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Pathways Home Project: Patient Self-management and Self-efficacy through the Deployment of ICTs

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Abstract

This research-in-progress paper presents an examination of, and reflections on, the challenges of using information and communication technologies (ICTs) to support patients suffering chronic respiratory conditions to achieve increased levels of self-management and self-efficacy. These research insights arise as part of the planning and on-going implementation of the Pathways Home for Respiratory Illness project (Pathways). This project seeks to assist patients with either chronic obstructive pulmonary disease (COPD) or cystic fibrosis (CF) to acquire skills that empower them to comprehend and initiate action in relation to alterations in their conditions. The overall aim of Pathways is to evaluate the impact of these newly acquired skills for improving health outcomes at individual and population levels and is due for completion in 2008.

Achieving benefits from the introduction of ICTs as part of processes aimed at building sustainable self-efficacy and self-management is very difficult, not least because of a desire to avoid simply replacing patient dependency on health professionals with dependency on technology. Reflections on the challenges and experiences within the project to-date illuminate some implicit assumptions underpinning existing IS models for evaluating impact in terms of adoption, usage and benefit and the end-points we presume in our system development processes.

Keywords: *Patient Centred Design, Patient Empowerment, eHealth Research, Self-efficacy*

1. Introduction

The nature and demand for medical procedures, medications and healthcare services have been dramatically transformed due to the impact of medical innovations in fighting disease and increasing life expectancy. These transformations have radically increased the need for high quality, cost effective approaches to chronic diseases and/or complex medical conditions. A number of approaches that empower patients to participate directly in their own care are increasingly being explored as a means of improving disease treatment, management and education. Underpinning the adoption of these approaches are assumptions that patients are willing and able to take on these new responsibilities and that when they do, the result will be positive in terms of quality of care and health outcomes. While most evaluations to date report some benefit, the variety of methodologies and assessment procedures used, make comparisons of efficacy difficult and highlight the complexity and uncertainty associated with supporting self-management of chronic illness (Warsi et al., 2004).

Simultaneously, eHealth initiatives have been identified as a critical component in the development of responses to the growing crisis in health care service delivery. By improving information access, information delivery, update and evaluation, ICTs certainly have strong potential. However, many approaches continue to downplay the socio-technical, clinical and legal challenges that need to be overcome before benefits can be fully realised. There is a considerable literature claiming positive impacts arising from the introduction of ICTs in health care and more specifically, in the self-management of chronic illness (Celler et al., 2003). However, recent strategic evaluations of research reporting positive benefits from the introduction of ICTs into health have begun to question their reliability and revealed many measures of success have little to do with improvements in care or patient outcomes (Wyatt, 2004).

Developing and deploying ICTs to support self-efficacy and self-management of chronic illness is highly complex. At a practical level it is evident that understanding the users is important both for approaches to building self-efficacy and self-management and also in our considerations of how and what ICTs should be utilised. This research reflects on the experience of information systems researchers involved in addressing these issues within a multi-disciplinary eHealth team. Specifically, the research highlights the need to ensure that ICT solutions draw on a detailed understanding of patients, their needs and complex interactions with health professionals, the health system and their wider environment. "finding out prior to design what the unique requirements are, and designing to support them, is much more cost-effective in the long run than finding out after launch that your design does not meet requirements" (Mayhew, 2001).

The paper outlines a patient-centred conceptual model for guiding the approach to the development and deployment of ICTs within the Pathways home project. Specifically, this approach draws on perspectives for empowering patients through the building of self-efficacy and self-management based on existing models of chronic disease management. From a technology perspective, the approach is also informed by theoretical insights drawn from a range of design approaches indicating that successful design and deployment of ICTs relies on understanding users needs and ensuring technology is both easy to use and useful (Singh et al., 2003).

