December 2004

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Eva Murray
University of Tasmania

Carol Pollard
University of Tasmania

Recommended Citation

Murray, Eva and Pollard, Carol, "Electronic Health Records (EHR): Developing a New 'Healthcare Information Needs' Model from Multiple Stakeholders' Perspectives" (2004). *ACIS 2004 Proceedings*. 45.
http://aisel.aisnet.org/acis2004/45

Electronic Health Records (EHR): Developing a New 'Healthcare Information Needs' Model from Multiple Stakeholders' Perspectives

Eva Murray
Carol Pollard

School of Information Systems
University of Tasmania
Hobart, Australia
Email: emurray@utas.edu.au

Abstract

To supply effective patient management and care, healthcare professionals must manage an ever-increasing amount of patient data. Generally, these data are distributed across numerous sources and involve mainly paper-based systems. Poorly organised patient information can cause confusion for healthcare professionals, resulting in medical errors and patient frustration. The Australian government is addressing this issue by investing in new information systems to capture patient data electronically. For these projects to succeed it is essential that the information needs of multiple stakeholders are met. This research will investigate the information needs of various stakeholders in the aged care sector with the aim of developing a new information needs model.

Keywords

E-Health, Electronic Health Record (EHR), paper-based, HealthConnect, MediConnect, Community Client Health Profile (CCHP), Stakeholder analysis, health informatics, information needs, aged care.

INTRODUCTION

The Australian Government across all levels is investing heavily in capturing patients' health data via information systems, such as HealthConnect (National), MediConnect (National) and CCHP (Regional). It is anticipated that recording patient data in electronic format rather than in paper-based format will assist in improving quality and safety of care, reduce variability of care and increase the efficiency and effectiveness of healthcare professionals (Parker et al. 2004).

Such information systems can also help in reducing medication errors and provide clinical decision support to assist in the decision making of all healthcare professionals. Furthermore, it could be argued that these systems have the potential to counteract the effects of an increasing staff shortage problem, particularly in nursing, by decreasing redundant responsibilities, streamlining patient data collection and enhancing communication (Meadows, 2002). As these systems are developed and implemented there is an increased need for analysis into whether these systems are meeting the information needs of various stakeholders. If such analysis is not performed, the systems may not be accepted and used by the main stakeholders. As a result, the new technology may become an expensive failure. By conducting research into multiple stakeholders' information needs, there is a greater chance that the goals of these projects will be attained (Ammenwerth et al. 2003).

This paper will discuss the research impetus and the evolution of current paper-based systems. It will also explore the issues surrounding the need for electronic health records (EHR) by examining the current Australian situation and the current dominant perspectives in health informatics. In doing so, the discussion will highlight those areas in which research may be lacking and identify gaps in understanding by stakeholder groups. The paper will also outline the proposed theory and methodological approach that will be used to guide and inform this study. Finally, the paper will present a summary of the importance of such research into the evolving field of e-health and electronic patient record management.

RESEARCH IMPETUS

One of the authors suffered through a very frustrating two and half years as her mother's (Mum) primary carer. The following vignette is this author's story: Mum had an aggressive throat/neck cancer that required an operation in Sydney (St Vincent's Private) and after care treatment at the Hobart Private Hospital (Hyperbaric treatment), Royal Hobart Hospital (Chemotherapy), Launceston General Hospital (Radiotherapy) and St Johns Private Hospital (Constipation – a side effect of treatment) as well as community and palliative care nurses providing care at Mum's home. At all stages of care communication between healthcare providers was a major issue. Patient record management and retention practices were overly complicated. Records were held in several different locations, mostly in paper-based format. This resulted in frustration for the author's family due to:

- Several CT scans had to be repeated, as the scans were lost and not recorded on the computer system.
- Repeating health information constantly.
- Mum's records were not sent to treating doctors in time or at all.
- Varying/conflicting opinions regarding treatment.
- Lack of patient/family information regarding various treatment options.

Although the doctors and nurses were extremely caring and wanted to do the best they could for the patient, it appeared that the information collected regarding Mum's treatment was embedded in patient notes across various locations (hospitals, specialists and GP etc) that resulted in disorganised narrative format and no holistic record of her treatment. During this experience, the carer was constantly contemplating the following question:

- Why is the health system not using information systems more effectively to manage patients' data to improve accessibility, dissemination and retention practices?

It was this question that provided the motivation for this research in an endeavour to help improve healthcare experiences for other patients and their families.

