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Social Care Informatics: Beginning to Face up to the Reality of the Mixed Services Economy?

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Abstract: An ‘eCare’ approach needs to takes a wider view than e-health, by considering issues of support and well-being alongside treatment and cure. This paper considers the challenges of taking this wider approach in the context of the mixed services economy – public, private and voluntary sector - currently developing in the UK. These challenges also offer an insight into the emerging field of Social Care Informatics - a relatively unexplored territory with uncertain boundaries and a scarcity of research. The history of Social Care Informatics developments in the UK is outlined, together with the challenges of meeting the current expectations of government policy while addressing the challenges inherent in the mixed services economy. It is argued that the lack of investment and an equal lack of skilled resources have hampered progress, while the low level of research in this area creates a risk that inappropriate solutions may be imposed. The opportunities for development in this field are explored, along with the potential for developing informatics solutions for the service user as well as the service provider.

Keywords: eCare, eHealth, Social Care Informatics

1. Introduction – eHealth and eCare: Role of Social Care Informatics

The concept and applications of ‘eHealth’ have become well established and continue to develop rapidly. The general focus of these developments has been on formal healthcare organisations and systems, and supporting clinical care; approaches to eHealth are often largely centred around illness or the health problems of particular cohorts of the population (e.g. older people). Some innovative approaches are beginning to appear - such as the FP6 OLDES project [1], which includes social networking applications as well telemedicine as part of its ‘whole systems’ approach - but they tend to be exceptions to the overall trend.

The core definition of ‘health’ - as enshrined in the constitution of the World Health Organisation - is that of “a state of physical, mental and social well-being, and not merely the absence of disease” [2]. Prevention and overall ‘well-ness’ are as relevant as cure or treatment, and the maintenance of wellbeing should be considered a key aspect of health services and of wider society [3]. The hitherto current approach, perhaps more appropriately termed ‘e-Treatment,’ may (in time) rediscover ‘health’ – and researchers, policy makers, developers, and users of the applications based on these design assumptions may find benefits in examining these wider aspects of the ‘health’ agenda.

Given that this is unlikely to be the case in the short term, and recognising the current lack of focus on care issues by the health informatics community (and its sponsors), we seek, as both researchers and practitioners, to re-frame and balance the agenda from a care perspective. As we have suggested, 'health' extends well beyond the formal health sector, and a vital contributor to the health and wellbeing (both physical and social) of citizens is Social Care: the range of services delivered, in the UK, by a complex mixed service economy that includes public, private and voluntary community sectors – an 'organisational aquarium' [4]. For those with a physical or functional impairment or disadvantage, social care is vital in supporting daily living, and thus in ensuring that health and wellbeing are maintained. For those receiving healthcare treatment, especially for serious or enduring conditions, it is a partner without which health systems could not function adequately. Social care encompasses social work support, assistance with mobility and aid for daily living tasks such as meals, cleaning and shopping. It supports and protects those at risk, enables individuals to maintain their independence, and includes the provision of residential care when needed. Record keeping – and appropriate co-ordination and record sharing between agencies - is clearly important in the development and delivery of all of these services, and that increasingly requires the harnessing of modern electronic systems.

In many European countries, including the UK, the direction of health and care policy requires social care information systems to develop in response to demands for multi-agency, cross service integration and to the need to support a greater focus on prevention, well-being, and self-determined person-focused care. The area is rich yet challenging as it has at its heart the welfare of the most vulnerable members of society, while being delivered by a complex and developing mixed economy of social care providers. With the overall ageing of society, and longer survival of those with chronic illnesses and other complex multi-faceted problems, its relevance is increasing, yet awareness of it is not. In the UK it remains a 'Cinderella' in comparison to the 'spoilt princesses' of e-health [4], and therefore provides both an urgent challenge, and opportunity, for study and development.

1.1 Social Care Records

Social care records have different characteristics to health records. With healthcare records there is a wealth of technical detail – investigations, physiological and laboratory data, diagnoses, prescribing and other treatment plans, and the like [5], whilst intentionally there is little information about third parties. Health records can be described as deep but narrow.

