer-based approaches which, compared to the traditional paper-based ones, allow the management of a big amount of stimuli. These stimuli may be reused and recombined to create new exercises, whose difficulty level should be adapted to the patient's performance. This work proposes an ontological organization of the stimuli, to support the automatic generation of new exercises, tailored on the patient's preferences and skills. The ontology has been integrated into an existing cognitive rehabilitation tool [1], to test the new functionalities made possible by this approach.

Keywords:
Ontology, Cognitive rehabilitation, Exercise adaptation.

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The impact of Information and Communication Technologies - ICT in health promotion: an experiment with diabetes type 2 patients

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We developed a web platform to provide educational materials on diabetes for patients with diabetes type 2 and also to offer the possibility to interact with experts and other patients during 4 months. Patients were selected from health maintenance organizations HMO institutions in Montevideo, and after a survey about habits and knowledge about their condition, they were invited to a workshop to be introduced to the platform. Preliminary results show particular interest in nutrition subjects and passive participation.

Keywords:
Health promotion, Health education, Information technology, Secondary prevention, Diabetes Mellitus Type 2

Types of the Healthcare Information Provision e-Business on the Internet

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The objectives of the study was to; firstly, define healthcare information provision industry, and classify/analyze healthcare information industry business models, secondly, propose strategic guidelines for healthcare information industry development. A survey was conducted to investigate private companies that provide healthcare information. Through literature review of previous researches on internet business model classification, four major model classification systems were chosen and healthcare information business models were classified. Appropriate guidelines were proposed based on the composite opinions derived from the participating companies. In order to realize the industrialization and development of health information provision industry, it is important to educate the general with the help of government and cooperation with field experts.

Keywords:
Internet health information, Healthcare contents, Business model

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Developing a concept map for "increasing medication safety and patient compliance by developing patient-oriented mobile phone applications"; results of a conceptualization research

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Medication errors are very common worldwide and potentially affect almost all patients especially those with chronic diseases. There have been a few reports in the literature of mobile phone applications for reducing medication errors. We decided to do an extensive literature review and gather the available evidences and prepared a knowledge-based process for developing patient-oriented mobile applications for medication safety and compliance which hopefully encourages healthcare managers and stakeholders to use our research results. This knowledge-based process for developing patient-oriented mobile applications for medication safety and compliance is helpful to patients and providers in: registering and updating the patient's medications, their dosages and timing; reminding to take medications on-time; checking for any interactions; finding related educational materials; and other usages.

Keywords:
Medication safety, Mobile phone applications

A circular model for the e-Health at the household

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In this paper we present a circular approach that takes into account all the processes starting from and arriving to the patient for household e-Health. The management of healthcare documents, the prevention based on the knowledge of risk factors and the support during therapy administration are the key points of the path. The circular model is based on the cooperation between different software tools, each devoted to a single phase of the whole process.

Keywords:
Consumer health information, Health care IT.

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A study on the Linguistic and Functional Health Literacy and Chronic Disease Information

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Health literacy is one of major health issues in developing health education material and program The purposes of this study are to identify health literacy of the persons with chronic disease, to identify disease knowledge depending on a health literacy level, and to verify the correlation between them. Over 200 patients with hypertension or diabetics at a tertiary hospital were participated in the study. The survey was conducted using REALM (Rapid Estimate of Adult Literacy in Medicine) and S-TOFHLA (Short Test of Functional Health Literacy in Adults) as health literacy measurement tools, and disease knowledge measurement tools. The findings indicated that the health education and health care information need to be tailored according to the target user's health literacy and disease knowledge.

Keywords:
Health literacy, Chronic disease, Information

Health and wellbeing related information management in families with small children

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Understanding how families manage health and wellbeing related information in their everyday life is important in the design of appropriate information and communication technology (ICT) supported tools and services for them. The aim of this poster is to present a study in which we investigated health and wellbeing related information management activities and needs of families with small children taking Eastern Finnish families as an example. A qualitative study design was applied using the method of longitudinal virtual focus group discussion with eight households (n=8) over four weeks of time. Main information management activities were identified and grouped according to the different roles that families with small children play in society when seeking health and wellbeing: as users of health and social services, as consumers in the market of goods and services, and as citizens seeking a sense of wellbeing in its widest meaning. The study provides baseline understanding of everyday information management activities of families with small children to be applied further in ICT supported health and wellbeing service design.

Keywords:
Consumer health information, Family health, Information management, Qualitative research.

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Designing the Information Architecture for Personal Health and Wellbeing Systems

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Access to the personal health information and knowledge related to personal conditions and situations promotes citizens' interest of wellbeing and promotes personal empowerment in managing personal information and wellbeing. When developing health and wellbeing systems for individuals we have to make design decisions which are justified by the needs of the individuals. We use an activity-driven approach in information analysis to ensure that individuals' real needs will be taken into account to define the information architecture that works as a tool for the design decisions. In this study we present the activity-driven information analysis aiming at the information architecture of personal health and wellbeing systems. As results we 1) analyse individuals' information management needs in their everyday life activities; 2) present a reference model for personal information analysis; 3) produce a framework for designing the information architecture for personal information management.

Keywords:

Personal health records, Consumer health information, Information management, Systems analysis, Software design

Design preferences and characteristics of a website for monitoring HIV medication adherence in Peru

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The objective of this paper is to document design preferences and characteristics of a website monitoring the HIV medication adherence of people living with HIV/AIDS (PLWHA). The website is part of an mHealth solution that combines the use of short messaging services and the Internet to improve adherence to antiretroviral therapy. We conducted a qualitative study with adult PLWHA in a community-based clinic in Lima, Peru using focus groups. 26 HIV-positive individuals participated in four focus groups (20 men, 6 women). The participants reacted positively to the website and specified that they wanted the website to be confidential, socially interactive and easy to use). It was also important to participants that the website contain a motivational pet or character. There was no clear consensus on the aesthetic features of the website. This study suggests that PLWHA in this setting desire a confidential, easy-to-use, socially interactive website with animated characters to assist both their health care providers and themselves in monitoring their HIV medication adherence.

Keywords:

HIV, Adherence, Website, Focus groups, mHealth, Peru.

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Classification of Application Services for Personal Wellbeing Information Management

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Personal information management has been proposed as an important enabler for individual empowerment in relation to wellbeing and health information. In the MyWellbeing project in Finland, a citizen-driven concept of "Coper" and related architectural and functional guidelines have been specified. We present the classification of identified application services to support personal wellbeing information management.

Keywords:
Citizen empowerment, Service-oriented architecture, Standards, Personal health records, Interoperability

A Content Analysis of Information Exchange in an Arial Fibrillation Online Support Group

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Atrial fibrillation (AF) affects about 2.3 million Americans, and increases the risk of embolic stroke by about 4-5 times. The goal of the present study was to analyze content of messages exchanged between participants in an online AF support group using qualitative methodology in order to identify and classify major topics which are being discussed by the group participants. Using Grounded Theory, we conducted a content analysis of 626 messages, which were grouped into seven categories. We described the content of messages in each category. In addition, proportion of initial posts and responses to them was analyzed depending on message category. Practical implications of qualitative analysis of messages posted on an online support group are discussed.

Keywords:
Atrial fibrillation, Online support group, Qualitative analysis, Knowledge gaps, Social support

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"Safer at Home" – Technology supported coordination & cooperation

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"Safer at home" is a pilot project between Lovisenberg Diakonale Sykehus and 4 (of 15) local district administrations and the Agency for Nursing Homes in the City of Oslo. The objective is to investigate if and how information technology can improve the coordination between the hospital and the four districts and/or nursing homes – resulting in a better and more integrated health care for the individual patient.

Patient Involvement in a Software Development Project - Developing an Electronic Diary for Patients Suffering Extreme Obesity

Sturla Rising

Vestfold Hospital Trust, Clinic for Physical Medicine and Rehabilitation

Lifestyle diseases, such as obesity and its coherent complications, are a growing problem in the Western world. The combination of lifestyle related morbidity and an aging population will contribute significantly to widen the gap between healthcare resource availability and needs in most countries. In design – including that of software - user driven or participatory design methods of innovation have been promising when it comes to developing better products. Throughout this project, patients are used as resources in all steps of the interaction process that is involved in developing an electronic diary. The purpose is to investigate whether patients need special treatment during the process.

Keywords:

Telemedicine, Personal health systems, Home care, Participatory design, Chronic disease, Patient centered medicine, Medical informatics, ehealth.

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Web-based Individual Plan in Norway: An opportunity for improved cooperation?

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"Individual Plan" (IP) is an approach to organizing multidisciplinary care in Norway. A web based tool, SamPro, is designed for supporting this planning. In a qualitative study we explored the challenges and opportunities that a web-based tool for IPs offers to patients and professionals in their collaborative care teams. Patients expressed they become empowered through communication and documentation possibilities. Plan coordinators experienced an improved overview in the plans. Being a system super user became an additional task for them. Other professionals involved in the groups did seldom collaborate and document through the system. They reported technical problems and insecurity more often.

Keywords:
Individual plan, Integrated care, Patient-centred care.

Participatory Design of a Physical Activity Intervention for Latino Adolescents Using Facebook

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Persuasive technologies are interactive computing systems designed to intentionally change attitudes and/or behaviors. Little is known about the efficacy of harnessing such technologies to promote health among at-risk adolescents. We conceptualized Facebook, an innovative social utility used by more than 200 million people, as a "palette" for the delivery of multi-faceted, theoretically-based, and culturally and linguistically appropriate health promotion strategies. We are designing a Facebook application that will embrace the functional triad (tool, social actor, and medium) of roles for computing technology toward the goal of promoting activity. Persuasive strategies will target motivation for physical activity, perceived competence for exercising regularly, and perceived enjoyment of physical activity. During a summer education program, nine Latino adolescents participated in sessions to create preliminary designs and functional specifications for three components of the proposed application: physical activity mash-up, goal setting and activity monitoring, and reward/award structures.

Keywords:
Social utility, Participatory design, Adolescents, Physical activity, Latino

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G. Image and Signal Processing

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Pioneering Territory-Wide Sharing of Radiological Examination Results in Hong Kong

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Under a Public-Private Interface (PPI) initiative, a pilot project was implemented to examine the feasibility of diverting patients to private healthcare providers to conduct radiological examinations, which enables prompter clinical care. Radiological examination results taken in private healthcare providers are electronically transferred to Hong Kong Hospital Authority (HKHA), the public healthcare provider in the territory, where the patients originally sought care. These results are further incorporated by HKHA IT infrastructure and be combined with the Authority's patient-based, longitudinal medical record. In this way patients are given more flexibility while selecting public or private radiology investigation services and prompter clinical decision can be made. This directly improves the quality and safety of patient care.

Keywords:

Radiological examination, Private-public interface, Patient care, Electronic patient record

An automated System for Brain Tumor Detection from MR Images

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Radiologists carefully look into medical images, and diagnose a patient's disease by obtaining useful information and interpreting medical images with their experience, knowledge, and wisdom. Brain tumor identification is a crucial and complicated job for radiologist. Brain tumor identification form MR images consist of several stages. Segmentation is considered as an essential step in medical image analysis and classification. Manual brain MR images segmentation is a difficult task. Radiologist and other medical experts spend plenty of time for manually segmenting brain MR images and this is non-repeatable task. Therefore automatic segmentation of brain MR images is needed for accurately segmenting White Matter (WM), Gray Matter (GM) and Cerebrospinal Fluid (CSF) tissues of brain and performing this segmentation within short span of time. This is a very critical issue because wrong identification can lead to severe results. Major objectives of our system are following: 1) Classify the brain MR image as normal or abnormal accurately. 2) Perform segmentation within short span of time. 3) Provide a system to radiologist a system which is self explanatory and easy to operate 4) Enable the radiologist to accurately identify the region of tumor in MR image.

Keywords:

Thresholding, MRI, Segmentation, Fuzzy partition

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Automatic Threshold Measuring in Mammographic Density Screening

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This paper proposes an improving approach to quantitative classification of mammographic image density. Since the mid-1980s, some of studies have shown a moderate to strong statistically significant association between percent breast density and breast cancer risk. We propose the use of agglomerative hierarchical clustering which means an automatic decision of the threshold of segmentation. Current quantitative methods have some problems such as an automatic decision of threshold, lower percent breast density in digital mammograms and limitation of the brightness or pixel depth in 2D mammography, accordingly proposed method may have a role in routine mammographic analysis for the purpose of automatic decision of threshold.

Keywords:
Mammographic density, Breast density, Agglomerative hierarchical clustering, Threshold.

A Tool for the Evaluation of 3D Kinematics of Newborns at Risk

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Quantitative analysis can help to improve the comprehension of human movements and their underlying control mechanisms. Furthermore it has been shown that certain characteristic movements are an indicator for the status of the central nervous system of newborns. This article introduces a tool which enables a detailed visualization and quantification of infant movements. Movements recorded with an electromagnetic tracking system can be transformed in order to reveal subtle movement features. The presented tool can be used to acquire a better understanding of infant movements and identify prognostic markers for neurologic impairments.

Keywords:
Human movement analysis, Data visualization

H. Emerging Technologies

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Evolution of Nanomedicine, Bioinformatics and Grid computing in medical bibliographic databases

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Medical advances have experienced progress due to the emergence of Nanomedicine and Human Genome Project gave another vision to the Bioinformatics field. As data grows exponentially, Grid Technologies are needed to manage this kind of data. The objective of this study is to describe how these disciplines are represented in Medline. A search of text words was performed and each category results were analyzed. There is an accurate representation of Nanomedicine and Bioinformatics, in contrast of the lack of adequate representation of Grid computing in Medline. The objective of this study is to describe how Nanomedicine, Bioinformatics and Grid Computing are represented in Medline

Keywords:
Nanomedicine, Bioinformatics, Grid computing, Databases, Bibliographic.

A Sensor Enabled Smart Space for Health Research

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The Smart Space research facility described here provides a laboratory environment for investigating technology-oriented aspects of new models of health care for out-of-hospital settings. It provides an instrumented, configurable space for simulating, modelling, observing and measuring health care activities using various new information and communications technologies (ICT). This environment allows a wide range of subjective and observational studies to be performed in tandem with gathering quantitative experimental results, using wearable ambulatory devices and embedded sensors. This is intended to help develop and improve new health care processes, allow benchmarking and evaluation of alternatives, facilitate collaboration between technology and health experts, and assure ongoing continuity of related research via e-Science mechanisms.

Keywords:
Ambulatory monitoring, Data collection, Data mining

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Post implementation views of end users of Picture Archiving and Communication System (PACS) in Nelson Mandela Academic Hospital (NMAH), Mthatha, South Africa

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NMAH is a level 2 and 3 academic hospital in Mthatha, Eastern Cape Province of South Africa. In the process of modernizing the hospital, the PACS & RIS (Radiographic Information System) system was installed and handed over in August 2004 it was removed one year later. The objective is to explore the views of end users of PACS service in NMAH.

Keywords:
PAC's Radiology, Imaging, Picture archiving, Implementation

Enabling the Health Internet - Market-Friendly Information Extraction of Online Healthcare Sources

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The Health Internet is the future of American healthcare. It is the patient-facing system with information about you and your condition. Admittedly, the vision of the Health Internet is evolving as this paper is being written and many aspects of it will no doubt change within the next few months. However, there are several things that will remain constant. The primary one being that the Health Internet will be a portal that integrates data from many different online sources. Unfortunately, current techniques for acquiring this information from these sources may have significant negative effects. In order to support the continued creation of novel healthcare applications (like the Health Internet), we define a process to ensure best practices for both Web publishers and end users. These techniques allow for continued innovation while respecting the source's terms and conditions. In turn, all parties involve will avoid a dramatic decline in both traffic and revenue, while enabling the integration of health information for the greater good – the patient's wellness.

Keywords:
Internet, Data collection, Information storage and retrieval

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WISE Healthcare: Enabling Medical Collaboration in a Web 2.0 World

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Web technologies are heralding a new era in healthcare information systems. The march towards healthcare social networks, the increased use of Web 2.0 technology to communicate medical findings and the prevalence of online sources, such as WebMD and medpedia are signaling a transformation in healthcare culture and enabling new forms of collaboration. This paper describes novel Enterprise Content Management (ECM) technology - WISE (WISdom of the Enterprise) - that seamlessly enables this new form of cooperative healthcare operation.

Keywords:
Collaboration, World Wide Web

Adaptation of a Computerized Patient Simulator for Continuous Medical Education of Isolated Care Professionals in Sub-Saharan Africa

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The aim of this study is to explore the feasibility of using a computerized patient simulator as a tool for continuous medical education and decision support for health professionals in district hospitals in Sub-Saharan Africa.

Keywords:
Computerized patient simulator, Telemedicine, Clinical reasoning, Capacity building, Isolated healthcare professionals, Africa.

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Use of Widget Technology to Rapidly Disseminate Medical and Treatment Information Directly to Health Workers' Computer Desktops and PDAs

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To assess the long term utility of using widget technology to disseminate instructional material on New York State Guidelines for post exposure prophylaxis (PEP) for HIV, the diagnosis and management of Acute HIV Infection (AHI), and implementing HIV testing in clinic settings. St. Vincent Medical Centers (SVH) in New York City, created an AIDS Widget application (AWA) to stream instructional data directly to providers' computer desktops via a Widget application. Users download AWA from a central website www.ceitraining.org. Results indicate that the innovative use of Widget technology may have substantial application for delivery of crucial health instruction/information and technology.

Keywords:
Widget technology, Health education, Information exchange

Collaborative international research on biomaterial in the age of Web 2.0

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We propose a research infrastructure allowing participating biobanks and partners to manage, annotate and exchange sample stock among each other. Descriptive attributes are maintained utilizing a set of categorized annotations dynamically expandable by the users using Web 2.0-inspired techniques, thus covering any of the otherwise isolated individual and specialized annotation sets. A free, modular open-source client will allow to manage sample stock as well as to contribute to the infrastructure. The client can be used on multiple machines by several users simultaneously. Rights management allows delegating tasks, and automatic import of existing data is supported as well as secure online backup. The presented system will connect researchers from different fields of research by uniting their isolated and fragmented data and sample stock in a comprehensive, user-centric database to the benefit of international research and the patients.

Keywords:
Biobanks, Web 2.0, Medical informatics computing, Information storage and retrieval, Online systems

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Privacy for Healthcare Social Networks

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There has recently been an increase in both industry-specific social networks, such as Sermo and PatientsLikeMe in the healthcare domain, and an increase in the membership and activity levels of these networks. Privacy concerns are of more importance in these networks than general-purpose social networks, such as Facebook, Orkut and MySpace. In this work, we present the results of our work on developing privacy technology for social networks.

Keywords:
Privacy, Internet

The Potential of Twitter for Early Warning and Outbreak Detection

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The use of user-generated content in Web 2.0 tools for predicting outbreaks has been seen as a great potential, however, the recent swine flu outbreak in April-May 2009 truly demonstrated the potential of these media for early warning systems. We have run a pilot study collecting tweets containing words related to influenza since May 2009 and collected over a million tweets until August 2009. An evaluation and data mining of this unique database is ongoing while the preliminary results are very promising.

