33rd Annual International Conference of the IEEE EMBS
Boston, Massachusetts USA, August 30 - September 3, 2011

Using Participatory Design in a Health Information System

Leonor Teixeira, *Member, IEEE*, Vasco Saavedra, Carlos Ferreira, Beatriz Sousa Santos *Member, IEEE*

Abstract—this article describes the experience of developing an interactive Health Information System (iHIS) currently under test in a hospital, which benefited from the practices of the User-Centred Design (UCD), in a Participatory Design (PD) approach. Techniques from the Human-Computer Interaction (HCI) and/or Usability Engineering (UE), combined with traditional Software Engineering (SE), allowed an effective and usable solution from the user's point of view. The good results usually achieved with this approach were confirmed. Despite these good results, we deem that if there is not some control of the procedure by the project manager, it may be difficult to end the requirement analysis, since requirement reformulation is fostered.

I. Introduction

The development process of interactive Health Information Systems (iHISs), albeit with major contributions coming from the Software Engineering (SE), has recently integrated methods from other knowledge areas to cover the social and human aspects associated with the interaction component. During the development process of this type of the Information System (IS), we must consider, not only the functional and technical specifications, but also all the aspects related to the user interface and the interaction process. From the user's point of view, an IS is usually used and evaluated as a whole, and the separation between technical/functional and the user-interface components is not possible. However, conceptually these components can be designed using concepts from different knowledge areas. While the former is defined from the user's specification, and is generally addressed by SE, the user-interface component is associated with Human-Computer Interaction (HCI) and/or Usability Engineering (UE). The development according to principles of User-Centred Design (UCD) arises from the attempt to merge best practices from these two knowledge areas (SE and HCI/UE), and the user is a key element in the development process, as well as the tasks and context of use. This approach may involve the user in an active or passive role. When the user is actively involved, i.e., she/he is integrated into the project team and participates in the decisions, we are facing a Participatory Design (PD) approach [1-2].

This article aims to present the experience of developing an iHIS currently under test in a hospital, which benefited from the practices of the UCD, in a PD approach. A set of techniques from the HCI and UE, combined with traditional SE, allowed an effective and usable solution from the user's point of view. Based on this experience, and in accordance with the literature review, the good results that are usually achieved with application of UCD approaches in PD development are confirmed. However, despite these good results, experience with this project led to believe that if there is not a some control of the procedure by the project manager, the process of changing requirements can become endless, due to the favourable environment for a quick change of ideas, and consequently favourable to requirement reformulation.

II. iHIS Development Using a Participatory Design Approach: Background and Practical Project

In the context of the iHISs, the development approaches commonly used are based on a different logic than what is used in traditional industry. For a long time, the prevailing culture in this area has been to train people to adapt to technology and not adapt the technology to the characteristics of people [3]. However, some work in this domain has given methodological contributions that attempt to 'reverse' this paradigm, paying attention to human and social components of iHISs, and not just technical and technological aspects [4-5]. Other studies attempted to place the user in the central development process of the iHIS, arguing that is one of the most important steps to provide a quality product [6-7]. In fact, the literature confirms that the methods of analysis and design centred in the user, and focused on continuous assessment using iterative processes based on formative evaluation, have been the most sought in the development of iHISs [8-14].

In this article we present the development approach of an iHIS (*hemo@care)* [15-16] based on the principles of the UCD, and PD to help us engage users into the design and

Manuscript received April 15, 2011. This work was made in collaboration with the Hematology Service of Coimbra Hospital Center (HS_CHC) and the Portuguese Association of Hemophilia (PAH), in Portugal.

Leonor Teixeira is with the Department of Economics, Management and Industrial Engineering, and Governance, Competitiveness and Public Politics (GOVCOPP), and the Institute of Electronics and Telematics Engineering of Aveiro (IEETA), Aveiro University, Portugal (corresponding author. phone: +351-234-370361; fax: +351-234-370215; e-mail: lteixeira@ua.pt).

Vasco Saavedra is with the Department of Economics, Management and Industrial Engineering, Aveiro University, Portugal (vsaavedra@ua.pt).

Carlos Ferreira is with the Department of Economics, Management and Industrial Engineering, Aveiro University, Aveiro, Portugal and Operational Research Centre (CIO), Lisbon University, Portugal (carlosf@ua.pt).

Beatriz Sousa Santos is with the Department of Electronics, Telecommunications and Informatics and the Institute of Electronics and Telematics Engineering of Aveiro (IEETA), Aveiro University, Portugal (bss@ua.pt).

bring in their tacit work knowledge. This approach was based on the analysis of the best practices in the development of ISs in healthcare reported in the literature, and resulted from a combination of techniques and methods from the HCI/UE with the traditional methodologies of SE.