2. The Pathways Home for Respiratory Illness Project

2.1 Background

The Pathways Home project aims to assist patients with either chronic obstructive pulmonary disease (COPD) or cystic fibrosis (CF) to achieve increased levels of self-

management and self efficacy in relation to these respiratory conditions through the provision of mentors coupled with the use of electronic self-monitoring techniques. Self-monitoring and recording of symptoms in an electronic format that can then be both viewed in a graphical longitudinal form by the patient. The aim is to contribute to patients acquiring the skills for early identification, comprehension and response to their conditions in order to reduce and/or prevent the occurrence of severe exacerbations requiring hospitalisation. At the broadest level, the Pathways Home project seeks to evaluate the impact of these newly acquired skills for improving health outcomes at individual and population levels. Subject to the results of the project there is an opportunity to consider applying these technologically supported self-management approaches to other chronic illnesses.

2.2 The Project Team

The project team consists of a small multi-disciplinary group of expert respiratory clinicians, nursing specialists and IS researchers. While previous research has highlighted the navigation of power relations as an important factor in multi-disciplinary team formation within the medical field (Atwal and Caldwell, 2005), the commitment of the project team to a patient centred approach has facilitated open-ness to the on-going negotiation of positions and roles. This has generated vigorous and rigorous discussions amongst the team in developing the project approach and in balancing the different paradigmatic perspectives of each discipline. In particular, this has been evident around the linking of random controlled trial methodologies with the more qualitative approaches as deployed by the nursing specialists and IS researchers.

Despite a strong commitment to engage and involve project participants as early as possible, the practical requirements to acquire initial project funding and to obtain ethics approvals meant that the over-arching parameters of project design and implementation were made solely by the team. However, following participant recruitment, mechanisms were put in place to facilitate their direct input into the project. For example, in relation to the patients and technology interface every effort was made to ensure that changes were initiated by the patients and not imposed by the project team. Therefore, patients when commencing the collection of daily symptom diaries were offered a range of input mechanisms. Unless the patients were regular computer users, they were able to commence the project using paper based data collection methods with the transition to computers and computer training only started when requests to do so came from the patients themselves.

2.3 The Project Participants

There are two groups of participants involved in the Pathways Home project: The nurse mentors and the patients (COPD & CF). The mentors¹ are comprised of a group of Community Health Nurses whose role is to act in partnership with the patients assigned to them to facilitate their development of self-efficacy and self-management. While considerable research is being conducted with mentors as part of the Pathways Project including on the development and use of ICTs, these issues are beyond the scope of this paper.

The patients are taken from two separate cohorts. The patients in the COPD cohort are generally older people between the ages of 50 and 90. Many of the COPD patients have little or no experience with information technology and many have other conditions that make manipulation and/or visualisation of small pieces of equipment difficult. This has

¹ It should be noted that Mentors for the CF patient cohort are comprised of a more diverse range of health professionals than Community Health nurses who interact with the COPD patient cohort.

implications for the technology and systems design and implementation. The patients in the CF cohort are generally younger between the ages of 16 and 45. These patients are generally more experienced with technology and many have their own computers and Internet access. Although there are some social restrictions upon this group they also tend to be physically more mobile than the COPD cohort.

2.4 IS Research Perspective

From an IS perspective the two key issues for consideration within this paper are: Firstly, how can we interactively support patients' development of self-efficacy and self-management and how can we meaningfully evaluate the impact, role and/or benefit of the ICT systems in these processes. Secondly, given that the project is aimed at developing self-efficacy and empowering patients, how can we ensure that the ICT systems developed interactively do not end-up simply replacing patient dependence on health professionals with a dependence upon the technology i.e. the concerning being that patients should not end-up simply monitoring their symptoms without actually developing the self-efficacy and self-management skills necessary to identify and actively respond to changes in their well-being. This consideration led the IS researchers to extend their conceptual framework to include the possibility that any system built should be seen as part of the training in self-efficacy and empowerment rather than as an end-point in itself.