In contrast, the records generally collected and held by those responsible for coordinating social care (Councils with Social Services Responsibilities (CSSRs) in the UK), are shallower but much wider, containing information on context as well as conditions. Social care requires an understanding – and thus a recording – of the service user's personal circumstances, including their interactions with and contributions from family and other informal carers. It is equally important to note any limitations to those contributions, and the effects on carers as individuals – thus family and professional commitments, and stresses or potential employment effects of caring, are noted. And while knowing about the support and commitments of others can be vital, some of the data imparted to social care services is highly sensitive and personal – not least adverse interpersonal relationships, behavioural dimensions, or causality of problems. This sensitivity – together with the complexities of the mixed economy within which it needs to be managed - leads to a challenging subset of confidentiality and sharing issues, balancing the effective delivery of social care for the benefit of the core client with the need to avoid harm or distress to others. Disclosure of specific facts to others actively involved, including informal carers, may be essential for ensuring effective support is given.

2. Defining the Landscape: Transition from IT to Informatics in the UK

Social Care Informatics – the knowledge, skills and tools that enable the delivery of care services through facilitating provision of such records – is a relatively unexplored territory with uncertain boundaries and a scarcity of research. The lack of academic input into career development in local government (social services in particular) coupled with an historical lack of funding from government in comparison to e-health and e-government, has resulted in an equally low level of academic interest in the development of social care informatics . Yet, as with health care or other services, social care and its clients stand to gain much from appropriate developments in technology and information management.

IT systems were initially introduced into the social care environment in the UK as administrative tools, aimed at improving efficiencies within the service and supporting the production of statutory returns to government and inspection bodies [6, 7]. Individual projects explored the support of frontline practice in both health and social care to varying degrees, and learning could be drawn from similar projects undertaken in the USA [8] and in Europe [9. 10], but it was not until 2001 that UK government policy formally recognised that 'Information is a fundamental and crucial element in the delivery of quality social care services' [11] and the foundations for a more integrated Informatics approach were laid.

As part of the national Information for Social Care (IfSC) implementation, funding was provided for a number of 'demonstrator projects. These projects were encouraged to be business, rather than technology focused and included mapping social care business processes, and support for information sharing with health, as well as the Virtual Electronic Social Care Record project (VESCR). This project developed a prototype record, exploring the issues underpinning the development of a fully electronic record for social care. It showed the value of practitioner input into system design and helped identify the potential offered by the use of technology to both information specialists and practitioners [12].

The overall response to the IfSC initiative varied from Local Authority to Local Authority, but a number of them began to undertake work to extend the use of technology and information tools into front line services. Much of this work has not been generally documented or formally researched, and the success, or otherwise, of Electronic Social Care Record (ESCR) developments is therefore difficult to measure. A survey across all English CSSRs, undertaken in 2007 [13], identified that progress has been made, but that certain key themes and issues remained. These included difficulties in cultural change, engagement with practitioners, lack of clear business cases and the need to compete against other priorities. Technical and organisational issues around integration with partner agencies had made limited progress, there was a lack of quality IT solutions, and a range of issues around skills and resources, including IT literacy and the knowledge to build and implement systems. A key question for many was ‘what exactly is an ESCR?’

The need to develop (and understand) effective care records is well recognised, and there is a very real demand for information tools to support the delivery of care services. As early as 1997 Hudson [14] made a plea for attention to be given to developing computer support systems to ‘address the day to day realities of actually doing practice…the needs of all actors within the organization; clients, practitioners, supervisors, managers, administrators, and program evaluators.’ Much of the current policy being developed in the UK assumes that Informatics solutions will be in place to support and deliver new approaches to care. Yet, while there has been huge investment within the NHS in the form of the National Programme for IT, there has been little equivalent funding for CSSRs, who are struggling to keep pace. Developments in the private sector have, inevitably, focused on finance and administration rather than delivery of care, and the voluntary sector, with the exception of some of the larger national charities, generally has little resource to spare for development work and tends to depend on the lead of the Local Authorities.

The highlighting of issues concerning information management and information sharing by high profile public inquires has added further demands for the integrated management of social care information. UK initiatives designed to support a more integrated approach to children's services, such as 'Contact Point,' and the integrated children's system (ICS), are based on expectations of greater use of technology. Similar policy developments in Adult services assume that information systems will be in place to support greater integration between agencies, and that practitioners and service users will have access to information tools that enable the efficient and effective delivery of personalised care.

