The role of User-Centred Design within Online Community Development

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\textbf{Abstract.} Research has shown the benefits of using information and communication technology (ICT) to improve the information available, the communication methods and the individual’s self-awareness of their own conditions within the chronic disease domain. However, development of complex multi-purpose systems requires significant input from all potential user groups to ensure all requirements are met. This paper explores the issues relating to system analysis, specification and design when patients are not included in the planning, drawing upon the experiences of the development of a community based patient support system.

\textbf{Keywords.} User-centred design, online communities, patient-centred systems

1. Introduction

The use of information and communication technology (ICT) in health service provision over the last two decades is fast becoming commonplace and applicable to a broader range of situations \cite{1, 2}. This paper will use a community based patient support system project to demonstrate and explore the issues relating to system analysis, specification and design when patients are not included in the planning.

In Tasmania a team of clinicians, researchers and information technology developers is currently exploring methods to provide a means of overcoming geographical and medical barriers to communication, mentoring and health service delivery within the cystic fibrosis (CF) community. Tasmania has a high incidence of CF and many of the people with CF are geographically dispersed and isolated within this island state. This can create logistical challenges in accessing specialised services for some families. This can lead to decreased attendance at regular clinical appointments and the adoption of a reactive approach to care, rather than a proactive, preventative approach \cite{3}. More specifically, there are commonly a number of virulent and resistant respiratory bacterial associated with CF. The possibility of cross contamination with one or more of these bacterium has led to the increased separation of patients when in hospital or attending outpatients clinics. The flow-on effect of this is further isolation of the people with CF and their families particularly in relation to
any regular contact between people with CF that may provide a base for a supportive network [4].

Research has shown the potential of using ICT to improve the information available, the communication methods and the individual’s self-awareness of their own conditions within the chronic disease domain [5]. The role that ICTs can play within enabling and fostering self-management behaviours has been encouraging, but not conclusive. Some research has demonstrated that individuals not only increase their own knowledge and levels of self-efficacy for self-management but additionally have improvements in some clinical outcomes and enjoy greater levels of social support [1, 2].

Building upon previous research [6-8] in the use of ICT and self-management, the research team from the University of Tasmania and the Department of Health and Human Services decided that expansion of the original research may provide further benefit to the CF community. The revised project included web and mobile based education, self-monitoring and mentoring resources, specific for the CF community. The intention is to create an online community for individuals and families living with CF, allowing for the sharing of experiences and ultimately the improvement of self-management abilities.

2. The Challenge

Norman and Draper (1986) first developed the concept of user-centred systems design, stressing the importance of ensuring that systems development occurred through a high level of understanding of the user’s situation and requirements. This understanding however did not necessarily need the active involvement of the users themselves [9]. Through their own exploration of user-centred system design literature and processes, Gulliksen et al [9] identified the following 12 principles of user-centred design (UCD) developed in order to improve upon the varying existing definitions of the concept [9].

<table>
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<th>Table 1. Table adapted from Gulliksen et al [9]. p409.</th>
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In the field of health informatics (HI) emphasis on principles 1, 2, 4, 6, 9 and 10 may ensure the design process captures all stakeholders within the project, particularly when the end-users involve both the health service professionals and health service recipients. This emphasis provides an avenue to include all apparent and non-apparent orientations to the systems development.

The challenge for HI is that many user-centred approaches don’t involve all of the stakeholder groups until the final phase of the systems development lifecycle. This is particularly apparent within those system developments that include patients as a beneficiary or end user of the enhanced or altered service. In these cases initial development phases are reliant upon representation and conceptualisation of ‘the typical patient’ as provided by health care professionals. This creates assumptions about the requirements of the end-users, the usage behaviours that will be present and inherent prejudices each individual will have towards the final product.

The late use of user-centred system design within the systems development lifecycle can then translate a potential holistic project into one of a narrowed focus. The communication between the design and project team may become frustrated as assumptions and agenda’s cloud the representations of the health service recipient end users. The communication processes may also become cyclic in nature, encountering similar problems with the design but without the potential solution the included involvement of all stakeholders can bring.

