

Towards an Assistive Technology to Support Chronic Pain Self-Management: Designing for Adoption and Adherence

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NOTE BY THE UNIVERSITY

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ABSTRACT

Chronic pain requires ongoing support and negatively affects quality of life for those concerned. Patients often experience difficulties applying the physical and psychological pain management strategies taught on self-management programmes and long-term improvements to patient outcomes are not always realised.

This study investigates how technology could assist chronic pain self-management. Taking a user-centred approach it exams reasons why technology initiatives might fail to deliver improved patient outcomes and explores possible solutions to mitigate those barriers to adoption and adherence. A complex web of physical, psychological, medical, emotional and social factors influence individual pain self-management practices. We investigated how these factors can be evaluated to design a technology that caters for this complexity.

The study adapts the patient-centred methodology of de Rouck, Jacobs & Leys (2008) to include analysis of risk factors to adoption and adherence. Transcripts of exploratory interviews are qualitatively analysed to produce three primary Personas used to analyse the risks and create social use cases. The transcripts consist of interviews with eleven patients (nine female and two male, with an average age of 55), who are attending, or have completed, a pain management programme and four transcripts from senior Pain Management Clinic practitioners. Design ideas are produced from the social use cases and then discussed with one practitioner and two discharged patients (one female, one male) interested in championing improved pain self-management provision. Discussions also led to nine additional patients' need statements, supplementing those identified by O'Connor (2008) and a set of criteria for measuring the effectiveness of the resulting technology.

Findings indicate that Personas help designers understand the range of individual, multiple requirements for an assistive technology. We suggest that adding a stage to the methodology, 'Analysing risk factors' helps break down the complexity of pain management practices, giving insight into alternative social use case scenarios that fit varied individual lifestyles, self-images and approaches to managing pain. This understanding can help in designing a flexible system that satisfies a broader range of needs and increases the chances of the technology delivering adherence to self-management and improved patient outcomes. This approach might be applied to other self-management systems where complexity of needs exists.

Finally, we suggest that success should be measured primarily in terms of long-term improvements in physical, psychological and medical outcomes and offer a means of quantifying these outcomes. Establishing acceptance criteria at the outset increases the chances of implementing a technology that meets user needs.

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CHAPTER 1. INTRODUCTION

The Pain Society defines chronic (or persistent) pain as continuous, long-term pain that lasts more than twelve weeks, or beyond the time that healing would have been thought to occur after trauma or surgery. Almost ten million Britons suffer pain almost daily. This has a negative impact on people's quality of life and is costly to the nation. Figures for the actual costs of treating chronic pain are unknown but costs incurred by the National Health Service in treating back pain alone were estimated to be £500,000 back in 1993. The cost to the exchequer for disability benefits in respect of back pain is estimated to be £5 billion per annum. The TUC reported that British businesses lose an estimated 4.9 million days to employee absenteeism through work related back pain and the National Rheumatoid Arthritis Society estimate that 9.4 million working days are lost through Rheumatoid Arthritis (www.britishpainsociety.org).

There is a trend towards encouraging patients to co-participate in their own care and engage in self-management of their condition (Cummings, Chau & Turner, 2008). Self-management is defined as the ability of a patient to deal with all that a chronic illness entails, including symptoms, treatment, physical and social consequences and lifestyle changes (Barlow, Wright, Sheasby, Turner & Hainsworth, 2002). With effective self-management, the patient can monitor his or her condition and make the cognitive, behavioural and emotional changes necessary to maintain a satisfactory quality of life (Barlow, Wright, Sheasby, Turner & Hainsworth, 2002). Self-management support includes knowledge-based patient education, education to develop problem-solving skills and improve self-efficacy (defined as a person's belief in his or her ability to succeed in a particular situation (Bandura, 2001)) and the skills to apply knowledge in real-life situations that matter to patients (Coleman & Newton, 2005). The Pain Management Clinic (PMC) at University College London Hospital provides individual or group-based COPE ("Changing the Outcomes of Pain Experiences") training. Patients, who suffer from chronic pain and are chosen for the programme, are given information such as the paper-based COPE training manual and attend sessions at the clinic to learn pain self-management skills. The benefits associated with successful pain self-management include improved lifestyle, reduced dependency on prescribed medication (Okifuji, 2003) and reduced costs such as medical care. Despite these potential benefits, the dropout rate from the programme is high. At completion of the COPE pain management programme only 70% of the patients who attended will be using the skills learned. This figure decreases to 30% over time (O'Connor, 2008¹).