Information for Social care set a deadline of 2007 for the implementation of comprehensive ESCRs across the whole of England. Only a few Local Authorities have managed to deliver systems that reflect the definition provided at the time. Other initiatives have diverted resources and generated new requirements, many of which no longer fit within the 'single record' model initially promoted. Work currently being undertaken in Cheshire, for instance, has moved the service user's assessment and care record out of the well defined boundaries of the Local Authority and given it a community focus. The development is based on a shared publication model, with virtual records and linked systems, governed access to data and tailored views based on the needs of the agencies and actors requiring access. Others LA's have focused on developing more holistic case records, with unstructured data being stored in document management systems alongside the more traditionally structured client records. Each of these approaches has merits, and potentially provides part of the solution required – but the development of such systems has been happening in isolation, driven entirely at local level, thereby creating duplication of efforts across the sector, over-investment of resources, and little dissemination of learning and innovation. While there is a general view that these kinds of systems are necessary, understanding of what an ESCR might be, and the benefits it might provide, remains fragmented and there is little clarity of where effort needs to be focused and why.

The demand for guidance and co-ordination in this area has begun to be recognised in the UK. The formation of a national ESCR Implementation Board, the funding of projects to investigate the technical integration of social care systems with the NHS National Care Record service, and the extension of the remit of other national information boards to cover social care as well as health, serve to illustrate a growing awareness of the issues. As yet, there is still a low level understanding of what Social Care informatics tools need to look like, how they should be developed, or what they need to do. In contrast to the amount of research undertaken into social care practice for a range of client groups, very little has been done to investigate the issues around implementing social care records – let alone the challenges in managing and maintaining this kind of information across the complex, mixed economy that supports the commissioning and delivery of care. Projects that have been undertaken (such as Framework for a Multi-Agency Environment [15]) illustrate the complexity of the emerging socio-technical environment and the challenges inherent in developing systems that are robust, secure and deliver what is required. There is a danger that, without a shared understanding of these challenges, health or business models will be inappropriately adopted or imposed. There are opportunities to benefit from further research in the UK as well as learning from experiences in Europe and the rest of the world.

3. The Challenges of a Mixed Economy

The 2003 SOCCARE Project identified that social care is a universal and familiar phenomenon but its flexible organisation as well as co-operation between informal communities and formal organisations has been problematic in all European welfare states. Due to the ongoing profound changes in European family and population structures, working patterns and welfare systems, the problems of providing social care in a flexible and responsive way are becoming even more urgent, forming one of the major policy questions of Europe in the 21st century [2]. More recently the UK Department of Health described a model for the delivery of care as: ‘Local authority leadership accompanied by authentic partnership working with the local NHS, other statutory agencies, third and private sector providers, users and carers and the wider local community to create a new, high quality care system which is fair, accessible and responsive to the individual needs of those who use services and their carers.’ [16].

Both of these statements clearly highlight the complexity of the social care economy – a flexible, evolving, environment that encompasses public, private and voluntary sector provision. To date, the primary lead on developing and delivering Social Care informatics in the UK (as in many other countries) sits with the CSSRs, who are wrestling with the need to address the requirements of care services within the wider context currently transforming local government and citizen services. However, the provision of such services is by a range of autonomous providers including private sector, not-for-profit organisations, and the local authority itself as a service provider. Systems are now being developed that span multi-agency, cross sector services, and the diverse values that organisations bring to such developments adds further complexity. The need to create sets of resources that can be shared and collectively governed – either in consortia, or as third party provision – challenges traditional approaches to both process and practice. There are also expectations that new social care markets, driven by policies for integrated working and the development of self determined personalised care, will emerge from distinctions now being drawn between financing, purchasing and management of services. Competitive forces and market mechanisms will play a part in the future delivery of care throughout the EU.

These challenges – along with the pace of change demanded by current policy – tend to result in conflict over resources and pressures to deliver incomplete and potentially incompatible solutions. Much of the current integration agenda has pushed Health and Social Care Informatics developments towards ‘whole systems’ approaches with an ever widening scope, but with little clarity about how to manage and define boundaries. At the same time, public concern is growing over the insidious nature of surveillance in modern society and fears are raised over threats to privacy and confidentiality.