Keywords:
Infection, social networking, outbreak detection, Web 2.0.

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Mobile Clinical Assistant in Hospital Information System (HIS) Environment: Are We Ready?

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Mobile Clinical Assistant (MCA) provides real time data entry for the clinicians and nurses in HIS environment. Observation showed that in an IT hospital, doctors and nurses tend to transcribe data on to a piece of paper and then keyed in the data into the system at their own convenience. This situation will jeopardize patient safety and defeat the purpose of ICT in improving patient care. To improve efficiency of nursing care, a pilot project on the use of mobile clinical assistant (MCA) was conducted in Serdang Hospital, Malaysia one of the hospitals with total hospital information system (THIS). The efficiency of nursing care was determined by measuring data latency before and after the implementation of MCA. The acceptance level of adopting MCA was also measured. The results showed that MCA did improved the efficiency of real time clerking for nursing care, however the acceptance level of adopting the technology is generally lower than expected.

Keywords:
Mobile clinical assistant, Point of care clinical documentation, Improve efficiency, User acceptance level.

Blackberry eLearning Platform for Interactive Patient Education

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Cell phones can potentially serve as a powerful health communication channel. However, the value of cell phones for interactive patient education has not been studied systematically. We developed an interactive patient learning system for use on Blackberry devices to educate health consumers about hypertension and to enforce knowledge retention by questioning the user. The system uses the Blackberry's internet connection to retrieve hypertension information from a knowledge database and is guided by adult learning theories. Multimedia hypertension curriculum is delivered in an interactive format. The application was successfully implemented and tested on the BlackBerry 7100i smartphone with Nextel as a service provider. A feasibility evaluation demonstrated high acceptance by potential health consumers and statistically significant increase in hypertension knowledge score after using the mobile education platform.

Keywords:
Mobile health, Hypertension, Health information

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Technical Feasibility Study of 3G Stroke Consultation

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The study assesses the potential for enhanced community based tele-consultation for stroke patients in the South Eastern Trust area of Northern Ireland. We have used a tele-consultation approach, which can be utilized by a health professional in conjunction with a scheduled home visit. It provides a synchronous telecommunications link to a consultant neurologist located in the main hospital. Third generation telephony (3G) provides wireless connectivity at 'mid-broadband' data rates (128-500kbps), and these services are becoming available in parts of the North Down peninsula. The technical feasibility study has shown that clinical tele-consultations for stroke follow-up is feasible given 3G duplex data rates of 500kbps. Lower rates 200-500kbps can sustain calls, albeit at poorer quality. Services are available in the larger population centres, less so in the more rural areas.

Keywords:

Teleconsultation, Mobile, 3G, Telemedicine, Stroke

GALILEO: An Integrated Cardiology Teleconsultation System in Chile

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Timely evaluation of cardiologic patients by a specialist can be vital for their prognosis and outcome; in the Chilean public health context, high demand, lack of specialists and centralized imaging tests often result in waiting lists and delayed cardiologist assessment and intervention. GALILEO, a teleconsultation, teleimaging and tele-EKG platform has been in use since October 2008 in Chile's Bío-bío region, and has shown potential for significant reduction of time on patient referral to cardiologist response, reduction of patients' waiting lists for specialist assessment, overall positive impact on patient management and better use of the limited specialist time available versus the traditional patient referral system. This work's objective is to demonstrate these advantages.

Keywords:

Cardiology, Telemedicine.

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Providing Easy Access to Visualization for Biomedical Research

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With the MediGRID a Grid Computing Infrastructure for the German biomedical community was deployed as part of the German Grid Infrastructure D-Grid. Currently this foundation is used to build up an additional countrywide visualization infrastructure for biomedical researchers. Therefore three new visualization clusters were installed in 2009 to extend the MediGRID infrastructure. It is possible to use the clusters in different ways in response to the demands. By using an integrated and already deployed solution, researchers do not need to spend time and money to build up own systems. Further the communication between two or more professionals can be improved by shared visualizations. The sites are now working on standardized ways to utilize this infrastructure to reduce the threshold for naïve research users. The poster describes the architecture and functionality of this infrastructure.

Keywords:
3D-Visualization, Grid computing, Multi center research

The Lower Saxony Research Network *Design of Environments for Ageing* (GAL) A Brief Introduction

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And others at the Lower Saxony Research Network Design of Environments for Ageing
*www.altersgerechte-*lebenswelten*.de.*

Worldwide, ageing societies are bringing challenges for new ways of living and health care. Health-enabling technologies offer new opportunities. In order to identify, enhance and evaluate such new information and communication technologies the “Lower Saxony Research Network Design of Environments for Ageing” (GAL) has been launched in 2008.

Keywords:
Health-enabling technologies, Ambient-assisted living.

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Acquiring and analyzing epileptic seizure motion data – technical considerations

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Introduction: Epilepsy is one of the most chronic diseases. Sudden seizures cause the total loss of body control and result in a decreased quality of life. These seizures also impose a high risk of partly severe injuries. In order to detect any epileptic seizures, it is imperative to continuously monitor the patients. Current possibilities (e.g. combined video and electroencephalogram monitoring) are reliable but limited to stationary, short term observation. Thus, wearable systems with automated seizure-detection are needed. Here, accelerometer-based motion sensors seem promising. For the development of the required detection-algorithm, motion data of real epileptic seizures must be acquired and analyzed. Aim: This contribution describes the development of a comprehensive system for the acquisition and analysis of epileptic seizure motion data. Method: Requirements for system development were collected by combining literature review and qualitative expert interviews. The system development mainly applies open-source solutions. Results: A concise list of requirements for the acquisition of motion data. An easily usable data acquisition interface. A graphical analysis system that comprises mathematical processing functions. Conclusion: The developed systems help acquiring characteristic motion features of epileptic seizures that are essential for detection algorithms.

Keywords:
Patient monitoring, Epilepsy, Acceleration

Mobile Learning Object in Advanced Cardiac Life Support: an application of a persuasive technology in nursing

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The mobile learning stands out as a great chance to become the most used mean for learning, since the affording cost of the mobile devices is much lower than the cost of a computer. The research on m-learning must consider the importance of the student's mobility and learning not only on the technology. The aim of this study is to investigate the effect on the Nursing students´ learning through the application of the mobile learning object in CPR – ACLS with Guideview® program and the task load over the nursing students during the simulation in mannequin. The use of a cellular phone with the Guidevie® program in order to back up the nurse's decision during the Cardiac Respiratory Resuscitation service, has shown itself statistically significant related to the control group that used printer paper during the process. Therefore, besides acting as a learning support, the program can be comprehended as a procedure which is incorporated to the service in a persuasive way.

Keywords:
Cellular phone, Learning, Persuasive communication, Nursing, CPR

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I. Knowledge Management and Decision Support

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Standardizing Inter-Institution Care via Ontologically-Modelled Clinical Pathways

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In this paper we pursue the standardization of care for a specific condition across multiple institutions. Our approach is to represent institution-specific Clinical Pathways (CP) using an ontological model and then aligning the common care activities between multiple CP, based on their semantic descriptions, to generate a standardized care model. We developed an execution engine that transforms the ontological standardized care model to a state-graph that can be executed with patient data and practitioner input at the point-of-care.

Keywords:
Clinical pathways, Prostate cancer, Ontologies, Semantic web, Knowledge representation

A Regional Guideline System for 40.000 Users – The Importance of User Participation and Management Commitment.

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As a part of the regional quality strategy and as a prerequisite for accreditation in hospitals, the Capital Region in Denmark will implement a new system for providing easy access to valid, coherent and updated policies, guidelines and protocols. The implementation of such a system is mainly an organisational challenge. This paper highlights the importance of user participation and management commitment when developing a specification for an electronic guideline system. The main functionality of the required system is also described.

Keywords:
Guidelines, Quality system, User involvement, Management.

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Ontology Modeling for Handling Co-Morbidities in Decision Support Systems

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This poster present a decision support framework for ontology based handling of clinical pathways (CP) of co-morbid Chronic Heart Failure (CHF) and Atrial Fibrillation (AF). Our knowledge management (KM) approach for synchronization of co-morbid clinical processes include; (i) knowledge synthesis-selection, interpretation, and augmentation of statements, logic and temporal relations within and across CHF and AF clinical practice guidelines (CPGs) to create CPs (ii) CP knowledge formalization-using semantically rich OWL constructs to unambiguously model implicit functional and temporal relations between concepts (iii) formalizing functional relations between care processes by defining co-morbid care plans to be executed in response to preconditions derived from both CHF and AF CPs (iv) execution of ontology in a clinical decision support system, named COMET, that after identifying a co-morbid incident can recommend appropriate care plans along with relevant information and protective measures to ensure patient safety.

Keywords:
Co-morbidity, Ontology, Decision support system

Development of a Guideline-Based Decision Support System Prototype for Collaborative Primary Healthcare

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IBM Research – China

Delivering effective and efficient primary healthcare services is crucial as it requires knowledgeable physicians who treat a wide range of diseases and periodical monitoring of patients. We propose to make the task easier by the collaboration of a guideline-based decision support system and a mobile communication platform through which the monitored patient data could be processed instantly. In particular, we focus on the demonstration of executing guidelines for long-lasting care process using a standard-based business process engine. As a result, we have implemented a system prototype which proves the effectiveness of our approach by running an exemplary guideline.

Keywords:
Decision support system, Clinical guideline, Primary care, Mobile healthcare

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Clinical workflow and practice-based evidence

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Integrated care pathways (ICPs), a fine-grained form of medical guideline including the explicit recording of any deviation, have been perceived as overly prescriptive, limiting clinical freedom and promoting cookbook medicine. However, feeding the results of the analysis of 'variance' into the development of pathways could be an effective way of capturing evidence from practice. This paper is a summary of our research into the development and use of ICPs, and their research potential.

Keywords:
Guidelines, Knowledge management, Care pathways

Web Catalogue of Electronically Published Clinical Practice Guidelines in the Czech Republic

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As a preliminary collector of information for decision support systems and due to the absence of web tools and services for clinical practice guidelines organization and searching in the Czech Republic the prototype of a specialized online catalogue was developed. The database allows the collection of 34 parameters for each document. Nowadays this web service includes information about more than 250 documents of clinical practice guidelines published electronically by Czech medical societies.

Keywords:
Medical informatics, Clinical practice guidelines, Internet

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Towards Seperation of Medical and Workflow Knowledge in Modeling Clinical Guidelines: A Semantic Web based Framework for Executing Clinical Guidelines

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We present a semantic web based framework for modeling and executing Clinical Practice Guidelines (CPG). Our modeling of CPG distinguishes between the medical and workflow knowledge inherent within a CPG. We have developed two OWL-based ontologies—a CPG ontology that models the medial knowledge, and a Clinical Workflow ontology that models the CPG's execution logic using UML Activity Diagrams and OWL-S. We have developed a CPG execution engine based on Place Transition Nets that allows both the verification of a modeled CPG and its execution at the point-of-care.

***Keywords**:*
Clinical practice guidelines, Clinical workflow, Knowledge modeling, Semantic web, Ontology

Correspondence between Guidelines for Antibiotic Treatment and Microbiological Outcome – Analysis of Cases of Pneumonia in the Swedish Intensive Care Registry

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To treat severe pneumonia needing intensive care you must have guidelines for what antibiotic to use based on knowledge of local antibiograms. The objective of this study was to compare national guidelines for pneumonia with antibiograms from ICU patients with pneumonia. Data from the Swedish national registry of intensive care have been used to set up a model for this comparison. Primary diagnosis of pneumonia was divided in two groups – hospital and community acquired respectively – by route of admission. In community acquired pneumonia we found a failure rate of 6 and 10 % for the two recommended treatment regimes respectively according to antibiogram. In hospital acquired pneumonia the rate of failure was 3 and 5 %. Since patterns of antibiotic resistance change over time it is very important to update guidelines on a regular basis. This method contributes to do such updates based on clinical outcome. To improve this method further there is a need for standardized terminologies and information models for semantic interoperability between clinical and laboratory information systems.

Keywords:
Practice guidelines, Evidence-based practice, Quality of health care, Data interpretation, Information systems, Semantic interoperability

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Unanticipated consequences of hospital-based insulin management improvement program

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Hypo/hyperglycemia is associated with adverse clinical outcomes in the inpatient setting. We introduced a hospital-wide inpatient glucose management program at Johns Hopkins Hospital in January 2006 to facilitate uniform glucose management policies and staff education based on current clinical practice guidelines. During that time, a spectrum of initiatives were implemented to improve hospital-wide glycemic control, including a Hypoglycemia Policy (7/06), a diabetes nursing superuser program (1/07), a Hyperglycemia Policy, and uniform computerized subcutaneous insulin orderset (11/07). After implementation of the program, the frequency of hypoglycemia significantly decreased from 1/1/07 to 12/31/08. In contrast, the frequency of hyperglycemia increased from 1/1/07 to 12/31/07 but then began to decline after 1/1/08, following implementation of a hospital-wide standardized subcutaneous insulin orderset. These data are informative in identifying unanticipated consequences of an insulin management program focused entirely on hypoglycemia. A balanced approach in implementing insulin management guidelines is warranted.

***Keywords**:*
Hypoglycemia, Hyperglycemia, Clinical guidelines

Prototype of a High-Alert Medications Decision Support System

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High-alert medications (HAMs) are associated with serious harmful events. Comprehensive medication safety improving strategy is needed to reduce adverse events related to HAMs, including limitation of access to drugs, standardization of orders, alert system for high doses and critical events, etc. Process analysis with activity diagram and error matrix regarding selected five HAMs was done. Clinical knowledgebase was made by pharmacists, nurses, PI experts, and IT experts. HAMs clinical knowledgebase composed of core message, adverse event type happened, drug interactions, monitoring items, similar drugs information, hospital clinical guidelines, and routine drug information. Prototype of HAMs decision support system was designed to use in computerized physician order entry system. HAM icons, core messages, and alert for overdose services included to this system.

Keywords:
High-alert medication, Patient safety, Adverse drug event, Decision support, Clinical guideline

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Development Journey of Clinical Data Analysis and Reporting System (CDARS) in Hospital Authority of Hong Kong

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The Clinical Data Analysis and Reporting System (CDARS) has been implemented in Hospital Authority of Hong Kong (HA) to provide value-added information to support different aspects of healthcare services for management decision, clinical audit, planning and research. It facilitates the retrieval of clinical data captured from different operational systems for analysis and reporting and provides good quality information to support retrospective clinical and management decisions by integrating the clinical data resided in Data Warehouse.

Keywords:
Information systems, Clinical decision support system

Arden-Syntax-Based Clinical Decision Support Software

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We describe an implemented software architecture for clinical decision support (CDS) based on the Health Level Seven (HL7) Arden Syntax for Medical Logic Systems. Arden Syntax's proven applicability as a medical knowledge representation and inference scheme makes it a good candidate for a service-oriented architecture for CDS systems. We developed a package of Arden-Syntax-based software components including compiler, rule engine, server, an integrated development environment (IDE), and web services for interoperability. We report on a large-scale implementation of this software system, which constituted the platform for an automated cockpit surveillance program for early identification and automated monitoring of hospital-acquired infections at 12 intensive care units (ICUs) serving adult patients, and 3 ICUs for neonatal care at the Vienna General Hospital. The Philips Care Vue intensive care medical information systems installed at the ICUs provide the necessary data. Arden Syntax, the service-oriented architecture, the extended medical knowledge packages, and the developed web-based user interfaces create a powerful tool for CDS at the infection control unit of this hospital.

Keywords:
Clinical decision support, Service-oriented architecture, Arden syntax, ICU, Hospital-acquired infections.

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Forward Chaining Inference vs. Binary Decision Support in an Electronic Health Record Application Based on Archetyped Data

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The implementation of computerized health information systems has a potential effectiveness related to the use of decision support engines. Decision engines based on Boolean logic are one of the most prevalent in current implementations, but the complexity of healthcare information does need more robust solutions, especially in fully implemented, semantic-sensitive, electronic health records. The purpose of this paper is to investigate the effects of two common approaches to decision support in Electronic Health Record (EHR) applications. The EHR uses archetyped data based on the multi-level modeling principles initially described in the openEHR specifications which were foundational to the formation of the ISO and CEN 13606 EHR standards. Forward chaining using CLIPS rules was compared to if-then-else constructs in terms of performance and code size. The results showed that forward chaining was much faster and required less coding, besides being more easily to maintain. The accuracy of the forward-chaining engine was 100%, considering the Boolean-based engine as the gold standard. This study confirms the validity of CLIPS-based inference engines for decision support in healthcare.

Keywords:
Computer-assisted decision making, Clinical decision support systems.

A View on the Current State of the MedFrame/CADIAG-IV Project

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CADIAG-IV is a data-driven fuzzy diagnostic expert system for computer-supported consultation in internal medicine based on the PC-based medical expert system shell MedFrame. MedFrame provides a medical institution with a set of powerful tools for developing knowledge bases and inference mechanisms and applying them as expert systems in clinical routine. CADIAG-IV is the first expert system completely based on MedFrame, significantly extending the usage of fuzzy concepts compared to its predecessors CADIAG-II and -III. After the implementation of the MedFrame core components, a high level inference engine for rule-based knowledge bases has been implemented and used for the realization of the CADIAG-II/-III inference process. In addition, the CADIAG-II/RHEUMA knowledge and patient data have been transferred from the original IBM host system to MedFrame. Currently, the realization of the CADIAG-IV inference, the integration of additional MedFrame components, and the implementation of the user interfaces is in progress. The results achieved so far confirm the applicability, correctness, and performance of the MedFrame concept and the CADIAG re-implementation.

Keywords:
Medical expert system, MedFrame, CADIAG, Fuzzy logic, Rheumatology.

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A Decision Support System based on Meta-heuristics and MCDA for Healthcare Service and Technology Optimal Location

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Regional managers must often deal with the necessity to correctly distributed healthcare services in their territory. The traditional approach taking into account only political considerations is risky. In order to improve the robustness of the solution it is better to add quantitative and objective information (such as patient numbers, travelling times and travelling distances) to the political criteria that control the decision-making process. In this work, we deal with the problem of choosing the facilities in which new expensive complex devices can be placed in order to improve the health care services offered by a regional health system.

Keywords:

Decision support systems, MCDA, Meta-heuristics, Biomedical devices

Modelling a tool for evaluation of innovative therapies

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Health economics are often related to the evaluation of health centres or the cost of innovative treatments, their reimbursement and effectiveness. In this paper we suggest an original model to evaluate a radiotherapy hospital network. Our study is based on informatics modelling and simulation. Its aim is to create a prototype for medical and economic evaluation. We suggest some hypothesis in order to evaluate the recruited population for each centre. Our design takes into account the characteristics of the patient, the description of the centre and the competition between health centres. The economic evaluation includes the cost description of a whole centre: construction investment and functioning. The final goal of our prototype is to compare different situations of recruitment and multiple health politics, referring real situations.