A. *Brief Description of hemo@care*

Hemo@care [15-16] is a Web-based application which aims to manage the clinical information in haemophilia care, as well as to support the process of registry and submission of the data generated in the home-treatments to the hospital where the patient is being monitored. In order to manage the data, this application has three actors: 'Patient' who has access to a restrict online area allowing the registry of all data generated from home treatments; 'Physician' responsible for the management of all patient's clinical data; and 'Nurse' responsible for managing the stocks of the drugs used, as well as the registry of the hospital-treatments.

B. *Development approach*

The approach used in the development of *hemo@care* was inspired by UCD techniques in a Participatory Design (PD) environment, using an iterative and incremental process, supported by traditional methods of Object Oriented Systems Analysis (OOSA), fig.1.

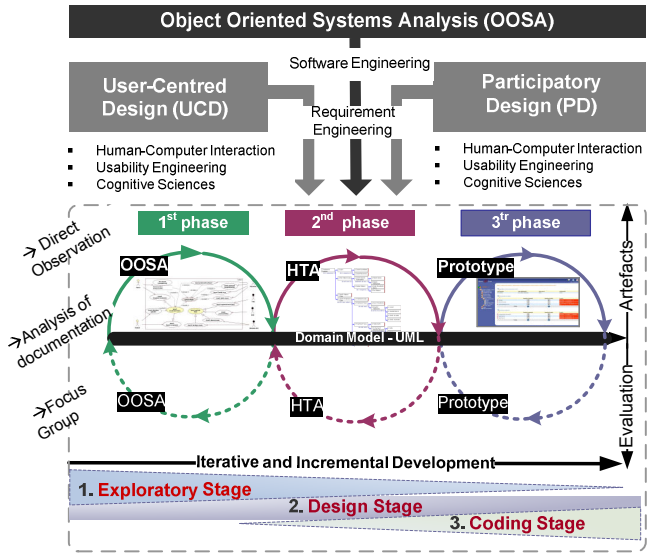

Fig. 1: Iterative and incremental development approach based on principles of UCD in a PD environment.

With this approach it was possible to confront the potential users with the artefacts resulting from the evolution of the iterative development, and, on that basis, to stimulate the discussion and obtain feedback in order to validate the previously found requirements, thus identifying new requirements. The UCD techniques contributed with mechanisms for gathering and evaluating data in order to understand the user needs in the specific context of the work. With the PD environment, mechanisms that allowed to integrate a group of potential users in the development team were used, having those users actively contributed to the (re)formulation of the system requirements. Two physicians, two nurses and one patient were part of the project team, and participated in scheduled meetings at appropriate times of the process. The OOSA component was supported by UML, used for documenting the results that emerged throughout the iterative development process and, whenever necessary, to report the results to other stakeholders (e.g. programmers), using a formal language.

All the techniques and methods used throughout the development process of *hemo@care* were grouped into three major stages (exploratory, design and coding stage) each having a set of inputs and outputs, and benefiting from the contributions from different knowledge areas. Next, a brief description of each stage is provided, as well as the main techniques and methods that contributed to the results of each of them.

Exploratory – This stage corresponds to the work in the early phases of the development process, and attempts to obtain the first data and the awareness of the problem domain. Analysis of documentation, direct observation and focus group were the main techniques used. These techniques were applied according to the principles of UCD taking into account the concepts of task, user and context. Their application has been combined in order to take advantage of methods triangulation and data triangulation, more specifically, to complete the information with new data obtained through new methods or techniques, while validating the previously collected data. The outputs of this stage are the understanding of the problem domain, and a set of data that allows construct a preliminary version of the Requirements Specification Document (RSD). This stage occurred in the first 3 months of the development cycle, after which we moved to the next stage.

Design – This stage added to the previous one a notation to support the representation of the conceptual model. Using a model it is possible to represent and display a complete abstraction of a complex reality, as well as make easier the requirements communication to other stakeholders and thus validate previously found results. Three different techniques (OOSA, HTA and Prototyping) of representation and evaluation were used [11].

- **Object-Oriented System Analysis (OOSA)** – UML was the first technique adopted and was chosen within the traditional system analysis available techniques, based on a paradigm of Object Oriented (OO). Several models were built, particularly the Use Case diagram and the Class diagram. The Class Diagram was used to document the results in terms of data modelling, while the Use Case diagram was extensively used to validate the functionality with the users, and also to find missing features (new functionality). Within the focus group, potential users involved in PD were confronted with the artefacts in order to discuss them, criticize and make suggestions for reformulation. Given the abstract terminology used by UML notation, which can be unintelligible for people

without computing science background, a facilitator mechanism for model presentation was necessary, and thus we converted use-cases into short stories or narratives (user stories) to describe the purpose of the system. User feedback was also based on small reports and later converted in use-cases. After three iterations, as there were no changes in the model, we moved to the next technique.