THEORETICAL BASIS

There are a number of reasons why the majority of information system initiatives fail within the healthcare sector. Most relate to human rather than technical factors, due to the unique qualities of the multiple stakeholder groups inherent in the healthcare system. More specifically, the needs of these stakeholders are not adequately addressed in terms of expectations, information requirements, training, communication, cultural issues and political considerations. This is despite the increasing need to value and manage the socio-political problems associated with designing and implementing successful complex technical systems (Heeks, et. al., 1999). Stakeholder analysis would appear to be a useful theoretical basis to explore the multiple perspectives of clinicians, patients, planners, providers and carers in healthcare facilities, where information systems affect their internal operations, power structure and interaction with external entities. Stakeholder analysis will be used in this research to firstly assist with the identification of the main stakeholders and secondly, to help gain a better understanding of the information needs of the various stakeholder groups (Pouloudi, 1999). A holistic view of stakeholders' perceptions is expected to contribute not only to addressing organisational and cultural issues of information systems initiatives, but also to promote a more social approach to information systems design, development and implementation in a healthcare setting.

BACKGROUND LITERATURE

General practitioners, nurses and healthcare providers have been recording paper-based patient medical notes to provide communication to other healthcare providers regarding treatment details of patients for over a hundred years. These early medical notes also served as a means of education, monitoring and treatment validation (Tang et al. 1999). Even the early paper-based systems were found to be inefficient; for instance, Florence Nightingale (1873) in her essay '*Notes on a Hospital*' commented on the inadequacies of the paper-based medical record system in satisfying information needs (in Tang et al. 1999). In addition, the healthcare service delivery model has become more highly specialised with GPs now being the conduit to the health system. In this new service delivery model patients may not only see their GP, they may also have several specialists and hospitals involved in their care. As a result, paper-based methods of record keeping result in multiple records being maintained for one patient. This results in fragmentation, various views of data, redundant/duplicate information and gaps in information (Rubin, 1995). Such a situation gives rise to medical errors, dangerous drug interactions and patient frustration. The vision for the electronic health record (EHR) is to ameliorate these issues, so as to provide data completeness, better quality of information exchange and to enhance the decision making process. It also aims to empower patients through access to their records, improve patient safety by reducing information bottlenecks and decreasing the need for patients to recall complicated medical history details (Parker et al. 2004).

Duckett (2002) reports that Australia spends about 8.5 percent of their GDP on healthcare, which compares favourably with that of the USA (13.7%), Canada (9.5%) and the UK (7%). This translates to approximate Commonwealth funding of $31.6 billion on Australian Healthcare Agreements over the five-year period spanning 1998-2003 (ABS, 2000). Despite these enormous expenditures into health, Australia's healthcare system has been rated 32nd in the world. France was rated as first and Italy as second. This was determined by ranking each country's health system against responsiveness, overall population health, fairness (gap between rich and poor) and government expenditure per person (World Health Report, 2000). This supports recent findings of Marceau and Bastri (2001) who describe the Australian healthcare system as '*very mixed,* *disintegrated and confusing'*. To address these deficiencies, Australia is currently developing several projects to improve healthcare information flow. These include:

HealthConnect: "A Health information network for all Australians" - Proposed by the National Electronic Health Records Taskforce, Health Connect collects health-related information about a "patient" in a standard electronic format at the point of care (hospital, GP). Subsequently, health providers can view a summary of health events regardless of location. This type of system is designed to enhance the quality and safety of health service delivery across the care continuum (Parker et al. 2004).

Medi*Connect* - an Australian Government initiative within the framework of *Health Online: A Health Information Action Plan for Australia*. This initiative is being developed by the Australian Government Department of Health and Ageing and the Health Insurance Commission (HIC) in consultation with healthcare professionals and consumer groups. During development, Medi*Connect* was known as the Better Medication Management System or the BMMS. The Medi*Connect* record will hold personal information such as name, address, date of birth and Medicare number or Department of Veterans' Affairs (DVA) file number. The electronic record will be stored with HIC, an agency that administers Medicare and other government health programs. With patients' consent, healthcare professionals will be able to view/modify and, when necessary, download information to help them treat patients appropriately. Patients will also be able to add information to their personal electronic record if they wish. A trial and evaluation of the systems was conducted in the communities of Launceston, Tasmania and Ballaratt, Victoria in 2003 (Parker et al. 2004).

Community Client Health Profile (CCHP) - a major initiative of the Tasmanian Department of Health and Human Services, which aims to improve the quality and coordination of services to its clients through the development of a single electronic health record for non hospital care. The CCHP is designed to capture the whole history of patient care rather than event summaries. The rollout of the CCHP is associated with the Statewide Client Registration Project (SCRP). This project encompasses the implementation of a statewide unique client identifier for all patients of the DHHS. This unique identifier links clients' CCHP data and as such, regardless of location, clients requiring treatment from a specialist can have their profile presented with a statewide unique client identifier. Such a system enables a holistic picture of patient care to be attained. It also simplifies co-ordination and communication between health centres (UnitTas, 2003).