Keywords:

Simulation, Design, Radiotherapy, Evaluation

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Allergy and cross-allergy medication decision support

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Checking known allergies when prescribing is mandatory, but time consuming. Few (if any) clinical decision support (CDS) databases contain information on cross-allergy reactions. This new centralized CDS module makes access to allergy as well as cross-allergy alerts available to hospitals. A centralized CDS service based on SNOMED CT allergy structure and a specially developed cross-allergy table is configured to work together. The CDS will respond to automatic web service requests from the hospital electronic medication system (EMS) during prescription and return allergy and cross-allergy information and alerts. The result is clinically useful information physicians can use as a basis for a more effective and safer treatment.

Keywords:
Decision support systems, Clinical - systematized nomenclature of medicine - hypersensitivity.

Peri-operative Diabetic Care Monitoring and Support System

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A computerized clinical guideline at the point of care is more efficient than a paper-based clinical guideline. Peri-operative diabetic care monitoring and support system were developed to enhance in-hospital care. It consisted of a computerized peri-operative diabetic blood sugar control guideline and diabetes alert monitoring system. The computerized peri-operative diabetic blood sugar control guideline was developed by diabetic center of Asan Medical Center, based on clinical data and existing paper-based clinical guidelines. The diabetes alert monitoring system was designed to monitor diabetic inpatients related data- hyperglycemia, hypoglycemia, abnormal hemoglobin A1C, inadequate anti-diabetic agents, etc. This system was managed by diabetes alert team in real-time. Effectiveness of this system and impact on improvement of diabetic care need more time.

Keywords:
Peri-operative, Diabetes, Clinical decision support system, Glucose control, Clinical practice guideline

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Decision Support System in diagnoses and prescription of physical activity

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The physical activity as well as exercise, have become allies in the prevention of diseases, especially those of chronic degenerative character. While it is agreed that the practice of physical exercise has a beneficial role for the health of the population, especially for the elderly; the health professional, because of a lack of specific training, has great difficulty to steer and guide their patients to a physical education professional to prescribe exercises that produce real benefits. The aim of this study is to diagnose behavior regarding physical activity, determine the optimal dose of exercise to be prescribed based on evidence, and integrate prescription of physical activity to the patient and medical records. This application, its validation and the evaluation of a new protocol could contribute directly to the prevention of chronic degenerative diseases.

Keywords:
Medical informatics, Physical activity, Physical activity prescription, Decision support system.

Development of a clinical decision support system for facial growing analysis by the cervical vertebral maturation method

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Thinking about prevention and early treatment of dentofacial deformities, which require care, as correct diagnosis and proper planning, determine the stage of skeletal maturation is very important to identify the growth phase of the patient. New Cervical Vertebral Maturation (CVM) method was used as a foundation to build a clinical decision support system (CDSS). One of the advantages of this method is that there is no need for additional x-ray exposure, once the cephalogram is already part of the orthodontic documentation of the patient. This study presents a CDSS under development, that helps the orthodontist determining the optimal timing to treat a series of dentofacial deformities. To build this system, classifiers were evaluated using a open-source software package. A preliminary assessment showed that the CDSS inference engine (IE) presented 81.88% of accuracy, indicating that the CDSS can have better precision, quality and productivity on CVM analysis.

Keywords:
Clinical decision support systems, Cervical vertebrae, Cephalometry, Dental informatics, Orthodontics

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Clinical Decision Support System in Celiac Disease Diagnose

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Diagnosing celiac disease (CD) is a complex task as it has several signs and symptoms common to the other diseases. The gold-standard for CD differentiation is the biopsy analysis of the small intestine. This study aimed at developing and evaluating a web-based clinical decision support system, including an automatic classification tool to recognize cases of CD. The system was designed to be friendly, and useful for CD treatment and follow-up. Phase I of the study concerned the implementation of a web-based system that comprised an electronic form for data collection. This system's usability assessment was carried out using the System Usability Scale (SUS). Phase I made possible the creation of a framework for clinical data recording, as well as the standardization of medical investigation procedures. The mean SUS score of 83.5±10.0 obtained showed the system's high level of usability. The present study is expected to contribute to establishing a computational resource to help CD diagnosing.

Keywords:
Clinical decision support systems, Celiac disease

A Clinical Decision Support System for Needs-driven Telemedicine Technology Development

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A telemedicine workstation was installed as pilot project at the Grabouw CHC in 2004/2005 to enable the communication of diagnostic information between CHCs and hospitals. Part of the eventual suspension of the pilot implementation of the telemedicine workstation at Grabouw CHC could possibly be attributed the fact that the technology-push phase was not preceded by a formal needs assessment. The paper presents the rationale and design behind a Clinical Decision Support System (DSS) to enable in future a needs-driven telemedicine workstation development.

Keywords:
Telemedicine, Telemedicine workstation, Clinical decision support systems

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A Comparison of Collaborative Filtering Methods for Medication Reconciliation

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Maintaining an accurate list of a patient's medications is a very challenging task for which the current solution is a process driven medication reconciliation approach. In this study, we extend our original data driven approach through the use of collaborative filtering algorithms to improve the accuracy of the medication list and test them using medication data from a long-term care clinic. The results are encouraging and suggest several promising directions for the future, including embedding these methods in current medication reconciliation processes and evaluating them in actual clinical settings.

Keywords:
Patient safety, Medication reconciliation, Collaborative filtering

A Decision-support Program for the Analysis of Sexual Maturation – A Novel Approach

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Introduction: Adolescents represent roughly 21% of the population, constituting a group with low demands for health services, but pubertal development evaluation represents a challenge to primary care physicians (PCP), who provide the first line of medical attention. Objective: Provide non-specialist medical practitioners with information on puberty and sexual maturity, through a user-friendly, knowledge-driven instrument for point-of-service (POS) use. Methodology: develop a Java™-based, decision-making system related to puberty and sexual maturity capable of running on Mac™, GNU Linux and Windows™ OSs. Results: The clinical decision support system (CDSS) comprises a Java™-based inference engine with 127 production rules and graphical user interface. Based on the construction of the knowledge base a 591-entry glossary was generated for user help. Information was evaluated by comparing the results generated by the system and those reported by 9 specialist medical practitioners. The evaluation rendered by specialists and the system was statistically significant by 1% with 77% of the specialists and their respective groups. The user interface was positively evaluated regarding all aspects by 55 physicians. Conclusion: We have collected information on puberty and sexual maturity and used that to develop an CDSS comprised of 127 production rules. The system was evaluated and displayed adequate performance when compared with diagnoses reported by specialist medical practitioners, and its user interface was validated by physicians. Due to the fact this is an open-source, Java™-based system, we believe it is suitable for deployment in the public healthcare system.

Keywords:
Expert system, Decision-support system, Clinical decision-support system, Knowledge-based decision-support system, Sexual maturation, Puberty, Anthropometry.

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Detection of High-Risk Patient for Drug Overdose in Renal Insufficiency

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Drug overdose in renal insufficiency is a major source of inpatients morbidity and, even mortality. Traditional drug overdose detection information system requires reference knowledge base (KB). However, KB is hard to build up, and KB maintaining requires much efforts. The purpose of this study is to develop a simple and portable detection algorithm for high-risk patient for drug overdose in renal insufficiency, even without a renal dosing reference KB. The detection model uses support vector machine (SVM) algorithm and requires 7 usual patients' and doctors' information. The model showed 83.81% of accuracy and 0.78 of AUC.

Keywords:
Drug overdose, Adverse drug events, Support vector machine, Renal insufficiency

Secondary data usage - driving quality change at point of entry in acute care settings

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Since 2002, infection prevention consultants (IPC's) in public hospitals in Victoria, Australia, have been collecting healthcare-associated infection (HAI) surveillance data on paper, and have been sending this into the VICNISS Coordinating centre (VCC) for collation, analysis and reporting. Some of these data are retrieved from existing electronic systems while other data has to be gleaned from the paper medical record. The VCC has developed a software application for the participating hospitals, known as SHIINe (Safer Hospitals Integrated Information Network) to facilitate HAI data collection, analysis and reporting. This software links to patient information systems, including the patient master index, theatre lists, and pathology systems. Through this, we hope to achieve more accurate and efficient data collection/input, to save IPC time, facilitate local report generation and achieve more timely, and hence more useful, data feedback. During integration of the SHIINe application into public hospitals, we found significant problems with data quality. These problems were not isolated to any one hospital or database. This finding prompted internal reviews of data entry / quality within these hospitals. Exposing the need for the electronic availability of quality data for secondary usage worked as an effective enabler for hospitals to improve their point of data entry practices. This made an important contribution to ensuring accurate and high quality patient data is recorded in these hospitals for purposes including and beyond HAI surveillance.

Keywords:
Hospital infections, Data sources, Data quality.

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Clinical Information Systems – A Universal approach to Structuring the Clinical Artefacts and Elements

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To develop a patient centric clinical system which has universal application across the full range of Clinical Pathways requires all clinical content artefacts to be uniquely named and structured, such that all elements can be re-used and that the needs of all clinical practitioners are recognised and supported. The key objectives were: 1) Harmonisation of language associated with the different professional groups and care settings, 2) Incorporating existing concepts in use across the NHS, including dependency models and classification schemas, 3) Demonstrating that generic, speciality initiated and disease focused actions could be grouped by pathway milestones along a Clinical Pathway, 4) To enable innovative changes to care delivery models

Keywords:
Clinical pathway, SNOMED clinical terms, Medical record linkage

A Preliminary Assessment of the Clinical Knowledge Management Capabilities of Commercially-available Electronic Health Records

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We undertook a study to explore the availability of various clinical knowledge management features, functions, tools and techniques provided by nine commercially available electronic health record (EHR) vendors serving the U.S.A. marketplace. We developed and fielded a 17-question survey to make these assessments. The survey asked questions about 1) the vendor's electronic health record (EHR) product, 2) the clinical decision support-related system tools and capabilities that each vendor provide, and 3) clinical content. The majority of the systems were capable of performing almost all of the key knowledge management functions we identified. If these well-designed systems are coupled with the other key socio-technical concepts required for safe and effective EHR implementation and use, we expect that the transformation of the healthcare enterprise that so many have predicted, is just around the corner.

Keywords:
Clinical decision support systems, Knowledge management, Computerized medical records systems

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Towards an integration of workflows and clinical guidelines

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The integration of workflows (WFs) and clinical practice guidelines (CPGs) modeling healthcare processes is a hot topic of research in Medical Informatics. Many computerized approaches have faced this problem, mostly extending current WF or CPG approaches to represent and manage integrated models which merge the content of both CPGs and WFs. We devised a case study, showing that there are many differences between CPGs and WFs as regards contents, focus, goals, users and editors. On the basis of such an analysis, we propose a different approach to integration. Our approach reconciles (i) the need of performing inferences on the integration of WK and CPG knowledge, with the users' requirements (ii) to focus only with the aspects of knowledge they are interested in, and (iii) to have a user-friendly representation of such a knowledge.

Keywords:
Clinical practice guidelines, Workflows, Integration

Unlocking Medical Archives with Multi-Modal Content to Deliver Enhanced Analytics

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A large number of healthcare institutions have significant stores of medical archives in their data centers, archive rooms and virtual records centers. Unfortunately, these archives are often kept only for administrative and or legal reasons and are not leveraged to enable differential diagnosis or operation efficiency. The traditional focus by academia and industry on analytics of textual data stored in databases, content management systems and the Web must also be augmented to handle multi-modal data that is prevalent in medical archives. We present technology that allows the extraction of the informational value derived from analyzing these multi-modal archives and the integration of this value into the healthcare entity's core decision support and research systems, in order to improve the entity's analytic capabilities.

Keywords:
Archives, Analysis

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Collaborative and Distributed Guideline Modeling in the Dementia Domain: An Evaluation Study of ACKTUS

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The task of transforming informal knowledge residing in individual experts and in domain knowledge sources to formal structures in clinical decision-support systems (CDSS) is addressed in this work. The system ACKTUS is currently being developed for informing the design of the user interface of a web-based CDSS for dementia care, and for functioning as a tool for development and updating of the integrated knowledge in an international collaborative setting [1].

Keywords:

Knowledge acquisition, Knowledge management, Evaluation, Dementia, Clinical practice guideline, Argumentation, Clinical decision-support systems

From Knowledge Management to Translational Research by Combining Clinical and Experimental Data with Public Available Knowledge for Breast Cancer Research

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Breast cancer therapy is confronted with the problem, that after surgical treatment and adjuvant therapy metastases occur in nearly 20% of patients independently of the lymph node status. The prognostic and predictive factors available allow prediction of recurrence with only moderate accuracy. This results in the fact, that the major proportion of patients gets adjuvant therapy of different kind although only a minority needs it. To predict metastasis risk we want to identify a risk pattern consisting of different biomarkers of postmenopausal breast cancer patients. Additionally data from public databases and knowledge from MEDLINE is combined with the experimental data in the BioXM platform.

Keywords:

Breast cancer, Metastases risk, Knowledge management, Data integration

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MediGrid Ontology for Description of Biomedical Algorithms

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Algorithms and recommended guidelines are one of the traditional tools for representation of knowledge in biomedicine. Using retrospective analysis of algorithms represented in medical literature and transformed into computer applications, we constructed a domain ontology of medical algorithms. This ontology is based on a phenomenological description of data processed by algorithms as indicators, which are transformed into other indicators.

Keywords:
Medical algorithms, Knowledge base, Biomedical ontology.

Metadata for clinical knowledge resources

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Both health professionals and patients/citizen today firstly turn to the world wide web to obtain health related knowledge. Important issues are: 1) How to find relevant documents that are appropriate for the reader and situation and 2) How to ensure that the found knowledge documents have a sufficient or at least declared quality control process? One way to address these questions is to use a standard set of metadata to be provided for each knowledge resource. A standard first developed in Europe CEN/TS 15699 is further developed into ISO 13119. In this paper the following questions are raised: 1) What are the possible uses of a standardised set of metadata for knowledge resources in health? and 2) What are the basic principles of the new standard

Keywords:
MZetadata, Decision support systems, Clinical knowledge resource

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Specialist Bayesian Pediatric Anthropometric System

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Monitorng growth is an important resource for evaluating the health of individuals and society. However, many Brazilian children are cared for by doctors who have not been trained as pediatricians. This study deals with the proposal and validation of a decision making support system to assist doctors who are not pediatricians to interpret anthropometric and graphic growth data, assisting them to carry out procedures relating to patient investigation, referral and follow-up. The system used a Bayesian network.. Validation compared the performance of the system, as well as the performance of general practitioners and pediatricians in relation to a gold standard developed by specialists. The overall sensitivity of the system was 84.5% whereas that of the pediatricians was 55.1% and that of the general practitioners was 46.5%. Specificity was 78.2%, being very close to that of the other groups. The system showed itself to be statistically valid for implementation in public health services, its performance enabling it to be used not only by general practitioners but also by pediatricians.

Keywords:
Bayesian network, Artificial intelligence, Anthropometry

Understanding Cognitive Artifacts: The Criticality of Multi-Method Study

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Cognitive artifacts are evidence of user knowledge and information needs. Cognitive artifacts have embedded clues to how they support the cognitive work of users. Developers often convert frequently used cognitive artifacts to IT applications. Before development of these applications, the purpose, value, use, and meaning of the cognitive artifact must be fully understood. Absent this understanding, these applications may increase the cognitive load of healthcare practitioners (HCP), increasing patient safety risks. Multi-method study of cognitive artifacts promotes a thorough understanding of how they support working memory, cognition, and critical thinking. This poster describes the iterative value of multiple methods to gain a robust understanding of personal clinical cognitive artifacts (PCCAT) prepared and used by nurses.

Keywords:
Cognitive artifact, HER, System design, System analysis, Research methods

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Appliance of a Agile Pattern Language Framework for Harmonizing the Intercommunication of Research Results in the eHealth Domain

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This article presents an approach for arranging, allocating and interchanging the gain in knowledge and experience during projects of the eHealth sector and related domains. The know-how is transcribed into design-patterns, whose concept has proven its effectiveness in versatile areas. A framework for specifying the pattern-structure that meets the specific requirements of the medical domain is defined.

Keywords:
Man-machine systems, Knowledge, Human engineering

Supporting medical decision in telecardiology: a patient-centered ontology-based approach

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The objective of the AKENATON project is to improve alert management and to support patient-centered medical decision in telecardiology. This requires to integrate information transmitted by implantable cardiac devices with clinical data extracted from patient. We present the role played by the ontology in the system for data integration and for decision support.

Keywords:
Ontology, Decision support techniques, Artificial cardiac pacemaker, Defibrillators

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Ontology of dental emergencies for diagnostic classification

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Computer assisted diagnosis systems are required to improve diagnosis and compliance with clinical guidelines. Expert systems have shown their limitations as they are difficult to maintain, to check consistency and to update knowledge. Current ontology editors like PROTÉGÉ and associated tools enable easy building and maintainance of knowledge bases and allow automated consistency checking with reasoners as Pellet. Can these tools be used for computer assisted diagnosis? This study aims at creating an ontology of dental emergencies and evaluate diagnostic classification possibilities of current generic reasoning tools.

A Framework for Integration of Data from new Technologies into the Clinical Workplace

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New technological developments, methods, and therapy procedures in health care lead to an overwhelming flood of individualized data. This huge amount of data needs to be faced at each encounter. A framework was developed to analyze the effects of the multilayer aspects of the information overload from new technologies even before these will be applied in practice to the patient physician communication in shared decision making processes. This framework is visually integrated into the hospital information system at the University Medical Center Goettingen.

Keywords:
Data display, Information management, Medical informatics applications, Decision support system

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Use of Fuzzy Logic in Quality Indicators and Applicability to the Arden Syntax

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Background: Fuzzy logic constructs have been suggested for the Arden Syntax to represent imprecise reasoning. Prior work has demonstrated their widespread presence in clinical practice guidelines (CPGs). Objective: Assess the prevalence of these constructs in quality indicators (QIs) to determine their utility in Arden. Methods: Fuzzy constructs were tabulated in a corpus of 392 QIs. Results: At least 1 construct was present in 50 QIs (12.8%). A total of 70 constructs were present, including 52 characterizing the degree of a state, 15 characterizing some inference and 3 denoting some temporal association. Conclusion: Fuzzy logic occurs commonly in QIs but not as commonly as in CPGs. Fuzzy constructs in knowledge formalisms may facilitate implementation of QIs.

Keywords:

Clinical decision support systems, Knowledge bases, Fuzzy logic.

Terminology & Standards Integration: Development of an Institutional Structured Reporting System

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A structured reporting system was designed to organize the radiological information into knowledge trees. Each one of these trees' concepts is represented in our clinical terminology server. The reports are generated and stored as a Clinical Document Architecture Release 2 including the narrative text, the links to the images, and each finding and observation represented as a coded entry.

Keywords:

Radiology information systems, Methods of documentation, Clinical document architecture, Controlled vocabularies.

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Knowledge acquisition for clinical trial phase categorization

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Phase classification is crucial for correct assessment of the scope of a clinical trial. The Ripple Down Rules method is used to develop an automated decision support system for classification. After training by human experts, the automated classification responses of the system are evaluated.