The PMC could potentially make more use of Information Technology to improve delivery of its programme. It has been suggested that Information and Communication Technologies (ICTs) can be used to improve the delivery of e-

¹ COPE statistics from PMC 2008

health initiatives, particularly in the support of self-efficacy and self-management of chronic illness (Celler, Lovell, & Basilakis, 2003). However, many approaches downplay the challenges that must be overcome before these benefits can be realised (Cummings & Turner, 2006). Chronic conditions require treatment at a number of levels including psychological, social, economic, and lifestyle changes, as well as the physical and treatment regimens. The benefits of introducing ICTs can only be realised if systems are based on an understanding of the needs of end-users and their wider environment (Cummings, Chau, & Turner in Wilson, E.V. (Ed.) 2008) and an understanding of the barriers that may account for non-acceptance of technological intervention.

The study by O'Connor (2008) identified three main themes that moderate patient adoption and adherence to self-management, namely, skill development; external support and encouragement; and information seeking and use. This dissertation investigates further the themes that moderate adoption and adherence by expanding the research to include barriers to the adoption of technology in the wider psychological and social environment relevant to pain self-management.

The investigation into patient needs and requirements involves the analysis of views from current and past COPE patients, individual patients and clinicians from the Pain Management Clinic. Barriers to active self-management and the known benefits and difficulties with existing technological solutions will also be explored in the literature to better understand the challenges and encourage exploration of solutions to overcome anticipated problems.

The outcome of the study is the identification of additional needs and design considerations for an effective technology to support pain self-management. The study takes a user-centred approach in order to understand user needs, as recommended by Cummings, Chau & Turner (2008). By way of progressing the work of O'Connor (2008), we utilise the methodology proposed by de Rouck, Jacobs & Leys (2008), and propose an additional methodological stage designed to identify and analyse the risks to adoption and adherence in complex chronic self-management systems.

Finally, the evaluation of the benefits of proposed technological solutions is often problematic (Garcia-Lizana & Sarria-Santamera, 2007). This dissertation will begin to explore a patient-centred way of measuring and quantifying the effectiveness of the proposed technology in preparation for the future development and testing phases of the project.

CHAPTER 2. LITERATURE REVIEW

2.1. Overview

Most evaluations of the effectiveness and efficacy of self-management programmes for people with chronic conditions report some benefits. For example, Barlow, Wright, Sheasby, Turner & Hainsworth (2002) were able to conclude that self-management interventions were beneficial in the short-term. Studies of the longer-term effects of self-management programmes and programmes aimed at chronic pain self-management are less conclusive. Warsi, La Valley, Wang, Avorn & Solomon (2003 & 2004) conducted meta-analysis in arthritis self-management and general self-management respectively. Both studies found that arthritis self-management education programmes were not associated with a statistically significant effect. Over time, people with chronic pain tend to do less and become upset by their condition (Zheng, Nugent, McCullagh, Black, Eccleston, Bradley, Hawley, Mawson, Wright & Mountain, 2008). According to Newman, Steed & Mulligan (2004), strategies for pain self-management are more complex than those for other chronic conditions. Conditions such as diabetes and asthma have clear strategies for achieving the goal of control over the condition. In contrast, strategies to deal with the symptoms of pain and the consequences of pain-related disability, such as disability caused by arthritis, are broader and more complex, involving both efforts to reduce pain and initiatives to improve physical and psychological functioning, which requires adherence to treatment; behavioural change; and new coping strategies. Cognitive, behavioural and emotional factors play a part in effectiveness (Barlow et. al., 2002).

2.2. Patient-Centred Approach to E-Health Solutions

Information and Communication Technologies (ICTs) offer the promise of supporting patient self-efficacy and self-management of chronic illness. Potential benefits include more information and greater patient control outside the clinical setting and the possibility of breaking down the barriers of time and place (Hesse & Shneiderman, 2007). Wilson & Lankton (2008) reported that patients with a chronic condition are disproportionately motivated to try out e-health technologies. However, there are indications that not all self-management technology is effective. For example, a systematic review by Garcia-Lizana & Sarria-Santamera (2007) suggests that systems used to improve education and social support are effective but it is not yet clear which features of an intervention guarantee positive outcomes. It is also evident that motivations are not sustained in the long-term. For example, Sassene & Hertzum (2008) found that, of the initial two thousand registrations for an asthma self-management system, only nine were regularly using the diary tool after one year. This failure was attributed to a failure to recognise non-technical, non-medical factors involving adoption and use of e-health systems rather than users' dissatisfaction with the features offered by the system. Such factors include