- **Task Analysis** – The second technique is widely used in the field of HCI, and was based on Hierarchical Task Analysis (HTA) [17]. The HTA representations were based on the outcome of the previous phase, where each complex use-case generated a HTA model. In this stage not all use-cases were converted into HTA models, but only the most complex involving a larger number of operations. The purpose of this stage was to validate the functionalities previously found, simultaneously trying to understand the user mental model in order to find the best sequence to present information within the scope of the functionality. This technique was also iterated three times.
- **Prototyping –** This method, well known within the IHC but also widely used in the context of Requirements Engineering (RE) [18], was the third method applied to simulate the user interface in order to be validated by users. A low-fidelity prototype was chosen, more specifically a horizontal prototype, developed using the 'throw-away' method. Mock-ups were created using HTML and placed in the logical sequence identified with the HTA.

The three techniques were applied in an iterative and incremental process in the sequence they were presented. Table 1 presents some advantages that stood out in the design stage from the application of each technique.

TABLE 1: ADVANTAGES VERIFIED WITH THE APPLICATION OF THE TECHNIQUES.

Technique	Advantage
OOSA (UML)	▪ OO representation suitable to the evolutionary paradigm of the project.
Task Analysis (HTA)	▪ Suitable to the understanding users' mental models; ▪ Suitable for the identification of sub-features and order of execution within high level functionalities; ▪ Notation easy to understand and appropriated for the communication process among people with different backgrounds.
Prototyping (Horizontal P.)	▪ Suitable for capturing navigability issues; ▪ Suitable to capture emerging requirements; ▪ Easy to understand model, promoting greater enthusiasm for participation in users.

Coding – The conceptual model emerging from the previous stage was converted into executable code, using an agile development approach, more specifically, *eXtreme Programming* (XP) [19]. This approach was chosen since the development is made by iterations, getting feedback quickly from the users through the test of the software versions. This approach is very consistent with the practice of UCD, and presents characteristics of an evolutionary prototype, which makes it suitable for projects that require dealing with unpredictable and rapidly changing requirements, as in the healthcare domain.

C. Summative Assessment of hemo@care: task observation, heuristic evaluation and test in real environment

After completing the *hemo@care* development, and according to principles of UCD in a PD environment, the application underwent, in a first phase, a summative evaluation based on task observation and heuristic evaluation. The purpose of this evaluation was to obtain feedback from a small group of analysers with expertise in HCI in order to identify usability problems.

The heuristic evaluation was performed by two evaluators on the basis of ten usability heuristics proposed by Nielsen [20]. Regarding the task observation, the emphasis was placed in the 'Patient' interface, not only because patients were less represented throughout the development process (only one patient was part of team), but also since patients can have very different profiles. Thus, 15 tasks of the role 'Patient' were chosen for evaluation, some were common to the 'Nurse' and 'Physician' roles. This type of evaluation involves the collaboration of users and observers. In this particular case, each observer had prior training, in order to record users' problems and comments, while the users try to complete the tasks without help. The data obtained from task observation and heuristic evaluation revealed positive results. Small improvements were made at the 'Patient' interface, regarding the interface design, and also in relocating some features which, by their importance, appeared in a place not salient enough. However, it should be noted as a limitation to the observation tasks test, that the observed group may not be entirely representative of the potential users, since they were not domain experts.

In a second phase, some informal evaluation was made. This covered the roles 'Physician' and 'Nurse', and was based on evaluations with real data and in a normal working environment. The users used a test application, simulating the use of a final solution, while they recorded all the difficulties felt with data entry and/or with information visualization. This type of evaluation, even if it does not use a formal protocol, requires the full involvement of users in many cases without the presence of any member of the development team. The registry of all the difficulties experienced by the user is very important to understand the real usability problems and in a next stage, implement the necessary improvements. In this particular case, this evaluation helped implementing minor improvements in *hemo@care*. The results obtained so far allowed confirming that the iterative and incremental approach based on

principles of UCD in a PD environment is adequate to develop iHISs as *hemo@care*.

III. Conclusion

Many researchers have recognized the importance of human and social factors for iHIS design; however, actual methods that account for social factors in the development process are largely unavailable [14]. The combination of techniques and methods of different knowledge areas can be a good solution, and PD helps in socio-technical design.