Keywords:
Clinical phase, Trial, Knowledge acquisition, Ripple Down Rules

Towards a process for Augmented Surgery Evaluation

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Quality evaluation in the field of Augmented Surgery (AS) is strategic for public health policy. Such an evaluation is complex, multi-factorial and not standardized. It first implies to be able to discover and to formalize the knowledge on the domain targeted by the device and to structure it. This paper presents the application of this approach to the evaluation of the Delivered Medical Service (DMS) during navigated knee surgery. Encouraging results are reported: a new relevant criterion has been discovered for the DMS evaluation of a device in AS.

Keywords:
Augmented surgery, Delivered medical service, Computer-assisted surgery, Quality, Medical device, Surgical model.

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Association Rules Mining Based Clinical Observations

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Healthcare institutes enrich the repository of patients' disease and/or risk factor related information in an increasing manner which could have been more useful by carrying out relational analysis. In this paper we have implemented Association Rules mining based a novel observation technique for finding co-occurrences of different clinical states (disease/s, risk factor/s) for a patient by using the healthcare/clinical data repository, applying different constraints (age, sexuality, profession) against the data.

Keywords:
Clinical states correlation, Association mining, Healthcare

Effect of change in life style on control of blood glucose in diabetes type 1 patients

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Diabetes Mellitus is a chronic disease which requires continuous monitoring. This control involves the recording of blood glucose measurements. Various changes in life style can affect blood glucose level but the overall balance is the result of these effects and changes in the dose of insulin. For better evaluation of changes in blood glucose, its deviation from the average value for each person in each period of the day was considered. In this research, the effect of some of these changes in life style including food intake, physical activity, napping, alcohol consumption, illness/ infection, menstrual period, stress and holiday/trip on blood glucose was evaluated. This study shows that in most of these changes in life style, the injected insulin dose is higher than required and should be better adjusted.

Keywords:
Diabetes mellitus, Telemedicine, Life style change, Blood glucose, Disease management.

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Interactive Assessment to Support Patient Care in Children With Cancer

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SiSom is a computerized, interactive assessment and communication tool to help children with cancer report symptoms and problems through animations, pictures and spoken text, and to assist clinicians in providing patient-centred care. In this exploratory study that tested effects of SiSom in patient consultations we found significant group differences in favor of the intervention group in number of symptoms addressed; level of child participation; and number of times the physician directly addressed the child. The study showed beginning evidence that SiSom can significantly improve patient-centered care for children with cancer.

Keywords:
Interactive assessment, Children, Cancer

Preliminary Estimation of the Disease Management Program in Japan: Relationship between Risk Factors and Medical Cost

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Since the 2008 health care reform, medical care insurers have an obligation to provide a specified health examination and health guidance for all Japanese people aged 40 to 74. This policy aims to decrease the number of patients with metabolic syndrome and the medical expenditure. Health examination results submitted in Health Level 7 (HL7)/ XML format are currently stored in a national database. This database also stores medical fee claim data to be utilized not only for statistical tracking but also for academic research. This preliminary study aims to clarify the relationship between metabolic syndrome risk factors and medical cost using log-linear regression analysis. Our study suggests that the medical cost per person in the high-risk group was higher; however, the ratio of the cost per person in the high-risk group to the total medical expenditure was lower than that of the other groups. Therefore, medical cost containment in Japan depends not only on health guidance for high risk groups but also on health education for no-risk groups that aren't targeted in the current program.

Keywords:
Specified health examination and health guidance, Medical cost, Disease management

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Schematic Framework for Clinical Language Technology Development in Intensive Care

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Fluent patient information flow is a prerequisite for clinical decision making. However, the flow is fragmented in intensive care. We identify interfaces for language technology components to support the flow. We present the components of profile-building, support-to-writing, attention-focusing, summarizing and proof-reading in a schematic framework. It covers the entire intensive care process and enables developing comprehensive software solutions by tying components together.

Keywords:
Computerized patient records, Critical care, Decision making, Intensive care, Natural language processing.

RIS-driven mining and visualisation of second-opinion candidates for telemetric-driven diagnostics

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Second-opinion in a diagnostic workflow improves quality but the lack of information who could be an expert according to a supposed finding is prejudicial to a general use. The aim is to encourage peer-to-peer second-opinion processes by context-sensitive visualization of experts with integrated links to picture- and voice-over-internet communication for ad-hoc collaboration.

Keywords:
Radiology, Diagnostics, Collaboration

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Semantic Search for Clinical Evidence Using PICO Framework

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Evidence based medicine (EBM) aims to apply the best available evidence gained from the scientific method to medical decision making. To make a best practice of EBM, we need to provide users an effective and efficient way to find the useful evidences. In this paper, we describe a PICO framework [1] based semantic search engine for clinical evidences. Our system has three features. Firstly, our search engine supports the searching on specific PICO elements. Secondly, our search engine integrates well defined knowledge in healthcare domain, such as SNOMED CT [2] (Systematized Nomenclature of Medicine - Clinical Terms), such that more complete search results could be returned. Finally, we extract key information of an evidence and display it in search result snippet to assist the critical appraisal phase in EBM. A preliminary evaluation is conducted to demonstrate the effectiveness of our system by comparing it with the keyword search on Cochrane Database.

Keywords:
Evidence-based medicine, SNOMED CT, IR

Automatic Clinical Alert Creation And Decision Support Through Real Time Event Monitoring And Active Data Feeding

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Manual alert input and activation is prone to missing and error. This paper illustrated the potential clinical benefits of an architectural model of continuously screening of clinical data in huge clinical data repository and actively feeding data into an integrated alert framework for automatic alert creation. To illustrate the feasibility of this generic model, a routine screening laboratory test results of Glucose-6-phosphate dehydrogenase (G6PD) in a huge data repository was continuously monitored, screened and fed into an alert framework where G6PD deficiency alert was automatically created in the electronic patient records according to pre-defined clinical criteria. Over three months after live run of the new services, 77 G6PD deficiency alerts were created by continuously screening of 2,073 G6PD reports among 34M of new laboratory results in the study period. Clinicians could be alerted and medication decision support would be activated to prevent clinicians from prescribing contraindicating medications. The model was shown to be performing, reliable and facilitating clinical care.

Keywords:
Alert, Clinical decision support, Event monitoring, Clinical data repository, Automation

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Generating RELAX-NG Schemas for Radiology Reporting Templates

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The objective of this work is to develop RELAX-NG schemas for representing radiology report templates that can be used in creation and validation of XML-encoded structured radiology reports.

Keywords:
RELAX-NG, Radiology, Structured reporting

Shared Drive: Information sharing in a dietetic service

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This poster presents a project on information sharing needs in a UK Nutrition and Dietetics Service. Against the web of permissions and access levels in the existing system, results from the project were used to streamline the business and information management processes through mapping shared and private information, then designing and implementing an adaptable information repository with well structured management and storage frameworks. Training needs were analysed and mapped to improve practice and so efficiency, effectiveness and quality of existing and future information, as well as conformity to information governance requirements.

Keywords:
Information storage, Retrieval, Sharing, Governance.

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Automatic speech recognition for the generation of medical reports studies

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We compare the performance of the computerized speech recognition system to convert voice medical radiological reports into text with the conventional hand transcription. We used the "Dragon Naturally Speaking Preferred Spanish version number 10" program. Automatic Speech recognition decreased the transcription time and reduced substantially the transcription costs. Speech recognition by computer is practical in radiological reports implementation. In our study, we found that hand writing transcription of digitized files of short Spanish radiological reports has an error of 5% compared to the gold standard. This grows to 13% when using the automatic speech recognition system, only 8% difference. Automatic speech recognition programs are useful for text transcription of short radiological reports in Spanish. We cannot say the same for other languages or clinical applications and, in each case, it would be advisable to test its efficiency.

Keywords:
Computerized speech recognition, Voice medical record, Text conversion

Web-based Case Reports Retrieval System by TF*IDF Method

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To learn from similar cases is one of the most important and beneficial processes for clinicians when they encounter a difficult case to make a diagnosis or decide treatment. Most of the databases of case records, however, were not available for comprehensive search. We built a database of more than 15,000 case reports from the Japanese Society of Internal Medicine as well as extraction of case reports from MEDLINE and conducted morphological analysis. Now we can provide to Japanese physicians the option to search for similar cases through the internet by using the TF*IDF method from JSIM homepage.

Keywords:
Case reports, Clinical laboratory information system

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An approach for a medical ontology based on UMLS to improve information retrieval in German language clinical text documents

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A large number of free text documents are created in clinical practice every day. These documents often contain critical information for clinical decision-making however automatic information extraction is complicated. Here we present an approach whereby an existing prototype for a medical information retrieval system is extended. Using a suitable knowledge representation, the mapping of German language free text terms and phrases to corresponding concepts is facilitated.

Keywords:
UMLS, Semantic, Information retrieval, NLP

Using Semantic Relations Extracted from Medline for Biomedical Question Answering

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It is challenging for biomedical researchers to stay current with the literature in their field. Information retrieval systems are widely used; however, they return documents that have to be read by the user to extract relevant information. We propose a methodology for question answering implemented in a prototype tool which returns answers (known facts) first, and only later the documents from which the facts are extracted. Our question answering methodology is based on semantic relations extraction from Medline with the SemRep natural language processing system. The extracted relations are organized in a database and made available for searching through a Web-based tool. Our approach is able to provide answers for a wide array of questions that arise in clinical work and biomedical research.

Keywords:
Text mining, Natural language processing, Medline, Question answering, Information extraction

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Presentation on a Method for Development of the Brazilian Health-related Content Web Search Portal

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The increase in the amount of available information on the world wide web is inexorable, which, on one hand, provides the web user with more information. On the other hand, however, web searches become increasingly more difficult to handle due to the increasing number of retrieved documents. The present study is a proposal of development for a Brazilian search portal specific for health-related content. The aim of such development is to provide web users, mainly the non-specialist ones, with the largest number possible of web pages relevant to their search terms and inferred search intentions. The usefulness of a search portal for web pages with health-related content is potentially enormous, and the challenge of its implementation is motivating.

Keywords:
Internet, Health, Information storage and retrieval, Pattern recognition system.

A Framework for Multiscale Comparison of Three-dimensional Trajectories Based on the Maxima on Curvature Scale Space

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In this poster we present a multiscale comparison method for three-dimensional trajectories. In order to deal with the problem that zero-crossings of curvature cannot be determined for space curve, we focused on the maxima of curvature. In experiments we demonstrate that reasonable correspondences were obtained on the simple but noisy trajectories.

Keywords:
Multivariate time series, Multiscale analysis, Trajectory mining.

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Data Mining validation model to predict future health care cost

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There is evidence that the use of a health care system is related to the health of its members (greater costs incurred poorer health status). An efficient manner to manage health care is through the identification of subgroups of patients with high-risk and resulting high costs, so as to optimize medical interventions. Clinical risk scores try to predict adverse medical outcomes based on clinical features and only a few scores are based on administrative data. The Health Information System allows us to design interventions based on the knowledge of possible future scenarios about health status of the assisted population. In our area, the Italian Hospital of Buenos Aires is a Health Maintenance Organization that currently assists 150,000 members whose information is systematized, standardized and stored in a Hospital Information system (HIS). In conjunction with SAS Institute, we created an analytical model. In this paper we propose to validate the model created.

Extracting Remarkable Temporal Patterns of Technical Terms in Medical Research Documents

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In temporal text mining, some importance indices such as simple appearance frequency, tf-idf, and differences of some indices play the key role to recognize remarkable trends of terms in sets of documents. However, most of conventional methods have treated their remarkable trends as discrete statuses for each time-point or fixed period. In order to find their trends as continuous statuses, we have considered the values of importance indices of the terms in each time-point as temporal behaviors of the terms. In this paper, we describe the method to extract remarkable temporal patterns by using linear trends of importance indices of technical terms related to migraine drug therapy on the documents from MEDLINE.

Keywords:
Text mining, Migraine, Drug therapy, Temporal patterns, Linear regression

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Extraction of Drug Combination related to Liver Dysfunction

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Today a great number of drugs are used in clinical medicine and because of such vast amount we cannot possibly research adverse reaction for all combinations of medicines. Here we searched adverse reaction (liver dysfunction) induced by medication retrospectively through ALT (GPT) temporal data and prescription history files at Chiba University Hospital. There were 3,240 cases of liver dysfunction which appeared during hospitalization in all 84,437 cases. We checked prescription histories of those cases and extracted each medication just before ALT reached its peak and calculated their appearance rate of adverse reaction. Some of them showed higher frequency in the combinations than monotherapy. These results require immediate medical consideration of specialists, though the method might be effective to search for the complicated or more than a three drug combination causing liver dysfunction.

Keywords:
Adverse reaction, Drug combination

Adverse Drug Events Detection by Data Mining of Electronic Health Records

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Adverse drug events (ADEs) are a public health issue. Their detection usually relies on spontaneous declarations and staff-operated reviews. The present work aims at (1) mining electronic health records to automatically identify ADEs (2) generating alert rules to prevent ADEs. Those rules will then be implemented into a clinical decision support system. Methodology: (1) data are aggregated in order to simplify their structure and to take the time into account. (2) cause-to-effect relationships are identified thanks to statistical methods. Results: data-mining of 55,000 hospital stays allows getting 255 validated rules in the field of anti-thrombotic agents and related ADEs. Other ADE-detection rules can be imported into the same repository and automatically evaluated in different medical departments. The results show the importance of segmentation and contextualization of the rules.

Keywords:
Adverse drug events, Patient safety, Data mining, Decision trees, Association rules, Electronic health records.

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Case-Based Reasoning for Pediatrics Developmental Disorders

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While 1 in 5 children suffers from Pediatrics Developmental disorders [1] (PDD), PDD specialists are operating in IT darkness; their domain is ontologically and taxonomically ill-defined and no prototypical cases or clinical decision making models are available to assist them [2]. PDD is pressing for Medical Informatics solutions, yet no prior research has been dedicated to developing Decision-Support Systems (DSS) or methodologies for PDD [2, 3]. This ongoing research is being conducted on a real-life case-base from a major PDD clinic in Israel[b], with the primary objective of constructing a robust Case-Based-Reasoning (CBR) agent to perform CBR retrieval to predict diagnoses of new cases. Heretofore we have implemented and tested the retrieval and reuse modules of the CBR cycle. Ultimately, the significance of such work is in helping to lay the foundations for a CBR system which allows clinicians to objectively utilize the whole of their collective past experience in order to individually produce better decisions in diagnosis and treatment of developmental disorders.

Keywords:
Development-disorders, CBR, LSA, LSI, DSS, Clustering-based feature weighing, Case-based retrieval

An alternative data mining oriented approach to the analysis of the long-term glucose counter-regulation to hypoglycemia in continuous glucose data

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The hypothesis of a long-term glucose counter-regulation to hypoglycemia has gained recent interest using continuous glucose monitoring technologies, but long-term studies are lacking. The aim of the study was to evaluate the phenomenon in continuous glucose monitoring data, without the assumptions regarding hypoglycemia time of day and manifestation of the long-term glucose counter-regulation found in the study designs of previous studies. We compared continuous glucose data and insulin data from people with type 1 diabetes after spontaneous hypoglycemic events with matched hypoglycemia-free control periods. No significant difference in sensor glucose was seen, but the insulin intake was higher for 24 hours after hypoglycemia. As insulin has hypoglycemic effects, blood glucose after hypoglycemia would have been elevated with similar insulin intake. The results are thus consistent with the hypothesized long-term glucose counter-regulation to hypoglycemia.

Keywords:
Type 1 diabetes mellitus, Continuous glucose sensors, Hypoglycemia

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A Cluster and Decision Trees Analytical Comparison of Compliance and Persistence to Fixed-Dose Combination versus Single Agent Combination Therapy for the Treatment of Type 2 Diabetes

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The use of combination therapy aims to reduce pill burden and increase compliance. The use of novel analytical techniques (such as clustering and decision trees) that can model and predict the outcome of patient compliance are needed. The objective of this study is to (1) assess the long-term compliance and persistence patterns in patients initiating thiazolidinedione (TZD) and metformin (MET) for the treatment of type-2 diabetes, and (2) to determine the influence of preceding therapies (history of metformin and/or thiazolidinedione) on compliance and persistence. (3) To examine features common to compliance patterns using data mining and analytical methods.

Keywords:
Cluster Aanalysis, Decision trees, Compliance, Drug therapy, Drug combinations, Diabetes Mellitus Type 2

Application of artificial intelligence techniques in renal transplantation: classification of nephrotoxicity and acute cellular rejection

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Complications associated with kidney transplant and immunosuppression can be prevented or treated effectively if diagnosed in early stages with post-transplant monitoring. One of the major problems is diseases during the first year of the transplanted kidney. To this purpose we used different classifiers to predict events of nephrotoxicity and acute cellular rejection. The classifiers were evaluated according to the value of sensitivity, specificity and area under ROC curve. The technique that had the best sensitivity rate prediction for the submission to the transplanted kidney biopsy was SVM (LIBSVM algorithm) with sensitivity rates of 0.87 (accuracy rate 79.86; specificity 0.70; AUC 0.79). A critical error is estimated in 7.5%. These results are encouraging with rates of trial and error consistent with work purpose. The purpose of this study is compare different artificial intelligence techniques in the prediction of events of nephrotoxicity and acute cellular rejection (ACR) in renal transplanted.

Keywords:
Organ transplants, Artificial intelligence, Kidney transplant, Clinical decision support system.

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Prediction of Early-Stage Chronic Kidney Disease in an HIV-Positive Population

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We assessed the feasibility of predicting an HIV-positive individual's two-year risk of developing chronic kidney disease (CKD) and examined the accuracy of several predictive models based on Bayesian networks, logistic regression, artificial neural networks and support vector machines. Our preliminary study used anonymized data from 92 patients currently seen at a specialty clinic for HIV-positive patients in Los Angeles (the OASIS Clinic). When the predictive models were trained and evaluated on the dataset of 92 patients using leave-one-out cross validation, the best predictive model was a Bayesian network model, with an area under the ROC curve of 0.693. The study suggests that computerized prediction of a CKD-free, HIV-positive patient's two-year risk of developing CKD is feasible. Risk prediction models developed for this purpose could assist clinicians in preventing or delaying the onset of CKD in HIV-positive patients.

Keywords:
HIV-associated nephropathy, Machine learning

Multi theme automatic quality detector for health web pages

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In the health information field, mechanisms to help assess quality appear to be more than ever a high priority need. The increasing volume of health information available online covers a large spectrum of health related topics. However, most of the time internet users have no indicators about the reliability of this information. State of the art approaches to address this problem consist of either machine learning algorithms or automatic evaluation with simple regular rules. In this poster, we present our multi theme reliability level based on a large corpus of low- and high quality web pages representing several health domains, complementary to our supervised detector based on generic quality criteria. We attempt to classify health web pages independently of the health domain, classifying them according to a scale of reliability. This study shows that an automatic recognition of low quality health pages was possible, with less than 2% error rate. However the question of domain dependency is still remaining and further studies are needed to evaluate the system's ability to deal with new health domain documents.

Keywords:
Trust, Health web reliability, Quality, Text categorization.

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What about trust in a question answering system?