While electronic health records have the potential to deliver benefits, there has been little empirical or theoretical evidence to demonstrate that such health informatics initiatives deliver the expected benefits, especially in terms of examining health informatics initiatives from multiple stakeholder perspectives. Cornford and Klecun-Dabrowska (2003) suggest that the current examination of health informatics in terms of societal aspects including social exclusion and empowerment is particularly challenging and often not addressed. They contend that research is often completed only in terms of patient satisfaction studies, cost effectiveness analysis and technical performance of the system. As Atkinson et al. (2001) also note, health informatics is driven by systems design methodologies, tools and techniques that yield technical solutions to organisational problems. In this paradigm, the human is represented by the technocentric term of '*user*', which neglects to include the complex social interactions of humans. Additionally, Horsfield and Peterson (2000) argue that the main discourse in health informatics is that of the '*information technology as progress*' discourse. This discourse is focused on the benefits of technologies in enhancing health outcomes by improving the effectiveness and efficiency of health services. This bias ensures that effective consumer discourse is largely marginalised.

As a result of the technocentric focus in health informatics a clear analysis of patients' views regarding EHR, has not been adequately illuminated. This holds true, particularly in terms of patients' understanding of how their data are used for research and the right of the patients to have direct personal privacy over their EHR (Rashbass, 2001). The small amount of research that has delved into patient perceptions regarding security and confidentiality discovered that, in general, patients are willing to have their health data stored in electronic format once informed of the implications. For instance, research conducted in response to new legislation passed in the U.S. that limits access to health records for research purposes discovered that over 95% of patients, once informed of the purpose of information usage; were prepared to have their medical information stored in EHR. This study surveyed more than 200 000 patients at the Mayo Clinic (Melton, 1997). Despite discussions with health consumer groups, that have revealed a guarded acceptance of EHR, particularly in the emergency department setting, there is still doubt regarding the usage of detailed EHR (Clarke, 2001).

A significant reason for lingering doubts, in relation to EHR, centres on the issue of privacy. There has been much debate regarding patient privacy issues (Clarke, 2001). The Australian HealthConnect project has been designed to empower patients by designing tight security controls to protect patients' anonymity, especially when data are aggregated for statistical and research purposes. Patients may also mask information so that only specified providers have access to their records. In addition, they have the right to control what information is recorded or can elect not to have an EHR. However, this right to privacy could create potential gaps in the EHR system, therefore resulting in the same problems as faced by the current paper-based system (HealthConnect Program Office, 2002).

Therefore the aim of this research is to identify the main stakeholders in the aged care sector and then capture their viewpoints by evaluating the delivery of healthcare information and stakeholders' needs from multiple perspectives in order to develop a new information needs model with a more socio-technical emphasis.

PROPOSED RESEARCH METHODOLOGY

This research proposes to conduct an empirical study into the delivery of health care information in the aged care sector and to examine the effectiveness of current initiatives within the Australian health system in satisfying various stakeholder information needs. It is important that such analyses are performed as this will help determine the extent to which real benefits are being gained (Ammenwerth et al, 2003). This analysis will consider the perspectives of patients, carers, providers, payers, technical staff, administrators, planners and healthcare professionals (clinicians, nurses, GPs).

More specifically, the aims of this research are to answer four main research questions:

- What are the information needs of the main stakeholders?
- How do the main stakeholders information needs differ from each other?
- What information is currently difficult to access?
- To what extent are the information needs of each of the stakeholder groups addressed?

A mixed methodology will be employed to guide this research. Mingers (2001a) suggests that a multi-method research approach is best suited to a phenomenon that is complex and multi-faceted. Furthermore, several authors have supported the notion that combining a number of methods from different paradigms for a research project provides a richer picture and enables a better understanding of the research topic (Galliers, 1994). Kaplan & Duchon (1988) suggest that using both methodologies to examine complex social interactions of information system use yields significant insights that neither method singly can supply. Since the healthcare system is a highly complicated social community consisting of a variety of stakeholder groups, who each hold diverse viewpoints regarding healthcare delivery (Clarke, 2001), a multi-method approach to capture the richness of this setting is necessary.

To this end, a qualitative semi-structured interviewing data collection technique using focus groups will be used in the first instance to establish questions that need to be posed. This data will be analysed using a bottom up approach based upon several stages of coding, which will enable the themes to emerge from the interviewees' narratives (Straus & Corbin, 1990). The data collected from the focus groups will be cross-referenced against published literature therefore assisting in the development of the survey instrument. The survey instrument will enable the capturing of a broad range of stakeholder viewpoints. Feeding the results from the qualitative initial interviews into a questionnaire will allow a more reliable instrument to be developed (Mingers, 2001a). Following validation of the instrument and statistical analysis of the data several respondents will be chosen for an interview based on their stakeholder perspective and their differing responses to the survey. Face-to-face interviews will be conducted to determine reasons for reported differences, thus allowing for a better understanding of the results. Participants will be selected with the assistance and advice from key players in the aged care sector, supporting health departments and consumer health groups.