The experiences of the ICT development team within this research project have been that the clinical team has a close relationship with their patient population and tend to protect them from outsiders. Attempts at early involvement of patients in the development of the system have experienced many barriers. The clinical team insisted upon having a polished, operational system before the patients were included. Thus the patients become final testers of the system rather than involved in the conceptualisation, design and development.

3. Several Orientations – One ICT Platform

Health care providers require objective evidence of not only the effectiveness, but the safety of ICT platform design [10]. This evidence is to be collected whilst removing any burden to patient safety and confidentiality, essentially excluding the majority of patients from a user design process. This, in turn, may create difficulties within the creation of a service platform for varying user needs when the overall needs analysis has taken place through a single user cohort on behalf of all users. In the example of the CF project, the health service providers have presented a conceptualisation of a ‘typical patient’ and encompassed those anticipated needs and behaviours into the requirements of the ICT platform.

The potential for a ‘needs gaps’ to arise once the participants finally have the opportunity to use the platform increases through this approach. One of the dilemma’s encountered within the project’s website design and development was trying to find a
balance between functionality and form. Functionality allows the participants and health care providers to use the site according to the design stipulations and ensures information security. The form of the site is concerned with the overall layout and style. How the users can access information, how task intensive that process is and how the users interact and perceive the site will assist them in achieving the highest level of functionality. As visual creatures, different users also find different layouts aesthetically pleasing. Through the design and development phase the ICT team were concerned with this balance. The underlying nature of such a site is that the functionality is of paramount importance; the site must be able to achieve what the research team had envisioned. However, all user groups must be drawn to the site and want to interact with it. Thus functionality and form are linked essentials.

Kushniruk et al [11] suggest the analysis of human computer interaction (HCI) issues can allow for the inclusion of user groups within the design stage, and continuously cycled through the implementation stages. Usability engineering can provide varying methods of analysis that allow for the study of how the end users interact with the platform [11]. These methods can provide the end users perspective within the development stages, allowing for cost effective, safe and practical platforms to be developed.

Consistent with changes in the health care system, health information systems as a discipline, has been undergoing a transformation in regard to the conceptualisation of ‘the patient’ in the overarching research and development process. Traditionally health information systems were designed primarily to meet the health care providers needs and requirements, in order to deliver patient care [12]. This is now evolving to the involvement of patients within the system, creating further avenues for health service interaction and information [12]. The additional involvement of the patient within the system indicates the need for increased involvement in the design processes to allow a more congruent method of ensuring the system fulfils the major requirements of both patient and health care provider. Broader user involvement in the design of the ICT platform can allow previously unidentified requirements to be worked into the system [10, 13]. Powell and Armstrong [14] promote the use of “health consumers” in the varying stages of HI research, noting that focus groups, workshops and intervention pre-tests are of particular value when the extra dimension of input is created. This involvement has the potential to shape future research projects to be truly multi-focused and increased the range of usability across the varying health care orientations.

Health informatics projects frequently evolve due to a perceived need’s gap identified by those involved in the provision of health care services or researcher within the area. The projects have ranging diversities and stakeholders can be limited to inter-professionals within a particular health service, a single unit within an organisation to those involving improving service and communication gaps for health care recipients.

4. Conclusion

To assist in remaining clear to the aims of health informatics, the involvement of users need to take place within the very first phase of the systems development lifecycle, incorporating the user-centred systems design principles most relevant to HI developments. Barriers to access and usability concepts can then be dealt with when presented by all project stakeholders, as first hand representations. Through this
interaction, and the involvement of a user-centred systems design, the need to implement ICT may prove to be of greater harm than good, or the role of the ICT may be that of service complimentary, rather than a true service provision platform.

With the initial conceptualisation of the revised project, the ICT team had the intentions of providing the health care recipients access to the development and design of the ICT platform, anticipating the formulation of the online community would stem from a user-centred design process. The clinical team found it difficult to facilitate this involvement in the design process and insisted that they only be involved once the platform was developed to a fully functional level. These differing views have led the project to difficult situation of continuous development that cannot be resolved easily until the involvement of all end-users becomes possible. This is not an unusual situation within health information systems development.

5. References