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A question answering system (QA) aims to answer a question asked in a natural form. This paper presents a solution using an existing medical QA developed by HON and investigates whether the relevance and reliability of the answers extracted conforms to the standards of the quality and trustworthy health web pages analyzed. The evaluation focuses on the comparison of the results between the QA searches through trustworthy health documents and the Google database (which include certified and non-certified websites). Results are merged and classified by a medical expert. We use Trec-eval measures for the evaluation. As a result, for a set of 100 questions, we obtain a MAP of 59% and a MRR of 76% for QAHON_honcode. According to our results, the trustworthiness of the database used influence the relevance and accuracy of the answers retrieved by the HON QA.

Keywords:
Trust, Reliability, Information retrieval.

Extracting Diagnoses and Drug-Abuse Patterns from Italian Clinical Reports of Patients with Headache Disorders

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The ever increasing interest in extracting valuable information from heterogeneous unstructured biomedical texts has yielded important contributions. However, most of the advances concern processing English reports and literature; this growth has not been equal for other languages, including Italian. This work is focused on processing discharge summaries, written in narrative Italian, related to patients admitted into a Headache Unit with the aim of extracting the type of discharge headache and, in case of a diagnosis of Medication Overuse Headache, also the original headache type leading to it. The evaluation of the system has given satisfactory results encouraging the application of these techniques for extracting automatically other relevant clinical information not available in structured form.

Keywords:
Text mining, Headache disorders, Natural language processing

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Improving Access to Medical Literature Using Multilingual Search Interfaces

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The vast majority of the internationally-published medical and scientific literature is published in English. However, most of the world's population speaks English as a non-native language, if at all. This linguistic situation creates a barrier to access for clinicians and scientists throughout the non-Anglophone world, and first manifests itself during the literature search process. This poster describes a multilingual search system that seeks to address the linguistic barrier using a combination of machine translation and linguistic support features. The poster also describes user-centered evaluation methods for multilingual interfaces.

Keywords:
Information storage and retrieval, Bibliographic databases, Translations, Information dissemination, Access to information.

K. Organizational, Economic, Workflow and Policy Issues

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Implementing a Census Tracking System to Improve the Real Time Reporting Capability in the Cleveland Clinic Informatics System

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To improve the real-time census tracking capability in Cleveland Clinic Florida, the Census Tracking System (CTS) was developed and implemented. CTS provides not only the real-time bed usage/status in the hospital, but also data with historical trends, allowing administration to accurately predict demand and capacity on a daily basis, along with current patient flow statistics. CTS improves the overall workflow throughout the hospital by efficiently facilitating inter-departmental communication between physicians, nursing staff, and environmental services.

Keywords:
Census tracking, Real time reporting, Workflow

Utilizing Technology and Collaboration to Improve Patient Throughput and Manage 100+% Capacity

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As demand for services increases, health care organizations must be able to efficiently diagnose and treat more patients utilizing fewer resources. Increasing demand requires faster patient throughput, optimally allowing for more admissions with the same staff and space; this faster throughput provides the hospital with additional "effective" beds. Beginning in 2004, M. D. Anderson Cancer Center faced a critical bed shortage as patients boarded for hours in the Emergency Center, Admissions, and Operating Rooms while beds became available. By focusing on the inpatient discharge process, M. D. Anderson developed short and long-term solutions: 1) formation of housekeeping room turnover teams, 2) creation of an escort-assisted discharge process, 3) assignment of discharge nurses, 4) selection of an electronic bed management system. In combination, all solutions show promise in achieving greater efficiencies and potentially a longer-term reduction in length of stay (LOS) and a capacity gain.

Keywords:
Length of stay, Patient discharge, Discharge planning, Transportation of patients, Housekeeping, Hospital, Electronic bed management

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Development and evaluation of the critical pathway for endoscopic submucosal dissection

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These days, endoscopic submucosal dissection (ESD) is ac-cepted effective alternatives to radical surgery for the treat-ment of UGI superficial neoplasm. The aim of this study is to determine an impact of a standardized critical pathway (CP) and an integrated education program for the early gastric cancer patients.The ESD CP was developed and implemented in Seoul National University Hospital, from June 2007 to December 2008. The CP programs included 1) standardized protocols based in EMR, 2) the integrated education pro-grams provided by doctor, nurse, and nutritionist to the pa-tients and their family members. We have performed ESD procedure on the very admission day in pathway group, while we implemented it on the 2nd day of stay in pre-pathway group. Our standardized critical pathways and integrated education programs for the patients who undergo ESD had an effect on reducing the length of hospitalization (from 4.2 days to 2.9 days) and the hospital cost per day (from 585 USD to 365 USD) with an improved patient's satisfaction.

Keywords:
Stomach neoplasm, Gastrointestinal endoscopy, Critical pathways

Development and Implementation of Critical Pathways in Electronic Medical Records Systems for Strabismus surgery in Children

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Objectives: The aim of this study was to decrease length of stay and to improve cost-effectiveness by developing and implementing Critical pathways (CPs) in Electronic medical records systems for strabismus surgery in children. Methods: CPs have been developed and implemented since 2006. The results of average annual length of stay, the number of surgery per month, total hospitalization costs and costs per day were compared between CPs group and total patients from 2006 to 2008. Results: The rate of CPs implemented was 97.1%, and the results of CPs group were nearly same as those of total patients in 2008. Average length of stay was reduced from 3.0 days to 1.7 days, and the number of surgery increased 1.9 times, costs per day increased twice as much while total hospitalization costs has not changed in both CPs group and total patients.

Keywords*:*
Critical pathway, Strabismus, Length of stay, Hospitalization costs

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Information Lifecycle Management in Healthcare Environment: An Integrated Approach

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The scope and structure of health information is complex; so as the management of it. Since 1995, the Hospital Authority (HA) has accumulated 8.9 million patient's records in her Clinical Management System (CMS). There is an increasing demand for sharing clinical data across various CMS modules. HA has developed a model to manage her information throughout its lifecycle. The model includes developing standardization principles to ensure the semantics of the captured data is being preserved; establishing a trio-party governance structure being led by clinicians, health informaticians and information technologists; building generic services, defining roles and workflow to facilitate data capturing, retrieving, transferring, and reporting. With this model, the HA has successfully developed an efficient and effective mechanism to manage her valuable asset and support meaningful reuse of her clinical data.

Keywords:
Information lifecycle management, Information architecture

Information Needs of Charge Nurses and Intensivists in Intensive Care

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In intensive care units, the shift leaders spend substantial amount of time in selecting and combining different kind of data to support their decision making during the coordination of patient care. Most of information systems for intensive care are focused on individual patients and provide detailed information only related to direct patient care. The systems should be more process-oriented in order to serve their multiprofessional users. Based on our previous study, we developed a questionnaire to define process-oriented information needs of intensive care charge nurses and intensivists for immediate decisions (ad hoc). In this paper, we describe the administration of our survey, report preliminary results of our study and evaluate the necessity of information for ad hoc decisions of shift leaders at intensive care.

Keywords:
Charge nurse, Coordination, Critical care, Decision making, Intensive care

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Situated Coordination Through Communication: A Field Study of Operating Room Personnel

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Operating rooms and other parts of the perioperative environment are among the costliest resources in a modern hospital, and the coordination of perioperative processes can be a challenge. Situated coordination – i.e. mutual adjustment during the course of action – is an important means of ad hoc coordination in hospitals, and our main objective was to understand how well communication between perioperative healthcare professionals supported situated coordination. We used a qualitative approach conducting interviews with and observations of domain experts. We found that verbal, one-to-one and just-in-time communication was widely used to notify each other about progress of important perioperative processes.

Keywords:
Awareness, Interprofessional relations, Operating room information systems, Hospital communication systems.

The use and management of information and technology in maternal healthcare: A case study in the Western Cape, South Africa

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Maternal healthcare is one of the Millennium Development Goal areas. In maternal healthcare, expecting mothers tend to visit a number of healthcare institutions and interact with the healthcare information systems throughout their pregnancy period. The interaction with different systems makes the management of patients and their data challenging. We present the first results of a study that aims at in-depth understanding of the use and management of information and technology in maternal healthcare in South Africa through a case study in Vredenburg, Western Cape.

Keywords:
Maternal healthcare, Health services, Information flows, In-formation technology, Healthcare management

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Applying process mining techniques to analyze clinical processes

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In a competitive health-care market, hospitals must deliver high quality care while reducing costs. To accomplish this goal, hospital managers need a thorough understanding of the actual Care Processes (CPs). Diffusion of ICT tools within hospitals, provide huge collections of data, useful for process analysis. Process Mining (PM), describing a family of a-posteriori analysis techniques, can be used to extract process-related information from data. We applied PM to data from hospitals in the Lombardia region, to analyze differences and performance of their CPs.

Keywords:
Care process, Workflow, Process analysis, Process mining

The Department of Knowledge Informatics and Translation: A Case Study with Implications for Academic Medicine

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This poster presents the development of a new department in the Indiana University School of Medicine (IUSM), one that addresses a number of contemporary challenges and introduces a new construct for knowledge management. Academic medicine is faced with many opportunities that could drastically change the face of medical practice. However, few medical schools are equipped to insure that researchers and clinicians have access to the tailored knowledge they need, when and where they need it, nor can they create knowledge relationships that could lead to new research and clinical practice. This department builds on medical school strengths, requirements and a theoretical framework of knowledge dimensions to establish a new hybrid discipline that utilizes the best precepts of knowledge management and medical informatics within an academic department designed to foster future research and manage two critical cores, the library and educational technology.

Keywords:
Information management, Medical informatics, Medical schools

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Breach Notification Laws and the American Patient

Tyrone Grandison

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Since California's pioneering Breath Notification Law (CA SB 1386 Senate Bill) came into effect on July 1, 2003, there has been a significant number of states that have crafted their own breach notification laws. The intent of these activities is to notify people whose information was compromised by the companies holding their data. In this work, we study the current Federal breach notification initiative and the impact on the American patient

Keywords:
Privacy, Jurisprudence

Plagiarism Protection by Software Comparison of Biomedical Scientific Papers – *Croatian Medical Journal* Pilot Study

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Pilot study included 84 abstracts of manuscripts submitted to Croatian Medical Journal (CMJ; www.cmj.hr). eTBlast software was used to compare the abstracts with those in Medline and WcopyFind program was used to compare full text manuscripts among themselves. Seven papers were suspected of plagiarism. Electronic plagiarism detection may have to be introduced as standard procedure in biomedical journals.

Keywords:
Croatian Medical Journal, Medical informatics, Plagiarism, Research integrity, Software

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Upgrading Regional ICT Technologies for Integrated Care

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There is universal usage of EHRs among public primary and secondary care providers in the Hospital District. Integration of care between these providers has been supported by healthcare information exchange (HIE) that has been refined from point-to-point messaging to wide-area networks. The aim of this paper was to assess progress achieved by HIE in information access and care management with shared EHRs. This was done by clustering results from both reported and unpublished studies [1]. Initially, eReferral and eConsultation messaging decreased the demand for secondary care services reducing first visits to the outpatient clinic with more patients treated at less cost. Advancing interoperability of federated repositories with a regional locator system (RLS) improved information access and shared EHRs. A usability interview of 30 physicians indicated that HIE benefited 85 % of the patients in one of several ways. Finally, aggregating data from four feeder data and EHR sources into a regional diabetes register (T2DR) allowed monitoring of clinical outcomes and quality of care.

Keywords:
Shared EHR, Health information exchange, eReferral, eConsultation, Record locator service, Diabetes register

eHealth Readiness and Needs Assessment Framework for Low Resource Communities in Developing Nations

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The study of successes and failures in eHealth initiatives has led to publications on good practices in eHealth implementation. Unfortunately, not many controlled studies able to provide strong evidence have been conducted, especially in developing countries and even less commonly involving underserved communities. Based on the level of evidence currently available in the peer reviewed literature and in previous experience in the field, the authors propose a framework on readiness and needs assessment for underserved communities in developing countries. With the expectation of raising attention of stakeholders to critical factors that need to be analyzed even during the early stages of considering eHealth as a potential solution to minimize health challenges of underserved communities in developing countries.

Keywords:
Telemedicine, Readiness, Needs assessment (MeSH thesaurus) eHealth, Framework, Readiness assessment, Needs assessment, Developing country and underserved communities.

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Can It-governance make a difference in Healthcare implementation?

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Business involvement in IT decision making is crucial for successful IT implementation and ownership. The Capital Region of Denmark (Region H) established IT Governance with business executive managers as committee chairmen. The result after 2 years with this ITG model is consolidation of 6 central EHCR modules and distribution to 30.000 users. The conclusion: IT governance with business executive managers as committee chairmen ensures focus and creates foundation for clinicians' accept of new IT-implementation projects.

Keywords:
IT-governance, Healthcare implementation

Hospital Information Systems: are they sufficiently helpful for the management of patient safety? Valuable lessons from the Japanese experience

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The authors examined how electronic health record systems improved healthcare safety. According to the survey of 503 hospitals in Japan, there was a gap between the system function and the operation of medical staffs. For the aim of the effective availability of EHR systems, the authors conclude that appropriate education for medical staffs is required to improve their accuracy and secure management. The Electronic Health Record (EHR) is a crucial means for establishing collaborative healthcare processes across multiple clinical specialties. The EHR depends on integrated hospital information systems that are designed to secure patient safety whilst fulfilling crucial information disclosure demands. This poster will draw out key lessons for the development of the next generation of EHRs based upon the practical experiences of Japanese health institutions.

Keywords:
Electronic health records, Safety management, Information management, Education, Professional

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Management of Electronic Medical Records and Images

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Seoul National University Hospital (SNUH) in Korea has utilized the electronic medical records (EMR) system since 2004 and the picture archiving and communication system (PACS) since 2002 in all hospital units. Therefore, all data such as medical records and images at SNUH have been stored in the digital storages. In addition, we have been scanning all the previous paper charts for easy access. However, the standard guideline or protocol to handle digital data and storages has not established yet. In this paper, we examined all digital storages at SNUH which contain medical records and images, and then discovered that the information lifecycle management strategy (ILM) would be beneficial to improve the efficiency of hospital information system. Based on the findings, we also developed the standard guidelines for EMR and PACS data.

Keywords:
Information storage, Information management, Information resources

Lessons from Jazz-An Improvisation Model for Change Management Strategy for Computerized Physician Order Entry (CPOE)

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We can learn lessons from jazz improvisation to guide our change management practices for implementation of CPOE.

Keywords:
Jazz, Improvisation, Change management, CPOE

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Innovative collaborations to improve data flow in Community Nursing

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Royal District Nursing Service, Melbourne, Australia

This poster will explain a community nursing service project that successfully used a blend of skills and experiences in nursing informatics, project management, human resource management and a firsthand understanding of contemporary clinical practice. An innovative interface between clinical activities and financial functions ensured availability of information and data flow. The key to this interface was the development of collaborative relationships between internal departments and external funding partners.

Keywords:
Nursing informatics, Community health nursing, Economics, Organisation & administration

Trustworthy e-Health Services facilitating effective cooperation

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University of Applied Sciences, Stralsund, Germany

Effective e-Health Services have to take the business perspective into account. This is achieved by deriving a four layer structure, thereby combining IT-related and business related layers. This structure is used for designing an e-Health service leading to distributed responsibilities and allowing for mutual cooperation in a state-wide approach. The reference implementation comprises a highly reliable central infrastructure providing second opinion, emergency consultation and remotely supervised examination in radiology. The implementation includes extended means to guarantee trustworthiness on multiple levels: (i) actively controlled network and application availability, (ii) automated routine performance tests fulfilling regulatory requirements and (iii) hub-to spoke and an end-to-end authentication. As a result, about half of the hospitals of the state have signed up to the services provided.

Keywords:
Health services, Quality assurance, Health telematics, Information management system

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Qualitative Issues Influencing the Electronic Integration of Medical and Dental Data

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Limited electronic information exchange between dentists and other health professionals arises not only from technical aspects but also from cultural, financial and historical issues. We report on the assessment of these issues by identifying and modeling:1) influencing factors; 2) relations between factors. The resulting model highlights the preponderance of limiting factors, which partially explain current lack of electronic data integration.

Keywords:
Data integration, Dentistry, Dental informatics, Barriers.

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L. Standards, Ontologies and Terminologies

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Mapping a Local Drug Interface Terminology to SNOMED CT

Daniel Luna[a], Antonio Arias[a], Hernan Navas[a], Cintia Budalich[a], Marcela Martínez[a], Laura Gambarte[a], Alejandro Lopez Osornio[b], Fernán González Bernaldo de Quirós[a]

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The use of standard terminologies is one of the requirements of interoperability among different clinical information systems. In healthcare, particularly with pharmaceutical products, controlled terminology is necessary. Pharmaceuticals have multiple components and controlled terminology plays a vital role in the exchange of information among different actors in the creation of a system of electronic prescriptions. The Hospital Italiano de Buenos Aires maintains an institutional database of pharmaceutical products at a national level. This work describes the process of mapping this knowledge base to SNOMED CT. This work is intended to describe the challenges encountered during the process of mapping of a reference terminology (SNOMEDCT) to an institutional database of pharmaceutical products (local drug interface terminology), who were created for the electronic prescription functionality in a large Healthcare Information System.

Keywords:
SNOMED CT, Interface terminology, Electronic prescription system.

Implementing rules to the control modeling with SNOMED CT

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SNOMED CT utilization as the reference standard terminology makes interoperability between clinical systems. SNOMED CT provides the creation of post-coordinated terms by the users, according to each local need. Even though the creation of these terms is free, there are a number of rules defined in the User Manual of SNOMED CT that must be performed. The Hospital Italiano of Buenos Aires (HIBA) has a Terminology Server for encoding medical terms using SNOMED CT as the reference vocabulary. The Hospital Italiano of Buenos Aires performed an interoperability test with the Nebraska Medical Center and found a high error rate in the post-coordinated terms (26%). Then it was decided to implement an automatic system of rules within the agreed Terminology Server defined in the User Manual of SNOMED CT. After the rules implementation, the error rate decreased from 26% to 2%. The aim of this paper is to describe the effectiveness of the control rules modeling to the post-coordination of terms.

Keywords*:*
SNOMED-CT, Rules modeling, Control modeling, Terminology server.

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Concept Group Design For An Effective Medical Vocabulary Utilization

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The aim of the present work is to design a model pattern for controlled vocabularies subset representation (see its UML representation below). Vocabularies utilization in informatics system faces some obstacles: their model representation heterogeneity; their size and organization. The pattern we present intends to address this last problem by including artifacts for subset representation in an existing unified model for vocabularies description. This subset, composed by vocabulary concepts (also called 'concept group'), stems from and complies with actual standards and projects for vocabulary description.

Electronic Thesaurus to Recover Information on Mammography

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Faculdade de Medicina de Ribeirão Preto, Universidade de São Paulo - Brazil

The goal of this study is to propose, investigate and develop a system which can represent electronic knowledge –thesaurus- in Portuguese in order to facilitate mammography report reading for the specialist and also to improve the recovery of existing information in them. In order to do so, the technique of finding out information in databases, the thesaurus structure and development, and web language were employed.