3. Research Focus and Conceptual Framework

At the broadest level, the IS components of this research project are underpinned by a patient-centred conceptual framework (Figure 1) initially developed by Chau, Cummings, Turner (2004). While there is a large amount of work already taking place in eHealth in the areas of assisting health professionals and supporting health authorities and health system managers, this framework advocates that a key focus for innovation in the eHealth domain should be on the patient and their interactions and inter-relationships as expressed in terms of their health information needs through the three concepts of prevention, maintenance and empowerment. This focus echoes the emergence of changing patient attitudes and willingness to participate more actively in their own care. As a 2003 survey on the UK's National Health Service revealed patients increasingly want more control over their information treatment and care (Granger, 2003). In this context, the framework has three dimensions:

1. Prevention - using eHealth information to help citizens maintain healthy lifestyles and prevent illness;
2. Maintenance - using eHealth information to help patients with existing health conditions to manage their illness and live independently for longer in their homes and/or communities; and
3. Empowerment - using eHealth information to enable patients to become more active and responsible in decision-making about their own treatment and care.

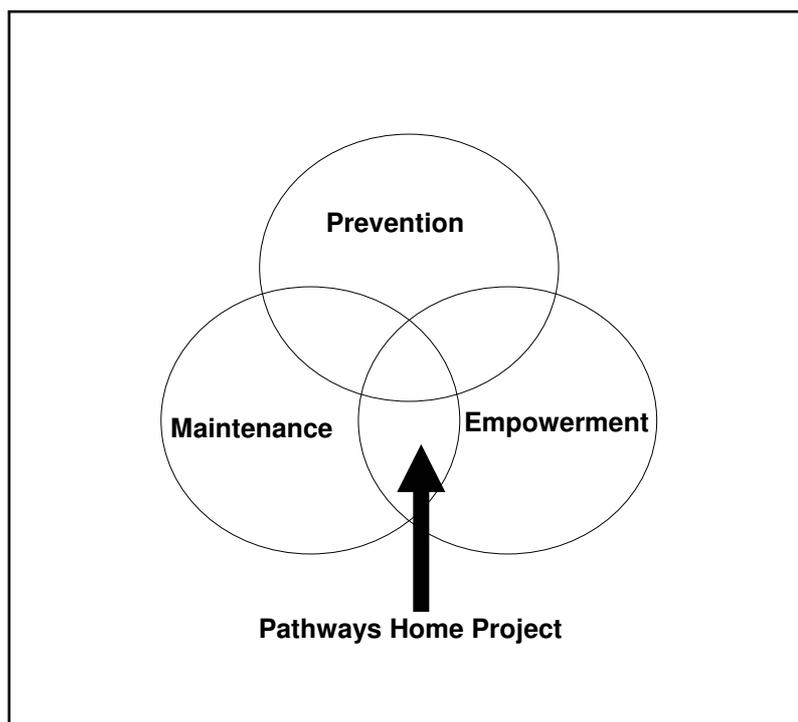


Figure 1: Patient Centred Conceptual Framework

Within this broad conceptual framework, the Pathways Home project can be located at the intersection of the maintenance and empowerment segments of the framework. The project aims to assist patients with chronic respiratory conditions (COPD and CF) to achieve increased levels of self-management, self-efficacy and empowerment in relation to their conditions through interactions with case mentors and through daily self-monitoring of symptoms.

4. Approaching Self-efficacy and Self-Management

This patient-focused approach is premised on the view that, where possible, patients should play a central role in decisions about their own health. The perspective underpinning this is that providing evidence-based knowledge to patients will enhance their ability to participate in decisions about their own care and contribute to the development of an increasingly effective patient-centred healthcare system (Hill, 1998). Within the area of chronic illness two important elements of the patient-centred approach are the concepts of self-efficacy and self-management.

Following Bandura (1994) self-efficacy is defined 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” (Bandura, 1994: 71).

Closely aligned to self-efficacy is the concept of self-management that involves individual chronically ill patients working in partnership with their carers and health professionals to manage their illness. Adapting the Flinders Human Behaviour & Health Research Unit (2004) approach, the aim in this project is to ensure that patients are able to self-manage to the extent that they have knowledge of their condition and of various treatment options. It also involves patients negotiating a plan of care and a review and

monitor process for the agreed plan including engagement in activities that protect and promote their health, monitor and manage the symptoms and signs of the condition, and manage the impact of the condition on physical functioning, emotions and interpersonal relationships.