The real costs of this kind of approach have yet to emerge: it is entirely possible that, rather than supporting genuine integration the systems now being designed are simply locking information into different shaped boxes. There are indications that integrating around a specific client group, such as older people or children, as is being promoted in the UK, hampers attempts to integrate, share information or join up agencies around other, partially overlapping client groups (e.g., the mentally ill, families, young carers etc.). [17]
Other challenges arise from a low awareness of the contribution that Information tools make in the support of practice and care delivery. Lack of research in this area inevitably results in inconsistency across systems and encourages supplier driven solutions. Rather than build bigger and more cumbersome databases, there is a need to explore how tensions between ‘whole systems’ approaches and the flexibility of more ‘open systems’ – which recognise the existence of fluid and ambiguous boundaries - can be resolved.

The social care sector is one where, it can be argued, there is a need to develop a robust and managed information economy – one based on the exchange of knowledge, information and services – to support the increasingly complex arrangements underpinning the commissioning and delivery of care.

4. Building Stronger Foundations: Issues, Opportunities and Ways Forward

Not only is the field of Social Care Informatics still in its infancy, but so is the ESCR market. In England six main suppliers dominate, with two of these supplying over 70% of the CSSRs responding to the survey. Seven authorities reported home grown or bespoke systems [13]. While there is a great deal of commonality between these systems, there is very little consistency, both technically and in relation to the structure and coding of the information they contain. Unlike Healthcare, Social Care does not yet utilise common coding systems (eg READ or SNOMED,) and recording practice varies from Authority to Authority.

The range of systems becomes much wider and contains much greater variation when use within the wider social care sector is factored in. Furthermore, as Health systems have been developed to provide health, rather than care solutions, interfacing the two produces a range of challenges, and these are multiplied as the requirement for integration extends to other agencies and service providers. It would clearly be impossible to wipe the slate clean and start with new systems across the board, even if it were possible to specify what those systems would need to provide. Future developments will have to build on the lessons learned from legacy and bespoke systems, while creating the infrastructure needed to deliver the flexible, responsive information economy that policy requires.

With the development of information sharing across a range of interagency and inter-sector boundaries, care providers need to ensure that they can instil trust and confidence in their service users, reassuring them that information about themselves and their families is well managed and kept secure. The lack of shared standards is a fundamental stumbling block in the development of the care economy; it inhibits data sharing, limits monitoring and measurement, and places unwelcome demand on informatics resources. As standards develop, they need to encompass far more than the basic layers of technology infrastructure and the coding of datasets within databases; they need to include consistent standards in business processes, in records structures and in user behaviours – and in the overall approaches to information management and governance.

Some of these standards already exist. Some may be imposed through central control. But for genuine benefit to be realised standards need to emerge through dialogue across a common community of practice, where knowledge, learning and experience can be shared and different perspectives – including that of the service user – can be identified and discussed. Without the development of such a community – with engagement, not just in the UK, but across the wider European context – progress is likely to be slow and uncertain

The NHS has attempted to address similar issues in the health economy through the creation of a centrally driven development and implementation programme – the National Programme for IT. Some of the standards created for this programme are being taken up by the private health sector. Although the programme has no direct mandate to impose such standards in the wider health economy, the sheer size and scale of the work inevitably influences views on the benefits of compliance. These kinds of influences do not currently exist within the mixed economy of social care, although market forces and the pressures of regulatory demand do tend to generate commonalities across care solutions. Local authorities in England bemoan the lack of funding and the dearth of central guidance from government – yet experiences in implementing the nationally defined Integrated Children's System suggest that rigidly imposed, centralised compliance models can be equally difficult to implement. Pilot work being undertaken to explore ways to integrate across the public sector boundaries of health and social care may offer a middle way – that of nationally provided standards and services supported by local design and implementation [18] Guidance is undoubtedly needed. Standards would appear to be essential. But there are also opportunities to encourage the emergence of new solutions, to study lessons learned elsewhere, and to review models employed outside of the UK.