Keywords:
Thesaurus, Mammography, Text mining

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Enhanced Mapping Method for Medical Terminology

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Medical terminology mapping imposes tremendous challenges in ensuring healthcare information sharing and developing structured physician-patient encounter documentation. Each hospital at present uses its own collection of mapping guidelines created by different departments. Though some mapping assistance programs are available, most of them focus on providing a 'suggestion list' of candidate concepts, lacking in objectivity needed for decision making, resulting in discordance in mapping results. We here propose a novel mapping method, which aims to increase trust for mapping results, and to facilitate ease of use. The method uses collective intelligence, which translates into collecting mapping results of terminology specialists, which subsequently are used as mapping guidelines for other mapping activities. The collected knowledge is housed at a remote server for efficient sharing of knowledge related mapping. The method has been implemented as an add-on module of a national terminology server called LexCare Suite.

Keywords:
Medical informatics, Electronic health records, Terminology, Information management, Knowledge.

Health Professionals' Choice of Keywords in an EHR System

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The aim with the present study was to describe how different health professions use different kind of terms when recording health care information. The Electronic Health Record (EHR) was introduced and implemented in order to improve patient safety and care quality. The EHR requires a uniform structure that includes established and shared terminologies for handling and exchanging information efficiently. Therefore it is of interest to investigate how different professions use the terminology e.g. keywords in the EHR. Eight professions' use of keywords in an EHR-system during a period of one year was investigated. The main finding is that different professions use different kind of keywords when recording health care information. The result indicates that the EHR system in the present study do not handle and exchange information efficiently.

Keywords:
Medical records systems, Computerized, Documentation

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Can a hole be inflamed? On the handling of anatomical cavities in SNOMED CT

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"Sinusitis" is, despite its name, not the inflammation of a nasal sinus cavity, but of the mucosa that delineates that cavity. In SNOMED CT this should be reflected, and all body cavities should be handled alike and in an ontologically well-founded way. A few basic theorems from the upper ontology GFO lead to a consistent handling of the problem. As a side effect, SNOMED CT would also have to improve the precision of its relations, replacing "finding-site" by "has-object" and "has-location" respectively.

Keywords:
SNOMED CT, Ontology, Anatomical cavities.

Multi-professional Terminology - a Common Language – for Needs Assessment in Social Services for Elderly in Sweden

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The objective was to develop a multi-professional terminology for needs assessment in social services for elderly persons in Sweden. Qualitative content analyses of such social services acts and focus-groups were used to create meaningful concepts. These have been linked to the International Classification of Functioning, Disability and Health (ICF) and mapped to the Systematized Nomen-clature of Medicine – Clinical Terms (SNOMED CT). The results showed ten needs areas for needs assessment of social services. The needs areas are structured in a hierarchical structure according to the ICF. The conclusion is that ICF and SNOMED CT could be used for developing a multi-professional terminology to describe the elderly persons' needs of social services.

Keywords:
International Classification of Functioning, Disability and health, Needs assessment, SNOMED CT, Social welfare, Terminology

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Multiaxial description of the French CCAM terminology for clinical procedures and mapping on the UMLS metathesaurus

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The French coding system of clinical procedures, the Classification Commune des Actes Médicaux (CCAM), is used in France for DRG databases and fee for services payment. CCAM is not included in the UMLS metathesaurus. This poster describes the mapping of CCAM on the UMLS Metathesaurus using MetaMap.

Keywords:
Semantic interoperability, Mapping, Terminology, Coding system, Multilingualism, Surgical (Clinical) procedures

Alignment between domain ontologies and SNOMED: three case studies

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Experiments on ontologies show increasingly clearly that the latter are only capable of representing small domains correctly and consensually. Hence, domain ontologies have been developed for particular applications, whereas reference ontologies tend to be used to draw together the results of specific applications. Here, we present the analysis and discussion of an alignment between three domain ontologies created by the I NS E R M UMR_S 872, Éq. 20 (OntoPneumo, OntoHTA and OntoReaChir) and the French translation of SNOMED v3.5. We propose a categorization of non-adherent decisions.

Keywords:
Ontology, Terminology alignment, Reference terminology, Inter face terminology, SNOMED.

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A method for automatic content classification in health informatics based on specialized thesaurus

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The purpose of this study is to present the results of a procedure for automatic classification of scientific articles in Health Informatics using a specific thesaurus. Statistical, vectorial, and artificial intelligence methods were applied to classify HI-related content. Statistical procedures and measures of accuracy, precision, recall, area under the ROC curve, and F1 measures were performed to measure the degree of similarity between terms of the specialized Health Informatics thesaurus and the selected articles. The percentage of accuracy achieved was 0.87, F1 measure was 0.88 and the area under the ROC curve was 0.94. The study results were positive showing a remarkable difference in the classification patterns, based on a specialized HI thesaurus, between specialized HI articles and those from Health.

Keywords:
Vocabulary, Controlled, Classification, Artificial intelligence.

Representation of Patient Terms for Symptoms and Health-Related Problems Using SNOMED CT(R)

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Given the increase in consumer-facing health-related systems, there is a need to link the interface terms used in such systems with formal representations of healthcare terms to facilitate communication with clinician-facing systems. Seven expert practicing oncology nurses used a Web-based terminology assessment and mapping application to evaluate 53-54 of 107 symptoms or problems on the "patient-friendliness" of the term and to determine the quality of match between the source terms and SNOMED CT concepts. Of 104 terms rated as user-friendly, 24 mapped to a single concept with a match quality of ≥6 for 19; 80 patient- reported multiple-term concepts mapped to SNOMED CT concepts with varying levels of match quality and; 23 terms had no appropriate matches. Single terms often present only a partial representation of a patient symptom/problem term. Reference terminology models provide a structure for concatenating concepts for complex patient terms that require multiple concepts for representation.

Keywords:
Patient symptoms, Shared decision making, Reference terminology, Interface terminology

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Generating a Disease Ontology using specialization and combinatory restriction rules

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This paper reports on the design of a method to generate a wide coverage disease ontology starting from a root concept: here Disease and using its related semantic structure we refer to as its description knowledge model as a seed to generate Disease subtypes by a stepwise specialization and controlled combination of the knowledge model's constituents organized within a primitive pre-existing domain ontology. The core algorithm was developed in Java using Eclipse. The generating module was related to Protégé as the support for the initial and generated ontologies and a connection to the DL toolbox. The generating module was also linked to ConExp used for the examination and validation of the generated ontology with the FCA toolbox. Experimental results showed us that the explicit statement of Principles of opposition of siblings in the primitive ontology provides an efficient mean to restrict the combinatory explosion and to enhance the human readability of generated hierarchy.

Keywords:
Ontology generation, Integration of terminologies, Semantic interoperability

Implementation of Interinstitutional and Transnational Remote Terminology Services

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Hospital Italiano de Buenos Aires (HIBA) implemented all the necessary changes in order to offer such services to other healthcare institutions, using the Internet as communication vehicle. The most integrated healthcare network of Chile, Megasalud decided to change their legacy system, to develop their own Healthcare Information System (HIS) and started to use Remote Terminology Services (RTS). After the implementation of these Terminology Services we tested the high performance for identifying free text added in their electronic health record, between 78% to 89% of text entered was recognized. The task of creating an institutional interface terminology provides an excellent service to the users, as they have liberty to enter information in free-text style. The aim of this study is to quantify the use of Remote Terminology Services (RTS) provided by the HIBA through a transnational and interinstitutional implementation.

Keywords:
Medical records systems, Natural language processing, Software, Vocabulary controlled, Systematized Nomenclature of Medicine.

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e-Publishing of Healthcare Code Systems

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A solution of electronic publishing of healthcare code systems is discussed. This solution supports official publication of code system content, documentations and instructions authorized by publishing authorities using digital signatures. All the code systems have both the human readable and machine processable format. Users may download code system content manually and applications may access this content through web-services. The solution is based on uniform data model of the code systems and on web-services specifications defined in ISO/HL7 FDIS 27951. Code system content and metadata are prepared using ISO/IEC 29500 workbook format. So this solution may be used internationally and may be considered as a source for ISO technical report.

Keywords:
Code system, Health informatics standard, Interoperability.

Status of Interoperability Requirements related to IHE Integration Profiles in Finland

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IHE (Integrating the Healthcare Enterprise) integration profiles provide means for uniform application of central interoperability standards for specific use cases in healthcare. This paper reports the results of a national survey and interviews which explored the current integration needs of healthcare organizations, application vendors and national health IT initiatives in relation to the requirements covered by IHE profiles. Factors influencing the adoption of external profiles or implementation guides of standards for local or national projects are discussed.

Keywords:
Interoperability, Standards, IHE, Health information systems

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Modeling and Integrating Terminologies into a French Multi-terminology Server

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The aim of the present work was: 1) to design a terminology meta-model (see its UML representation below) into which all terminology models can be integrated, 2) to design and to implement a process capable of integrating terminologies into a French-language health multi-terminology server, and 3) to map these terminologies.

The Development and Application of a Korean Clinical Data Dictionary

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Several English-speaking countries have already been developing concept-based clinical data dictionaries for effective data integration and management that guarantees interoperability in EMR environment, but such dictionaries are hardly usable in non-English-speaking countries, and this cannot be resolved simply through translation. In mixture environment Korean and English, we are in need of a clinical data dictionary for overcoming the problem. For that reason, we developed a Korean-type clinical data dictionary and proved its usefulness with EMR. As a result, we confirmed that our Clinical Data Dictionary has structure and contents that can effectively support the integration of data in different clinical environments.

Keywords:
Medical data dictionary, Data dictionary for EMR.

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An attempt to develop a fast and intuitive user interface for searching, identifying and comparing LOINC® Codes – The LOST (LOINC Search Tool)

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The increasing application of information and communication technology in healthcare delivery makes the utilization of domain specific languages necessary to ensure semantic interoperability between information systems. Although the basics for implementing interoperable systems already exist, there is a lack of simple aiding tools for working with these domain specific languages. The available tools for working with the current version of LOINC do not support efficient and simple functions for browsing or comparing terms. Therefore a simple user interface for searching, identifying and comparing LOINC terms has been developed. After deciding upon the technologies to use, the LOINC Search Tool (LOST) has been implemented as a Java™ application. The user interface has been designed using the paper based prototyping approach. The result of the implementation is a simple graphical tool for searching, identifying and comparing terms from the current version of the LOINC nomenclature. The practical value of the application has to be validated by analyzing user feedback, but the LOINC Search Tool has the potential to facilitate development of semantic interoperable communication in healthcare networks.

Keywords:
Informatics, Software, Logical Observation Identifiers Names and Codes.

Dementia: An under-coded problem

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Dementia imposes a significant challenge for healthcare systems, and can be under-coded in hospital patients. A review of coding in an Australian setting identified deficiencies which could impact on funding for dementia care, and for research. Further work is needed to clarify the impact of coding on decisions about funding for dementia care and research.

Keywords:
Dementia, Coding, Funding

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Evaluation of a program for identifying patients with diabetes from electronic health records in the information system

Leandro Biagini[a] , Alejandro Mauro[a], Claudio Torres Casanelli[a], Luisa Legorburu[a], Lisette Lucic[a], Marcela Pezzani[a], Pelayo Navarro[a], Daniel Luna[b] , Fernán González Bernaldo de Quirós[b], Marcelo Maira[a]

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Diabetes is a major cause of morbidity and mortality. Multiple strategies have been tried for managing populations that suffer from this disease; they all identified the need for correct patient identification. The objective was to assess the sensitivity, specificity, positive predictive value (PPV) and negative predictive value (NPV) of HIBA's Terminology Server (TSHIBA) for detection of diabetic patients in the Megasalud legacy health system.

Keywords:
Diabetes, Problem-oriented health record, Sensitivity and specificity, Clinical terminology.

What are the Barriers to the Submission of Good Quality Diagnosis Codes by Medical Practitioners in South Africa?

Luisa Whitelaw

Clinical Risk Management, Discovery Health, Sandton, South Africa – paper prepared by the author as a student of the University of Bath/Royal College of Surgeons of Edinburgh, as a research component towards the degree of MSc Health Informatics

While the use of ICD-10 codes in South Africa is legislated, various unofficial studies have shown the quality to be poor, in that there is little correlation of codes across sources. This study undertook to identify the barriers to the submission of accurate diagnosis codes by medical practitioners. A mixed methodology was used; one-on-one interviews were conducted with representatives of 6 doctor societies to identify the main quality barriers. The level of agreement with the identified barriers was measured through an on-line survey distributed to the doctors within these societies. There was no split between responses from the different specialist societies or between private and public doctors. The combined interview and survey results revealed the main barriers to be: mistrust of Medical Schemes' use of the ICD-10 codes, a lack of co-ordination and linking between different sources of coding and a fear of inadequate legal protection in the event that the use of an ICD-10 code(s) by a doctor causes a breech in patient confidentiality.

Keywords:
Quality, Barriers, Clinical coding, ICD-10, Data collection

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Implementation and Validation of a Tool for the Automatic Calculation of DRG

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Standards application for coding the medical information stored in Information Systems offers a series of advantages at the time of making management analysis. DRG (diagnosis related groups) code for calculation of the DRG code for each admission episode makes it possible to estimate costs as well as the consumption of hospital resources. With the purpose of running management processes to the information generated during admission episodes, the discharge summary was structured in several fields so that it could be then coded with ICD 9 CM and assigned a DRG code. The objective of this study is to compare an automatic coding tool for the discharge summary with DRG against a web tool (IRP). As the assignment of a DRG code was a manual process, the institution decided to develop a tool which would make those calculations automatically. Comparing the result from the newly developed tool to a web tool in 6566 clinical records were tested later the concordance of the system. Concordance was 98.43%, with a standard deviation of 98.1-98.7%.

Keywords:

Systematized Nomenclature of Medicine, Terminology, Information systems, Electronic health record.

M. Nursing Informatics

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Impact of Barcode Medication Administration on Nursing Activity Patterns in Taiwan

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The purpose of this study was to explore the impact of BCMA on nursing activity patterns and nurses' usage experience in Taiwan. A total of 4,940 observation items were collected by work sampling method on nurses who used BCMA and those who did not use, and interviewed were conducted to explore users' experiences.. The results of this study were as followed. First, nurses who used BCMA spent more time on indirect care and unit-related activities but less on medication-related activities. Second, nurses' direct care, indirect care, medication-related activities and personal time were significantly different on the day and night shifts. Finally, nurses commented that BCMA could enhance workflow and patient safety, however, hardware insufficiency and system functions needed further improvement. The study results could be a reference for BCMA outcome evaluation.

Keywords:
Barcode medication administration (BCMA), Work sampling observation, Interview, Usage experience.

Patient Perception of Information Sharing with Medical Professionals in Japan

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Patient information is shared widely among medical teams through EHR systems to improve quality and safety of care in Japan. However, in fact, medical personnel often and unnecessarily share patients' information with other personnel and professionals in daily care. Recently, the awareness of patients' privacy protection is growing in Japan. It is important to consider how to protect their privacy. A self-administered survey was conducted on 772 hospitalized patients. Questions on 4 core items on medical records regarding information privacy were asked. As a result, out of the 4 items, the last thing they wanted to be disclosed was "their family history." The closer relationship patients had with medical service personnel, the less they tended to hesitate to allow medical service personnel see their medical records.

Keywords:
Information sharing, Privacy, EHR system

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Measuring the level of acceptance of the Electronic Health Record

Ybranda Koster – de Jong, William Goossen

There is a need to measure the acceptance of the electronic health record (EHR). The purpose of this study is to gain insight in the relation between level of adoption, computer use, and acceptance of the EHR. This is a Quantitative non-experimental research in two pilot units in an academic hospital. Results: Employees with the same degree of adoption of the EHR score significantly the same on the acceptation of the EHR and the computer in general. There is no significant difference between the degree of acceptation of the computer in general and the degree of acceptation of the EHR between the units. The conclusion is that the questionnaires for acceptation of computers and the acceptation of EHR and the questions on adoption are found to be valid en reliable and can be used for further research.

Keywords:
Electronic health records, Acceptance, Nursing informatics.

Evaluation of Telehealth use in Home Care: A Proposed Study

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As chronic diseases have become prevalent and care resources are still limited, telehealth has been proposed as an alternative in addition to traditional treatments in the aging population. Although the benefits of technology use have been studied in recent years, the evaluation of teleheath has not been explored extensively. This study proposed a framework to evaluate the impact of telehealth use from different perspectives. Clients and care professionals from a long term care facility where telehealth has been implemented will be invited for this study. Individual interviews will be conducted to explore the impact of this technology use. Data of emergency visits and medical appointments will be obtained prior to and after the technology use to compare the differences. It is hoped that the technology use could benefit the client, their families, the care provider and the organization.

Keywords:
Telehealth, Technology, Long term care, Evaluation.

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Data Mining in Self-Management

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Self-management is recognized as a key component of strategies for health promotion, disease prevention, and acute and chronic disease management. Self-management data are increasingly available in digital form. Our objective was to explore the data mining literature to determine the extent to which data mining techniques had been applied to the domain of self-management. We searched multiple databases and manually reviewed and summarized studies according to the types and methods of data mining. Few studies have applied data mining to the topic of self-management and the range of methods applied is limited. Data mining techniques have the potential to improve our understanding of self-management.

Keywords:
Self-management, Self-care, Data mining

From Electronic Documentation to Evidence Based Nursing: Creating Data Marts for Analysis, Evaluation and Improvement of Processes in Patient Care

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The nursing documentation system in the Tyrolean federal hospitals produces an enormous amount of highly structured nursing data. We built an extensible data mart aggregating these data in combination with information on the patients' medical history and current living conditions. Using the workflow-based application KD^3 it is possible to easily explore, visualize and evaluate the data in order to reach our goal: finding new knowledge supporting evidence based, quality assured patient care.

Keywords:
Nursing informatics, Evidence based nursing, Nursing care management, Data marts, Knowledge discovery in databases

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Twenty Eight Years of CARING: An International Group for Informatics Nurses

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CARING is an international nursing informatics organization which began over twenty eight years ago in the Washington, DC area. It is the largest international nursing informatics group in the world, active in promoting education, networking, and job opportunities.

Keywords:
CARING, American Nursing Informatics Association (ANIA), Nursing informatics, Organization

Evaluation of a fall-risk assessment tool implemented in an EMR System

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This paper examines the routine clinical use and the validity of a built-in fall-risk assessment tool to identify patients at high risk for falls, which has implemented in the enterprise electronic medical record (EMR) system of a tertiary teaching hospital in Korea. The tool was developed using an evidence-based approach as a fall safety initiative. It is consisted of nine items with dichotomous score and the sum score ranges from 0 to 9. The cutoff score is six. A retrospective analysis of 1,934 inpatient admissions in 2007 was conducted. Falls status was ascertained from the hospital's accident self-report system and the review of electronic nursing records in the EMR system. This validity study assessed the sensitivity, specificity, positive predictive values and negative predictive values with the associated 95% CI. The results showed much low sensitivity at the current cutoff score. We found many weaknesses of the tool and great opportunities to improve our fall prevention practice.