From a technology perspective, developing and deploying information systems to support self-efficacy and self-management amongst chronically ill patients presents numerous challenges. Most significantly, the Pathways cohort of patients exhibit diverse levels of physical and psychological capacities as a result of their illness as well as a wide range of abilities, experiences, support mechanisms and interests in relation to participating in the project, building self-efficacy and self-management competencies, and, in adopting and utilising any technology solutions developed.

No technology in itself will produce self-efficacy. It is the process of daily monitoring of symptoms and making some associations between the each of the symptoms and the actions required to improve how the individual feels. The patient monitors their symptoms daily and enters them into a diary, either paper based or via a website or other technology, this entry is then added to the database which then provides a graphical longitudinal record for participants to view and make decisions based upon time sequenced data.

5. IT Development

Conventionally in the design of systems within multidisciplinary settings there are a range of techniques and approaches that can be used (Iivari et al., 2001, Singh et al., 2003, Mayhew, 2001, Barnard and Grudin, 1988, Grudin, 1990, Giaglis, 2001). Numerous approaches to systems analysis and design recognise that involving users is an important aspect of their design and deployment. Indeed, there is now a large volume of research into the adoption and use of technologies that reveals that to increase the probability that a consumer technology will be successful it is important that it meets the following criteria:

- To be easy to use;
- To provide relative value – in terms of cost, convenience, mix of channels or better ways of conducting the activity;
- To have acceptable social and cultural meanings
- To support the generation of trust (Singh et al., 2003)

Within the Pathways Home project a range of factors including: focus on the development of self-efficacy and self-management skills; the small size of the multidisciplinary team and the relatively short timeline it was necessary to explore rapid development techniques. From the literature, it was evident that feature driven design (FDD) has had success in enabling translation and communication with non-technical staff. As a result, to ensure balanced engagement across the multidisciplinary team it was decided that of the approaches that were available that FDD was the most appropriate design method.

Within this context it quickly became apparent that the system being built was not highly complex technically but rather faced complexity in relation to being flexible and adaptable to the diverse range of end-user requirements. As a result, the process of development itself became an important and integral part of the project team engagement and interaction with the project participants. While this actually resulted in slowing down the design process because of the high load of social networking and meeting alongside conventional feature set development and modelling of evolving stakeholder relationships and informational interactions, these activities achieve a high degree of project participation and commitment. At a practical level, the development work combined

UML modelling and feature driven design. This worked very well as a conduit for conceptually mapping the project out for the team. It stimulated the team to think about the data elements and enabled higher degrees of engagement with non-technical staff. For the IS researchers in the team, reflection on these activities also led to insights about conventional models of systems development life cycles that tend to contain system maintenance as the final step. This appears to presume that success will involve on-going and continuous reliance on the system built, however in the context of the Pathways Home project an alternative view can be articulated where technology reliance is not the ultimate aim but rather for patients to build self-efficacy and self-management skills so that they no longer need to formally monitor their symptoms via the system.

6. Future Research

The Pathways Home project will continue until 2008 and currently the IS researchers in the team are working on further on-going technology developments for the CF patient cohort. Critically, the next steps in the project will involve generating and testing criteria for meaningfully evaluating the impact, role and benefit of the technology interventions as part of the process of supporting self-efficacy and self-management.

7. Conclusion

This paper has outlined efforts to develop a patient-centred approach and has examined and reflected on the challenges of using information and communication technologies (ICTs) within the Pathways home project. This research-in-progress work draws on a range of approaches advocating how to support self-efficacy and self-management based on existing models of chronic disease management. From a technology perspective, this work is informed by theoretical insights drawn from a range of approaches that indicate that successful design and deployment of ICTs rely on understanding users needs and ensuring technology is both easy to use and useful (Singh et al., 2003). This paper has introduced the possibility that systems can be developed with a planned withdrawal phase and that within the eHealth domain this contributes to reconceptualising the end-points we perceive in our development life cycles.

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