Alongside these developments there is a growing awareness of the need for robust Information governance – the controls that ensure effective, ethical management of the information that these systems need to record and maintain. Systems need to be secure, as well as serviceable. They need to protect privacy, manage consent and confidentiality issues, and include mechanisms that monitor and maintain data quality. Access to data needs to be role based, with legitimate relationships between the data user and the service user it represents – and information extracted for the purposes of research, statistical review or performance monitoring needs to be appropriately anonymised (or pseudo-anonymised) before being made available for use in this way.

As Social Care Informatics is a relatively new field, skills and knowledge are in short supply. Training, courses and qualifications in health informatics are widely available, yet their equivalent in social care informatics is practically non-existent. Most of the people working in this area have developed their skills at the workface, either as care practitioners drawn into implementation projects, or as IT and information people who acquire their business skills through practical experience. Individuals with this hybrid of information and social care professional skills are often 'headhunted' by systems suppliers – although the benefits of their direct knowledge can dilute over time as they struggle to keep up with changes in policy and practice. Given the low level of research in this area and the comparative newness of the field, the lack of training opportunities and/or mechanisms for maintaining professional development is understandable, but undoubtedly adds to the difficulties that the three sectors – public, private and voluntary – experience when trying to recruit appropriately skilled and qualified staff. This demand for trained and knowledgeable resources offers opportunities to develop both research and learning in institutions with Health Informatics expertise, potentially working with colleagues already working in the field of social care practice.

The absence of a coherent national strategy has meant that English Authorities struggle to understand their information needs. In Wales and Scotland, work has been undertaken to define a more consistent approach to care records, but the issues facing the wider sector economy remain a huge challenge. A commonly shared understanding of these issues – underpinned by appropriate research and supported by an informed dialogue between developers and practitioners – would seem to be an essential component to inform both policy and strategy, not just in the UK, but across the EU as a whole. With increasing societal need and expectations, and pressure on human and financial resources, good informatics support to social care delivery is strongly needed.

5. Making it Personal: Supporting Choice and Self-directed Care

The current direction of social care policy in the UK is to promote and encourage greater choice and independence among service users.[16] The development of the personalisation approach, which focuses on self-assessment and self-directed care, brings additional challenges, with expectations that service users will be given the opportunity to plan, commission and manage their own packages of care. These developments will transform the service user from a passive recipient of services to an active member of the complex care economy, with an associated need for informatics services – not just for accessing their records but for managing and monitoring their care.

Opportunities are now arising to develop and deliver systems that directly support service users and bring them into the information economy. Self assessment, personal care planning, management of individual budgets and knowledge services for the expert patient and/or carer are all areas that will need relevant informatics skills and expertise to provide support. Issues around security of systems, user authentication, privacy and confidentiality will have to be addressed in the design and development of user-centred tools. The mechanisms for sharing and exchanging information will need to flexible enough to allow users to define their choice of boundaries – and enable them to change their mind as their needs and requirements change. Not every service user will need, or want, sophisticated information systems to support their care, nor every provider agency need to utilise such systems. However, it is likely that those who do will become influential in the development of Social Care Informatics and the skills and knowledge that will be needed.

6. Summary

This paper has attempted to outline some of the complexities that underpin the delivery of social care, and the new paradigm of informatics tools needed to support it. It has focused on issues related to the managing and monitoring care within a mixed economy, and the low level of knowledge, skills and investment currently available to meet the emerging challenges in this field. It has identified some of the opportunities that exist in an area which has not yet been extensively researched or defined. Other opportunities offered by emerging developments in technology have still to be explored: web 2.0, knowledge management, practice focused tools, telecare and other services all hold potential for taking forward the support of care and contributing to the management of the care economy.

As demand for social care will continue to challenge supply, robust information systems and tools will have a vital role in protecting the best interests of both clients and suppliers, together with governance protocols which command public trust. The complexities inherent in the mixed economy of care add to the challenges. Delivery of solutions is dependent on the development of an informed social care informatics community, able to build capacity, articulate requirements, and continue to respond to the challenges offered by policy and working in a mixed services economy. Social Care Informatics is a relatively unexplored area, but rich in opportunities for learning, research and development.

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