Keywords:
Falls, Risk assessment, Validation studies

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Discharging the patient from Hospital to Home-Care: An application attempting to combine E 2369 (CCR), ISO 13606-1, and prEN 13940 Standards

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The aim of this project was the development of an application attempting to combine E2369 (CCR), ISO 13606-1, and prEN 13940 Standards and to comply with them by adopting all crucial features, and the most innovative functional solutions, according to the requirements of those standards. The developed system consists of a first module that is responsible for the creation of a typical CCR that contains the appropriate demographic and administrative data, as well as the relevant clinical information, while a second module is responsible for the creation of a homecare plan which will be included in the Care Plan section of the CCR. Finally the system comprises of a prototype ontology based upon the HL7 – Clinical Document Architecture (CDA), and an application that converts the referral documents into a CDA–compliant format and the contents of the CDA–compliant documents into ontology instances.

Keywords:
CCR, Care plan, HL7 – Clinical Document Architecture

Development of a Computerized Material Management System in a University Hospital

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The aim of this study is to present the implementation of computerized management of materials system (CMS) of the University Hospital at the University of São Paulo (UH-USP). The UH has an expense with consumables which represent 49% of the cost of the hospital, a value above the reports found in the literature [1]. In the hospital, the materials were distributed to users, according to predetermined material quotas, being replaced at fixed dates. This traditional system, with manual control, had some problems, such as: monthly prevision with poorly programmed quotas, loss of inventory control, total lack of knowledge on consumption, waste and lack of material. Based on the facts above mentioned, it was planned to develop a computerized system for materials management with an interface with other existing programs in the hospital.

Keywords:
Material management in hospital, Just in time, Nursing informatics.

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How Did We Show the IT People What We Nurses Want about the System? The Case of Self-developed Ostomy Skin Assessment Tool with VBA

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The home-made Nursing Information Systems (NIS) have long been known to be done by IT people trained with using "Window-based" Interface building tools and a database-oriented thinking. However, for the healthcare professionals, we need to have an easy IT tool fitting into our workflow and thinking process. In this study, we used the VBA to design an Ostomy Skin Assessment Application to communicate to our IT people. The results support the positive value of using VBA as a communication tool for the system design.

Keywords:
System development, User interface, VBA

VP-Based Final Examination – a model to reach advanced level standards for the degree of Paediatric Nursing in Sweden

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Web-SP is a system for virtual patient, developed at Karolinska Institutet (KI) in Sweden. In this study, we examine Web-SP cases for assessing paediatric nursing students. To investigate the possibility of using Web-SP for assessing clinical reasoning skills and to study students acceptance and to determine whether the skills required of experienced paediatric registered nurses could be adequately assessed by the system. The intervention included a two-part of exams. The results show high levels of acceptance of the Web-SP as an examination method. Students also thought it was a good way to practice their clinical skills. Findings have relevance in the development of clinical information systems where clinical decision making is important.

Keywords:
Virtual patient, Nursing education, Clinical reasoning

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Development and Evaluation of Website about Nursing Care in Post Anesthesia Care Unit

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Introduction: The Post Anesthesia Care Unit (PACU) is the unit where patients under an anesthetic and surgical procedures must be kept to receive specialized nursing care. It is important for nurses to have access to the updated information to deliver care to the patients. Objectives: To develop a website about Post Anesthesia Care Unit related to the nursing care and evaluate its content. Methods: Research based on the DADI methodology. The evaluation was performed by practice nurses in the criteria of authority, general content, presentation and information reliability. Results: The website comprises 82 pages of information, photos and illustrations. The content was separated into stages to facilitate organization and subject understanding. Seventeen nurses evaluated it as excellent. Conclusion: The information available about the nursing care at PACU is reliable and valid.

Keyword:
Internet, Nursing informatics, Post anesthesia nursing.

Informatics Competencies Study in Iberoamerican Nursing Population

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Nowadays, many hospitals and health center of the Latino-American region have adopted information technology (IT), to help nurses in their practice. Less study has focused in computer literacy of Latino American nurses. The purpose of this study was to determine computer literacy and use of systems and technologies of the information amongst nurses. The on line survey was the instrument for data collection. The respondents were 435 Chilean and Latina-American nurses. The results of this study revealed that 99.7% of nurses to possess knowledge and abilities in the computer use, but not of tools of informatics science in health nurse practice. They demonstrate to discharge motivation and interest to use nursing informatics and consider necessary to become qualified.

Keywords:
Competencies, Nursing informatics, Education

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Design and Development of Tailored Interactive Education Program for Safe Medication of the Elderly

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Safe medication is one of major health issues in the elderly population who has chronic multiple diseases. The purpose of this paper was to describe a research in progress which purpose is to develop a tailored interactive education program using age friendly interface to prevent medication misuse and abuse of the elderly in the community settings. A program for safe medication is being developed using the following five processes: 1) Analysis stage 2) Designing stage 3) Content Framing and development stage 4) Program application stage 5) Evaluation stage. The completed program would be applied to the elderly in the community and tailored interactive education could be an effective teaching media of safe medication for the elderly in the information age.

Keywords:
Computer, Education, Elderly, Medication

The Top-up Nursing Degree Program of the Cyprus University of Technology

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Aim of this study is to describe the top-up degree program that is offered in Nursing, by the Nursing Department of Cyprus University of Technology (CUT), to the nursing professionals who are graduates of Nursing School of Cyprus. Aim of the program is to provide the graduates of the Nursing School with additional studies that lead to the acquisition of academic degree (top-up degree) in Nursing (or Nursing of Mental Health).

Keywords:
CUT, Top-up program, Nursing, Evaluation

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E-learning in the Undergraduate Nursing Course

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This study aimed to show validity of the experience of e-learning in a discipline with students in 4th semester of the Undergraduate Nursing Program of Nursing School, Sao Paulo University. The Nursing Education: Trends and Challenges discipline, intends to demonstrate that the educational process is inherent in nursing work in all its aspects. The workload is composed of 60 hours, with 30 hours devoted to classroom teaching and the other 30 hours to e-learning. The platform chosen for structuring the discipline was Moodle, because it has online open access. At the end of the course, students performed a simulation of educational action for evaluation purposes. Participation in virtual activities was also evaluated. This strategy enabled the collective construction of knowledge through discussions, studies and richer conclusions.

Keywords:
Education nursing, Distance education

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N. National and International Health IT Efforts and Implementations

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Alert information sharing – a proposed model

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Some types of information in Electronic Health Records can have a particular significance to ensure patient safety e.g. notes on severe hypersensitivity to medicines. In order to ensure that all health professionals take note of this, it is important that Alert Information is structured and can be shared between providers and systems. A defined structure is also a prerequisite for the use of such information for automatic decision support. This paper presents an analysis of requirements and describes a conceptual model and a visual symbol for presentation. This paper also discusses how alert signals can be generated. The first implementation of this has been made in the context of the Swedish National Patient Summary project and it is the basis for ongoing formal standardization in CEN and ISO.

Keywords:
Alert information, Decision support systems, Computerized medical records systems, Adverse drug reaction

Challenges of Electronic Health Records Implementation

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The author wish to share with congress participants, the experience gained and progress made in eight nations, having served at the national level as Senior Medical Record Consultant Adviser and visiting WHO Consultant, in GCC Countries (Kuwait, Saudi Arabia, Bahrain, Qatar, UAE, and Oman), besides serving in Afghanistan and India. The dramatic transformation from only 5-10% of hospitals which had good medical records in GCC Countries had changed after implementation of electronic health records to 70-80% of them have shown dramatic progress and their effective and efficient functioning is remarkable.

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Health Information Technology in Dubai: A Qualitative Study

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Little is known about heath user preference for information technology in Dubai. We assess this with a mainly qualitative approach, recording the first published use of focus groups as a methodology in Dubai. SMS technology is culturally embedded into Dubai society and is the preferred vehicle for health information.

Keywords:
Health information technology, Dubai, Middle East

Design and Evaluation of txt2MEDLINE and a Searchable Database of SMS Optimized, Clinical Guidelines for Clinicians in Botswana

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Currently clinicians in rural sub-Saharan Africa have limited access to the Internet, which may impede the practice of evidence-based medicine. However, wireless mobile phone access and use is extensive. The University of Pennsylvania in collaboration with the National Library of Medicine (NLM) launched txt2MEDLINE and a Short Messaging Service (SMS) optimized, searchable clinical guidelines in Botswana. This pilot project will enable clinicians to query and receive PubMed abstract summaries and country-specific clinical guidelines using mobile phones. The objective of this project is to evaluate the utility of these tools for clinicians in Botswana. It will be an added resource to a pre-existing telemedicine network. Establishing the usefulness of these resources may provide an effective working model for other countries where limited Internet access impedes upon patient care.

Keywords:
Telemedicine, Mobile phone, Continuing medical education, Text messaging, SMS

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Solutions in Global Women's Health Care Delivery: Use of Mobile Telemedicine for Cervical Cancer Screening

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Throughout the developing world, delivery of women's health care, specifically cervical cancer screening, is limited by cost and access to trained personnel. Visual inspection with application of 4% acetic acid (VIA) is a practical, inexpensive alternative to cytology-based screening in areas where women's health resources are limited. We present results of a prospective case control study evaluating the accuracy of off-site (remote) expert diagnosis using photographic images of the cervix with VIA (PIA) in HIV-positive women in Gaborone, Botswana. Mobile telemedicine using the 5 Megapixel camera-enabled Samsung Soul U900 cell phone to photograph the cervix after VIA allows clinicians in "see and treat" cervical cancer screening clinics to capture high quality images of the cervix. Photos can then be transmitted via the mobile phone to a gynecology specialist located remotely, in order to provide accurate diagnosis of precursor lesions, and appropriate triaging and implementation of therapy.

Keywords:
Mobile telemedicine, Cell phones, Cervical cancer screening, HPV, HIV/AIDS, Botswana

How integrated health IT systems improve efficiency of MRSA Surveillance in hospitals

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MRSA infection poses great health problem in the community. For decreasing MRSA nosocomial infection, hospitals have great resource to collect relevant clinical data related to MRSA infections to monitor the trends in hospitals and community and to develop protocol and guidelines of its control for infection management improvement. A clinical IT system, named MRSA Surveillance System, with integration of different clinical IT systems has been developed and implemented in hospitals of Hospital Authority of Hong Kong in 2007, in order to facilitate the originally labor-intensive data capture by frontline infection control teams related to MRSA surveillance and to provide updated and quality management reports for prompt MRSA infection identification and control. This integrated system improves efficiency of MRSA surveillance in hospitals.

Keywords:
MRSA infection, Nosocomial infection, Surveillance, Efficiency.

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Mutual Isolation and the Fight for Care: Exploring Home-based Healthcare in two South African Communities

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The 'duty' of home-based care is often imparted on non-government institutions that employ nurses and caregivers to provide care. These organisations are hampered by a capital barrier in that they rely on grants and donations. Therefore they are often not financially sustainable. This generally results in caregivers and nurses being underpaid and –resourced. A lack of resources translates into fractured coordination and systems when administering care. It has become crucial to redirect these systems so as to be more practical and effective. Yet this process cannot commence without understanding the many dynamics that shape the home-based healthcare context. A bottom-up ethnographic approach is therefore necessary to inform a proper care 'solution'. For this analysis, two communities in the Western and Eastern Cape of South Africa were assessed in their home-based healthcare endeavours. It was found that the care context is volatile and that caregivers require more resources to guarantee continued service. These findings are significant for understanding the 'grassroots' of home-based healthcare in South Africa for the possibility of developing a (technological) solution to care.

Keywords:

Home-based healthcare, Caregivers, Information flows, Fractured coordination, Care solution, Care context, Care network.

CHRONIOUS: A Multinational and Interdisciplinary European Project for Innovative E-Health Management of Chronic Patients at Home

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CHRONIOUS is a highly innovative Information and Com-munication Technologies (ICT) research initiative that aspires to implement its vision for ubiquitous health and lifestyle monitoring of people with chronic diseases. CHRONIOUS is funded by the European Union (ICT-2007.5.1: Personal health systems for monitoring and point-of-care diagnostics). CHRONIOUS, with a budget of 10.59 million €, is a multidisciplinary consortium composed by 19 partners - including industry, academia and hospitals - from 12 European countries. The CHRONIOUS project works on an innovative wearable system with intelligent sensors which can monitor patients' vital body parameters, context and environmental variables, patient motion and other activities such as drug and food intake. The system will assist both patients and physicians by providing tools for health status monitoring and decision support**.** In particular CHRONIOUS focuses on chronic kidney and pulmonary diseases.

Keywords:

Chronic diseases, Home care, e-health.

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LexCare Suite: Korean National Terminology Server for Interoperable EHR

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This poster describes our ongoing efforts spanning more than 5 year, in which a terminology server, comprising a centrally-managed terminology repository and terminology management applications, has been developed as part of a government-funded initiative to develop core technologies necessary to implement lifetime EHR. The server called LexCare Suite houses core standard reference terminologies such as International Classification of Disease (ICD-10), International Classification for Nursing Practice(ICNP), Systematized Nomenclature of Medicine(SNOMED-CT), Logical Observation Identifiers Names and Codes(LOINC), Korean Standard Terminology of Medicine(KOSTOM, a Korean equivalent of UMLS), and RxNORM. The server comprising LexCare Editor (a localized and customized LexGrid editor) and auxiliary modules is developed to meet the terminology needs of primary to tertiary hospitals in Korea. This paper introduces LexCare Suite in detail.

Keywords:
Electronic health records, Terminology, Medical records, Information system, Database, Medical informatics application

Indicators of Success for Clinical Engagement in Scotland's National eHealth Programme

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A survey of Nursing, Midwifery and Allied Health Professions (NMAHP) capability and capacity was undertaken to assess clinical engagement in Scotland's National eHealth Programme. The survey explored four themes; leadership and engagement; eHealth tools; eHealth skills; and knowledge management. The results were shared via a Clinical eHealth Toolkit in the form of" indicators of success" and linked with working examples of good practice to support engagement of all clinicians in eHealth.

Keyword:
Nurses, Midwives, Allied health professionals, Clinical engagement, eHealth

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Medical Informatics Efforts in Turkey

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Parallel to the developments in the world, health informatics field is experiencing a continuous growth in Turkey. Health informatics efforts in Turkey initiated in 1992 with the establishment of postgraduate Medical Informatics Education Program in Akdeniz University, Antalya. Today, six institutions provide postgraduate health informatics education in Turkey. In 1999, Turkish Medical Informatics Association (TURKMIA) was founded. Until today, TURKMIA organized several activities in order to fulfil its guiding role in health informatics in Turkey. In order to improve healthcare services in Turkey, "National Health Information System" project was initiated under the authority of Ministry of Health in 2003. In this study, a review of developments in the field of health informatics in Turkey will be presented.

Keywords:
Medical informatics, Informatics education, e-health, TURKMIA

Establishment of an Infrastructure to Support the Introduction of Electronic Signatures: a German Example

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Secure electronic documentation has become increasingly important in healthcare. However appropriate IT-infrastructures develop slowly in healthcare settings. This leads to uncertainties in healthcare industries and to tremendous costs caused by duplicate archiving of health records. We established a Competence Centre for Electronic Signatures in Healthcare (CCESigG) to support implementation and provide information services for electronic signatures. Our objective is to report about CCESigG and first experiences with its services. Institutions like CCESigG may accelerate the introduction of electronic signatures, particularly in those countries, which rely on these signatures regarding legal management and archiving of electronic health records.

Keywords:
Security, Digital signature, Electronic signature, Electronic health record, Integrity, Communication, archive

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Towards the Standardization and Promotion of Interoperability in eHealth

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Interoperability and solutions based on global clinical and administrative standards are considered a basic strategy to improve medical care. In this sense, several networked initia-tives in the development and promotion of Open-Source Soft-ware (OSS) are ongoing. However, these initiatives are not specifically conceived to function as collaborative resources for the multidisciplinary set of stakeholders involved in the different aspects of eHealth. In this context, SHARE project enhances this situation by means of a web platform for current and future actions in research, development and technology transfer in the field of OSS applied in the eHealth sector.

Keywords:
Open-source, eHealth, standards, interoperabili-ty, knowledge platform

Selecting Clinical Computing Hardware Devices for Hospital Wards: The Role of IT Vendors

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There is limited evidence available to inform decision making processes for selecting clinical computing hardware devices for implementation on hospital wards. We undertook a study to determine the role of IT vendors in this decision making process and to ascertain the factors that vendors deem important to consider in the selection of computing devices. Interviews were conducted with twelve vendors who provide hardware and/or software products to hospitals. Interviews were recorded and the transcripts were analyzed by coding of key concepts. The results highlight the need to assess information about a number of technology, workflow and environmental factors. The study provides a basis for developing a framework to assist decision makers in identifying the ideal devices to adequately support clinical work practices.

Keywords:
Computers, Computer systems, Decision making, Hospitals

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eHealth for all: Territory wide electronic health records in Hong Kong

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Electronic health records (eHR) definition varies across different countries. With the global push for eHR adoptions, only a few has achieved a longitudinal records at the point of care and there is no territory-wide eHR in the world yet. Since 2008, Hong Kong has embarked on an eHR journey to allow "records follow patients". This paper will detail the methods for building partnerships across the health sectors (both private and public) to achieve a common objective of HIE to support improved patient care, building on incremental extensions of core functionality and new pilot platforms and demonstrating adoption strategies and key principles (clinical, technical, policy) to support a territory wide next-gen EHR.

Keywords:
Electronic health records (eHR), Hong Kong, Medical records systems, Implementation.

Mapping to SNOMED CT in Sweden – a matter of quality

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A key objective of the Swedish IT strategy for health care is to ensure that all health records share a common terminology [1]. The national health organisations in Sweden have decided to use SNOMED CT and a clinical information model in adherence to EN 13606 and openEHR. Mapping clinical data to controlled terminologies is an important step towards achieving standardisation of data [2]. The reliability of SNOMED CT mapping is imperfect [3]. Thus, measures which lead to a high level of semantic agreement between mappers are of great importance when aiming at high quality. We have elaborated guiding principles and rules for the mapping activities and qualification requirements for mappers. An outline of the semantic boundary between the terminology and the clinical information model has been elaborated. Training has been carried out in order to obtain a common attitude to mapping. This poster describes the lessons learned.

Keywords:
SNOMED CT, Semantic mapping, Guiding principles, Clinical information model

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Governing quality in translation of SNOMED CT

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Translation of SNOMED CT is part of the national IT-strategy for health and welfare. The strategy identifies the Swedish special language for health and welfare as interdisciplinary and including of meta concepts with definitions, classifications and SNOMED CT. The special language is also a vital part of the national information structure and should be reliable and safe to use. The European effort to make it possible for the patient to share health data with a physician in another country is yet another aspect of quality in translation. The translation of concepts from one language to another is therefore of big importance. This poster points out one of the quality issues: the choice of and the qualification of recommended terms. The framework and process are vital to the outcome and the question we want the answer to is: will the recommended term be accepted by the professionals? This poster discusses used methods and lessons learned.

Keywords:
Terminology, SNOMED CT, Translation

The National information structure for eHealth in Sweden

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The National Board of Health and Welfare has been commissioned by the Swedish government to develop a generic National Information Structure. The Information Structure consists of three models: The generic Process-, Concept- and Information models. The National Information Structure will form the foundation for development of ICT solutions that support process oriented care and will also be used as a basis for forming a regulatory framework specifying the content, form and structure of information. It is our view that the specialisation and implementation of the generic models in eHealth solutions will contribute to improvements of the quality of the services delivered to patients. The foreseen benefits include better cooperation in the clinical work, systematic follow up, clinical decision support and enhanced patient safety. It will provide and enable effective use of secondary data to perform management and evaluation of patient outcomes.