CONCLUSION

EHR systems offer enormous potential to the healthcare industry and to the societies they serve. An EHR can improve administrative effectiveness, clinical efficacy and the health and awareness of the public. However, for EHR systems to deliver they will have to blend idealism and pragmatism. Thus, it will be imperative to maintain the long-term vision and expected project outcomes. To this end, EHR systems need to be empirically investigated at certain stages to ensure that these systems are meeting the information needs of key stakeholders. The main aim of this research is to develop a new healthcare information needs model from the perspectives of various stakeholders within the aged care sector. Such a model should assist developers in ensuring that existing systems and new systems satisfy the information needs of stakeholders and thus, increase the likelihood that these systems will be accepted and used by the various stakeholders (Ammenwerth et al, 2003).

REFERENCES

Ammenwerth, E., Graber, S., Herrmann, G., Burkle, T., & Konig, J. (2003). *Evaluation of health information systems – problems and challenges*. International Journal of Medical Informatics. Article in Press: 1-11

Atkinson, C., Eldabi, T., Paul, R. J. & Pouloudi, A. (2001) Investigating integrated socio-technical approaches to health informatics. *Proceedings of the 34th Hawaii International Conference on System Sciences*.

Australian Burea of Statistics (2000). Health – Healthcare delivery and financing. www.abs.org.au, Accessed 25-5-2004.

Clarke, R. (2001). Research challenges in emergent e-health technologies. http://www.anu.edu.au/people/Roger.Clarke/EC/eHlthRes.html, Accessed 29 June 2004

Cornford T., & Klecun-Dabrowska, E. (2003) Social exclusion and information systems in community healthcare. *Information Systems Perspectives and Challenges in the Context of Globalization.* 291-305.

Duckett, S. (2002). Healthcare in Australia. *Medshunters magazine.* Medhuntersmagazine.com, Accessed 25 May 2004.

Galliers, R. (1994). Relevance and rigour in information systems research: some personal reflections on issues facing the information system research community. *Computer Science Technology.* 54: 93-101

HealthConnect Program Office. (2002) Consent and electronic health records. http://www.health.gov.au/healthconnect/publications/publications.html#consent, Accessed 24 April 2004

Heeks R, Mundy D, Salazar A. (1999) Why Health Care Information Systems Succeed or Fail, Report No. 9,Working Paper Series. http://www.man.ac.uk/idpm/idpm_dp.htm#isps_wp, Accessed 15 August 2004

Horsfield, B. & Peterson, C. (2000). The hierarchy of discourses in the current diffusion of E-Health, telemedicine and telehealth in Australia, *Communications Research Forum*.

Kaplan, B. & Duchon, D. (1988). Combining qualitative and quantitative methods in information systems research: a case study. *MIS Quarterly.* 12: 571-586

Marceau, J., & Basri, E. (2001) Translation of innovation systems into industrial policy: the healthcare sector in Australia. *Industry and Innovation.* 8(3): 219-308.

Meadows, G. (2002) Nursing informatics: An evolving specialty. *Nursing Economics*. 20(6): 300-302

Melton J.L. (1997) The threat to medical-records research. *New England Journal of Medicine.* 337: 1466-1470

Mingers, J. (2001a) Combining IS research methods: towards a pluralist methodology. *Information system Research*, 12: 240-259

Parker, J., Hewitt, R., McWilliam, A., & Kelman, C. (2004) HealthConnect Indicative Benefits Report. http://www.health.gov.au/healthconnect/whats_new/whats_new.html, accessed 20 May 2004.

Pouloudi, A. (1999) Aspects of the stakeholder concept and their Implications for Information Systems Development, *Proceedings of the 32nd Hawaii International Conference on System Sciences*.

Rashbass (2001) The patient-owned, population-based electronic medical record: A revolutionary resource for clinical medicine. *Journal of the American Medical Association (JAMA).* 285(13): 1769

Rubin, R D. (1995) A customer view of CHINs. *Frontiers of Health Services Management.* 12(1): 44-50

Strauss, A.L. & Corbin, J. (1990). *Basics of qualitative research: grounded theory procedures and techniques,* CA USA: Sage Publications.

Tang, P.C., LaRosa, M.P., & Gorden, S.M. (1999). *Use of computer-based records, completeness of documentation, and appropriateness of documented clinical decisions.* Journal of the American Medical Informatics Association 6(3): 245-251

Unitas, (2003). Telehealth Tasmanian network project: evaluation outcomes report.

World Health Organisation (WHO), (2000). World Health Report 2000, http://www.who.int/whr2001/2001/archives/2000/en/, Accessed 06 May 2004

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