The development of the *hemo@care* has experienced one of these combinations and the present article described its process according the principles of the UCD, in a PD environment. This approach, in accordance with the literature, proved to be one of the most adequate to develop interactive ISs, applied in environments characterized with dynamic requirements, as the healthcare sector. In fact, developing interactive, reliable, effective and easy to use ISs, with a low learning curve is a challenge that the software development industry is facing. In the healthcare sector, characterized by extremely complex processes changing through time, and where the success of the ISs heavily depends on their reflection taken at the level of social and human aspects, traditional approaches to development will naturally have better results when integrated with knowledge coming from disciplines that involve the understanding of human and social factors, such as IHC and the UE. PD is an example of such approach and is based on proactive design methods that explicitly advocate active user participation throughout the design process [14]. The good results obtained in this experiment are most probably due to the fact that users were involved throughout the development process, contributing with their tacit work knowledge. However, despite these good results, we believe that if there is not some control of the procedure by the project manager, the process of requirements analysis can become endless, due to the favourable environment for quickly changing ideas, and consequently favourable to the reformulation of the requirements.

Acknowledgment

We are grateful to the professionals of *Haematology Service of Coimbra Hospital Center* (HS_CHC) and the *Portuguese Association of Haemophilia* (APH).

References

[1] S. Alazwari, "Participatory Design: Methodologies and Techniques," *Proceedings of Designing Usable Systems,* pp. 35-38, 2010.

[2] R. Almaghairbe, "Overview in Participatory Design," *Proceedings of Designing Usable Systems,* pp. 31-34, 2010.

[3] J. Zhang, "Human-centered computing in health information systems Part 1: analysis and design," *Journal of Biomedical Informatics,* vol. 38, pp. 1-3, 2005.

[4] M. Berg*, et al.*, "Considerations for sociotechnical design: experiences with an electronic patient record in a clinical context," *International Journal of Medical Informatics,* vol. 52, pp. 243-251, 1998.

[5] E. Coiera, "Putting the technical back into socio-technical systems research," *International Journal of Medical Informatics,* vol. 76, pp. S98-S103, 2007.

[6] M.-C. Beuscart-Zéphir*, et al.*, "User-centred, multidimensional assessment method of Clinical Information Systems: a case-study in anaesthesiology," *International Journal of Medical Informatics,* vol. 74, pp. 179-189, 2005.

[7] S. De Rouck*, et al.*, "A methodology for shifting the focus of e-health support design onto user needs: A case in the homecare field," *International Journal of Medical Informatics,* vol. 77, pp. 589-601, 2008.

[8] C. M. Johnson*, et al.*, "A user-centered framework for redesigning health care interfaces," *Journal of Biomedical Informatics,* vol. 38, pp. 75-87, 2005.

[9] S. Rinkus*, et al.*, "Human-centered design of a distributed knowledge management system," *Journal of Biomedical Informatics,* vol. 38, pp. 4-17, 2005.

[10] G. M. Samaras and R. L. Horst, "A systems engineering perspective on the human-centered design of health information systems," *Journal of Biomedical Informatics,* vol. 38, pp. 61-74, 2005.

[11] L. Teixeira*, et al.*, "User-centered requirements engineering in health information systems: A study in the hemophilia field," *Computer Methods and Programs in Biomedicine,* vol. In Press, (DOI: 10.1016/j.cmpb.2010.10.007).

[12] S. Pilemalm*, et al.*, "Integrating the Rational Unified Process and participatory design for development of socio-technical systems: a user participative approach," *Design Studies,* vol. 28, pp. 263-288, 2007.

[13] S. Pilemalm and T. Timpka, "Third generation participatory design in health informatics--Making user participation applicable to large-scale information system projects," *Journal of Biomedical Informatics,* vol. 41, pp. 327-339, 2008.

[14] C. Weng*, et al.*, "Participatory design of a collaborative clinical trial protocol writing system," *International Journal of Medical Informatics,* vol. 76, pp. S245-S251, 2007.

[15] L. Teixeira*, et al.*, "Improving the management of chronic diseases using web-based technologies: an application in hemophilia care," in *Engineering in Medicine and Biology Society (EMBC), 2010 Annual International Conference of the IEEE*, 2010, pp. 2184-2187.

[16] L. Teixeira*, et al.*, "Hemo@care - um Sistema Integrado de Gestão de Informação Clínica na área da Hemofilia," in *Actas da 9ª Conferência da Associação Portuguesa de Sistemas de Informação*, Viseu, Portugal, 2009. (in Portuguese).

[17] J. Annett, "Hierarchical Task Analysis," in *The Handbook of Task Analysis for Human-Computer Interaction*, D. Diaper and N. A. Stanton, Eds., ed Mahwah, New Jersey: Lawrence Erlbaum Associates, 2004, pp. 67-82.

[18] R. S. Pressman, *Software Engineering: a practitioner's approach*, 6th ed. Boston (MA): McGraw-Hill, 2005.

[19] K. Beck, "Embracing Change with Extreme Programming," *Computer,* vol. 32, pp. 70-77, 1999.

[20] J. Nielsen, *Usability engineering*. Boston: AP Professional, 1993.