Keywords:
Information structure, process model, concept model, information model, semantic interoperability.

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ALIAS: Alpine Hospital Networking for Improved Access to Telemedicine Services

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The ALIAS project is a European project funded by the Alpine Space programme started in August 2009. ALIAS addresses medical services and information inadequacy to ensure health care provisions in the Alpine Space where telemedicine services are not widely exploited. Alpine space touristic vocation during some periods of the year makes its healthcare structures "periodically" inadequate to face a widened request of services supply. On the other hand, a major receptivity of those structures during the rest of the year is unnecessary due to the low density of Alpine space local residents. ALIAS is aimed at linking together a number of Alpine space hospitals enabling the creation of a Network shaping the ALIAS Virtual Hospital Network (VHN) for sharing medical information, adopting telemedicine and best clinical practices, to improve the efficiency of hospitals in that area.

Keywords:
Integrated advanced information management systems, Computerized medical records systems, Telemedicine, Health services accessibility

Productivity and management tools in the Chilean hospital market

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The Project called "Productivity and Management Tools in the Chilean Hospital Market" being developed by the "Hospital Clínicc Universidad de Chile" (HCUCH), and the Inter-American Development Bank (IADB) aims to promote competitiveness in Chilean healthcare industry, so that there is a healthcare market with diverse companies offering healthcare services for public and private insurances companies. The specific goal is to increase the productivity of HCUCH and of small and medium size private hospitals, to facilitate the access to AUGE plan. This objective will be achieved by using new tools based on information and communication technologies for management and delivery of healthcare services. The Project is structured into four components: 1) To prepare the private sector of healthcare providers for management innovation, 2) To prepare the HCUCH for management innovation, 3) Technology transfer from HCUCH to private hospitals and 4) Monitoring, evaluation, communication of results and experience.

Keywords:
Hospital management, Teleradiology, Electronic health records.

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Countrywide implementation of Patient Appointment Reservation System in Lithuania

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20 project partners – the major Lithuanian Hospitals and Primary Care Centers - implemented European Union Structural Funds supported Electronic Patient Appointment Reservation Project (budget of 2.1 million EURO). The EU support was used for developing and adding new features to the Patient Appointment Reservation System of Vilnius University Hospital and spreading it nationwide. The System is based on modern Mobile and Information technologies, such as SMS, Mobile Sync, web services etc. The main objective was achieved - the System enables Patient to reserve an appointment to the GP and all level specialists. GP or any specialist can assist Patient and choose the best suitable consultant and book an appointment for his Patient at any participating institution.

Keywords:
Appointments, Online health services, Mobile technologies.

OpenXdata aides in monitoring and evaluating a National Dog bite and Rabies surveillance in a low resource setting of Pakistan

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National epidemiological surveys to estimate the burden of disease can become difficult to monitor with limited resources. When the project coordinator is located in one city, and surveillance is being carried out in several urban and rural sites, monitoring the field site becomes very difficult. With the use of cell phones as data collection tools, project coordinators can quickly get feedback on their fieldworkers and their data, which has proved invaluable in managing the study. The patient data captured by the cell phone is then transmitted via GPRS to a central server where it is stored in a database and integrated with Google Earth for later use in epidemiological research. Our implementation required field workers to sign in and sign out daily along with collecting relevant surveillance information. This data is then extracted from the database and presented visually within a google earth web portal.

Keywords:
OpenXdata, Oxd, Rabies, Dog bite, Epidemiology, Public health, Surveillance, Mobile phone, Electronic data collection

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Information Technology based process model for Health Insurance – Adoption and Implementation

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The scope of discussion involves an overview of the industry forces, policies that are responsible for the poor penetration of health insurance in India. This subsequently has an impact on the rate of adoption of IT amongst healthcare providers since, from the example of the US industry, health insurance companies are key influencers for adoption of IT for process stream lining and standardization. Various facets of technology that are discussed result in reduction of errors, process and data standardization, process turn-around time improvement, reduction of working capital etc. Technologies like ICD codes, electronic data interchange, electronic data entry methods, authorizations, centralized databases etc. have a strong role to play in this evolution. Coupled with this is the fact that government policies should stipulate minimum norms for IT technology compliance like HIPAA in the US, that can ensure the adoption and success of the technology model presented

Digital Libraries and Health Information Access in Lusaka, Zambia

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The goal of the Zambian Health Information Project is to enhance access to health information through customized health information portals on the eGranary Digital Library. Over the past year, a partnership between the University of Alabama at Birmingham's Sparkman Center for Global Health, the University of Iowa's WiderNet Project, and Zambian health institutions has been working to create portals of Medical, Nursing, and Public Health specific information for health faculty and students in Lusaka, Zambia. The eGranary offers an offline mechanism to access digital information, over an institution's local area network (LAN). This approach is especially appropriate to areas of the world where access to the Internet is limited. This poster will discuss the experience of portal creation and implementation of the digital library at health institutions in Lusaka, Zambia.

Keywords:
Digital libraries, International cooperation, Medical education, Computers, Internet

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Examining PACS Impacts in the Malaysian Context: Its Utilization and Potential Work Interruptions in Radiology Work Practices

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Utilization of a large-scale PACS has resulted in substantial changes in radiology work practice of a hospital-based radiology department in Malaysia. Based on a three-month period undertaking field work with this organization, this study found that PACS application has contributed to systematic radiology work processes as compared to the traditional-based radiology work practice that centered around the usage of x-ray film and paper-based medical record. Radiologists and radiographers were generally satisfied with the existing PACS infrastructure. However, this study also found that the radiologists and the radiographers have also experienced disruptions in their routine work practice. This paper reports evidence of the nature of interruptions linked with a large-scale PACS utilization in the radiology work practice. Analysis of the data reveals that both human and technical related factors are the root causes of the interruptions.

Keywords:
PACS (Radiology), Radiology information system, Malaysia

eSurveillance and eMonitoring for the epidemic of Chikungunya Dengue diseases in capital City New Delhi, INDIA

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Chikungunya (chik-en-GUN-yah), also called chikungunya virus disease or chikungunya fever, is a viral illness that is spread by the bite of infected mosquitoes. The disease resembles dengue fever, and is characterized by severe, sometimes persistent, joint pain (arthiritis), as well as fever and rash. It is rarely life-threatening. There is no specific treatment for chikungunya. Prevention centers on avoiding mosquito bites in areas where chikungunya virus may be present, and by eliminating mosquito breeding sight. The states affected by chikungunya are Andhra Pradesh, Karnataka, Maharasthra, Tamil Nadu, Madhya Pradesh, Gujarat, Kerala, A&N Island, NCT of Delhi, Rajasthan, Pondicherry, Goa. The number of suspected chikungunya fever cases reported.

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Current status of the new Healthcare Advice System that uses e-mail and electronic data exchange for prevention of metabolic syndrome: A study in Japan

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In April 2008, the Japanese government introduced "Health Checkups and Healthcare Advice with a Particular Focus on the Metabolic Syndrome" for all citizens aged between 40 and 74 years. The new system emphasizes on the requirement of an electronic data exchange based on the standardized XML format (HL7) between hospitals and medical insurance providers. All XML data are finally submitted to the government. In addition, it recommends the use of e-mail. The purpose of this study was to evaluate the effectiveness of the new healthcare advice system by analyzing XML data. Our data shows the difficulty encountered by adopting the standardized electronic data exchange owing to many errors in the XML data (error rate = 75%). We observed that for weight loss, intervention for 6 months was more effective than only 1 counseling session (-2.5 [3.3] kg vs. -1.1[2.5] kg; $P < 0.01$). In an intervention for weight loss, e-mail was more frequently used than was telephone. However, there were no significant correlations between the supporting methods and weight loss.

Keywords:
Metabolic syndrome, Weight management, e-mail

Assessment of Hypnotic Prescriptions in Adult Cancer Inpatients Reusing Data in a Clinical Data Warehouse

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Cancer mortality accounts for one-third of all disease mortalities in Japan. Hypnotics are common medications to treat cancer-related stress and other symptoms. Studies on hypnotic usages were mainly from survey data. In this study, we addressed this issue by reusing data in our clinical data warehouse (DWH). Adult cancer patients who were admitted for at least 7days (2007/4/1-2008/4/1) were defined as eligible study subjects. A multinomial logistic regression model was built to assess relationships between six dichotomous variables with hypnotic prescriptions. We identified 1,947 cases, among which 55.3% (1,076) were prescribed with hypnotics; 49.4% (961) were older than 65 years; 48.5 % (945) were females; 19.2% (374) had operation procedures; 29.6% (576) were admitted for more than 30 days; 47.4% (923) were prescribed with anticancer agents and 22.1 % (431) were prescribed with opioids. The overall model was well-fitted (χ^2=177.518, df=6, p=0.000). The Wald statistic of individual variables indicated that the adopted predictors were significantly related to the hypnotic prescriptions ($P<0.05$).

Keywords:
Data warehouse, Hypnotics, Cancer, Logistic regressions

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A Grid System for Timely Surveillance of Influenza/Pneumonia Using Death Records

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This poster demonstrates how to integrate grid data services, death certificates, analytical grid services, and natural language processing, to build a real time public health surveillance tool that uses data and services under the control of different administrative domains. The example used here provides insight on how a global public heath grid could be developed as a dynamically evolving ecosystem of grid enabled applications and data sources.

Keywords:
Public health surveillance, Grid computing, Public health grid

The Electronic Child Health Passport as an Effective Tool for Health-Promoting Educational Technologies

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Article 51 of the Federal Law “Education” states that any educational facility should provide necessary conditions to promote health among its students. Schools share this calling with parents and often compensate for the parents’ lack of initiative at home. The establishment of the Open Computerized School Health Monitoring System (further OCSHMS) pursues the goal to create a health-promoting school environment where the Electronic Child Health Passport is one of the key integrative tools.

Keywords:
EHR, Electronic health passport, Child health passport

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Development of a web site for information of the general public regarding travel diseases endemic in the Mediterranean basin: the Greek Case

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Travelers to different countries should be aware of the potential for acquiring diseases and injury which are not common in their own country. Immunizations, preventative medications, and general precautions should be considered prior to trips to different parts of the world. [1] Immunizations against diseases such as rabies, tetanus, diphtheria etc may be recommended or required for travelers to certain countries, as well as preventative medications against traveler's diarrhea, malaria, and tuberculosis may be necessary. Information on Travel Diseases, Vaccination requirements and general Travel Health advice are readily available through the WHO and the Department of Communicable Disease Surveillance and Response (CSR). Additionally, CDC also provides information on current travel medical recommendations and requirements for various countries all over the world.

Evaluating Health Information Exchange for Public Health

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We describe an innovative approach to evaluating health information exchange for public health (HIE for PH), representing one project being conducted by the multi-institutional Health Information Technology Evaluation Collaborative (HITEC) in New York State (USA). We use a modified DeLone and McLean framework to conduct a comparative case study of multiple stakeholders involved in HIE for PH applying qualitative and quantitative evaluation methods. We will present preliminary findings from an evaluation of six Regional Health Organizations (RHIOs) that are implementing a PH Use Case to demonstrate HIE within New York's centralized state health information network (SHIN-NY). This study combines existing approaches into a generalizable evaluation methodology that will produce policy relevant conclusions as well as criteria for longitudinal evaluation of state and regional HIE for PH initiatives.

Keywords:
Public health, Evaluation, Information exchange

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IntegraEpidoso: a web framework to integrate Epidoso data to spread data access for ease data analysis, ease share knowledge, and clusterization

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Epidoso [1] is a cohort research started in 1991 aimed to understand how people get older, lose some abilities, get sick and die. The first research started with 1500 elders living in São Paulo, in a neighborhood close to and surrounding Hospital São Paulo. One of the biggest difficult to Epidoso was to integrate and distribute data among researchers for analysis and suggestion of new studies. Project Epidoso was finished in 2005 and right after, Project Epidoso II started in 2007, with other 1500 elders. IntegraEpidoso aims to provide a web framework to join Epidoso and Epidoso II data so researchers can find all data in one place, where data are kept safe and available. Some epidemiological calculators will be available. At the end, one clusterization will be done to identify groups of elders with same socioeconomics and epidemiological patterns for better health promotion.

Keywords:
Web framework, Management information system, Epidoso, cluster analysis, Promotion of health.

Supporting Comparative Effectiveness Analysis for Fact Based Policy Development: An End-to-End Solution

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Pressure is building to ensure that limited healthcare resources are allocated to provide effective care. Policy decisions need to be made in an evidenced-based manner, a task poorly supported by existing systems. We present our solution, an end-to-end comparative effectiveness analysis (CEA) prototype scoped by a use case on obesity. CEA contrasts two or more competing programs based on clinical outcome and cost. The insight it provides can be used at the population level to guide decision makers. Our system integrates clinical data from multiple sources in a privacy- preserving manner, handles missing data, and uses a data warehouse cube to abstract information critical to policy makers. Knowledge about the relative impact of competing healthcare programs is published in dynamic, online dashboards to facilitate collaboration. Feedback from domain experts demonstrates the utility and usability of our preliminary work.

Keywords:
Public health informatics, Comparative effectiveness, Business intelligence, Clinical analysis.

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Propensity Score-Weighted Survival Model for the Benefit of Adjuvant Chemoradiotherapy for Gallbladder Cancer

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The efficacy of adjuvant chemoradiotherapy for biliary tract cancers remains controversial due to the absence of large randomized clinical trials for this rare disease. Survival prediction models created using retrospective data analysis can help clinicians and patients assess the potential benefit of adjuvant chemoradiotherapy based on specific tumor and patient characteristics. In this work, we created a nomogram based on the Surveillance, Epidemiology, and End Results (SEER)-Medicare dataset. As analyses comparing the effectiveness of treatments on non-randomized groups can be subject to treatment-selection bias, we used propensity score weighting to adjust for the imbalance of the covariates between the treatment and control groups. Our nomogram and web-based tool can be used to help make individualized adjuvant treatment recommendations for gallbladder cancer patients.

Keywords:
Survival analysis, Nomograms.

Spatial Decision Support Systems for Optimizing Health Services Delivery

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Disparities in health services delivery are a world-wide problem. Providing solutions, on the other hand, is a great challenge. Even in the best of circumstances, community needs will outstrip resource availability, not only in developing countries but also in the developed world. Resource optimization is therefore of vital importance. Particularly when considering the problem of infectious diseases, control and response can be greatly enhanced through the creation of an informatics scaffold that would ideally be generalizable and based on open source resources to permit the greatest possible distribution, adoption and sharing of knowledge. This poster will present a description of the methodology and current status of the work on creating a multimodal SDSS which incorporates Geographic Information Systems (GIS), dynamic risk mapping, remote sensing and advanced modeling techniques for addressing mosquito-borne infections in Third World settings. Modeling techniques are currently being refined, variables defined and international collaborative relationships fostered. Pilot sites for data collection have been identified.

Keywords:
Mosquito control; decision support techniques

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A Distributed Healthcare Quality and Outcomes Analysis Architecture

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Patient-centred quality monitoring and reporting is needed to improve the cost effectiveness of health services. A multi-vendor and multi-professional accessible layered architecture can meet common requirements of both clinician- and patient-reported outcome measures (PROMs). A distributed modular, layered collaborative standards-based architecture permits ethical information exchange between any set of trusted nodes, leveraging the interoperability, privacy and infrastructure frameworks of the IHE. The approach enables wider reach and cost- effectiveness for large-scale distributed implementations along the entire 'patient path'. The emergent vendor-neutral, internationalised translational computing system supports data aggregation and analysis in EHR-derived healthcare quality improvement and longitudinal outcomes studies.

Keywords:
Distributed systems, Translational computing

OpenMRS mobile integration into OpenMRS Multi-drug Resistant Tuberculosis (MDR-TB) module for improved management and monitoring of community based MDR-TB treatment program in a low-resource setting

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Multidrug-resistant Tuberculosis (MDR-TB) is becoming an increasing problem globally. Drug resistance occurs due to non-compliance of regular Tuberculosis (TB) treatment or via transmission through an MDR-TB patient. Community based treatment is used to improve compliance and generate awareness about prevention and cure. To monitor community care, mobile technology is used to collect data in the field, and monitor validity of the encounter by capturing the GPS location for point of data collection, to ensure that the treatment supporter was entering data at the appropriate location. Data collected on the mobile phone is uploaded via GPRS to the OpenMRS database with the MDR-TB module. This gives program managers a comprehensive database and helps them monitor the patients' progress and the treatment supporter's attendance and data entry at the patient's home. This technology has improved validity of the data collected and project managers have identified problems in their field site quickly and acted upon them accordingly.

Keywords:
MDR TB, TB, Tuberculosis, Drug-resistant, Compliance, monitor, Treatment, Mobile, OpenMRS, Electronic, Data collection.

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Impact of Medicare Part-D and Generic Drugs on Brand Name Competitors: Longterm Care Center Study

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On January 1, 2006, Medicare initiated the biggest change in its history by approving the Part D Prescription Drug Plan in an attempt to lower the soaring cost of prescription drugs dispensed to seniors, partly through conversion to generic drugs. Due to their unique characteristics: polypharmacy, homogeneous age structure, and high prevalence of chronic diseases, there are few studies of the impact of this program on long-term care residents, despite being its heaviest users of prescription medications. In this study, we address whether Part-D and generic availability have significant impact on the selection of brand-name drugs in a delivery setting managed through online orders and electronic prescriptions. Using HMG-CoA reductase inhibitor class (Statin, hereafter) as example, our data from an online pharmacy serving multiple long-term care facilities show that, in general, generic drugs substitute for their brand name counterparts and interfere with their brand name competitors.

Keywords:
Medicare part-D, Generics, Medication choice

Georeferencing Swine Flu in Buenos Aires, Argentina

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On July 16th, W.H.O. recommends a weekly report of a qualitative assessment of the geographical spread, trend of cases, intensity of A/H1N1 Influenza and its impact on the health care system. In this study we describe the geographical spread during the onset of the southern winter in 150.000 middle class Argentinean living in Buenos Aires and its surroundings. The process of georeferencing swine flu cases was carried out using our local Geographical Information Systems. This allowed us to understand the swine flu pattern to define the appropriateness of contingency policies adopted at the onset of the epidemic.

Keywords:
Geographic information systems, Hospital information systems, Computerized medical records systems, Swine Flu

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National Resource for Infection Control (NRIC) – conveying guidance during the Swine Flu outbreak: an Evaluation Study

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The National Resource for Infection Control (NRIC) www.nric.org.uk is the one stop shop for infection control guidance, policy documents and evidence based information. Funded by the Department of Health in the UK and content managed by domain experts, this online digital library has became widely established as a source of quality evidence for those seeking IC evidence. This poster will describe our evaluation study investigating user information needs and online behaviour during the swine flu outbreak in spring - summer 2009.

Keywords:

Infection control, web traffic evaluation, Web search

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