trust, flexibility and the need for systems to support the social networks that play a role in everyday wellbeing. Maitland & Chalmers (2006) suggest that many e-health systems focus on the individual in isolation and fail to exploit the motivational potential of collaboration, such as sharing between the patient and his social circle and the social interaction and support from peers. This view is supported by Consolvo, McDonald & Landay (2009), who argue that designers of persuasive technologies often draw on models such as Goal-setting Theory (Locke & Latham 2002) and the Transtheoretical Model of Behaviour Change (Prochaska & di Clemente 1982) but these models ignore the individual's social world. To ensure long-term use, technologies for discretionary use need to integrate into the individual's everyday life. Since they are likely to be used in varying circumstances, in both personal and work life, they must consider the social implications of this. Cummings, Chau and Taylor (2008) argue that the benefits of technology can only be realised if systems are designed and implemented with a detailed understanding of end-user needs and the complex interactions between patients and practitioners, the health system and the wider environment.

2.3. Risks and Challenges to the Design of an Effective Solution

As part of a patient-centred approach it is necessary to identify the factors, relevant to pain self-management, that may account for non-acceptance of technological intervention in order to design a solution that minimises those risks and maximises positive patient outcomes in the long-term. Studies have identified several categories of barriers and challenges that put the success of self-management programmes and clinical information systems at risk (Bodenheimer, Lorig, Holman & Grumbach, 2002; Cummings, Chau & Taylor, 2008; Consolvo, McDonald & Landay, 2009; Farzanfar, Frishkopf, Migneault & Friedman, 2005; Gallant, Irizarry & Boone, 2008; Gefen & Straub, 2000; Glasgow, Bull, Piette & Steiner, 2004; Jerant, von Friederichs-Fitzwater & Moore, 2005; Pare, 2008; Sassene & Herzum, 2008). Of particular interest in the context of pain self-management are human/user and usability risk factors. They include, but are not limited to the following:

2.3.1. Human/User

Poor computing skills and knowledge

Factors include the need for training and the flexibility for a technology to change as an individual's capabilities and experience changes (Cummings, Chau & Taylor, 2008). Flexibility might include measures such as shortcuts for expert users.

Trust and privacy

Gallant, Irizarry & Boone (2008) found that trust was associated with the reputations and specialties of physicians at the healthcare facilities. Privacy was a concern for participants with sensitive medical conditions. Participant responses suggested that users felt more secure with the system once they got to know and

trust it. Consolvo, McDonald & Landay (2009) recommend that users should be in control of who has what data.

Unrealistic Expectations

As an example, the AWeb system (Sassene & Hertzum, 2008) was enunciated as a system to improve asthmatics self-management and thereby relieving many asthmatics' symptoms. In reverting to non-use of the system, asthmatics rejected the assumption that defined AWeb as a better way to deal with asthma.

Personalisation and Control

Gallant, Irizarry & Boone (2008) suggest that tailored systems are valued more. Farzanfar et al. (2005) evaluated factors influencing use, non-use and under utilisation of systems and suggested that systems could be more acceptable to users if they are given significant control over interactions.

Individual Characteristics

Age, education level, social class, and illness type all have a bearing on how people approach and use a system. Design needs to take such individual differences into account. (Cummings, Chau & Taylor, 2008). For example, low levels of literacy have a direct effect on self-management outcomes (Coleman & Newton, 2005) and systems need to be able to deliver information using a variety of media.

Individual Motivations

With chronic conditions, patient awareness, capacity for active self-management and social context are as important as actions by health professionals in determining long-term health outcomes (Cummings, Chau & Turner, 2008).

Individual Goals

Sassene and Hertzum (2008) found that an incompatibility between the system image of its users 'striving to be symptom-free' and the actual goals of the users to 'feel capable' presented a barrier to adoption of the system. Consolvo, McDonald & Landay (2009) concur that a technology aimed at lifestyle behavioural change needs to be comprehensive and able to monitor a range of behaviours that contribute to the users' desired lifestyle, not just a few specific behaviours that the technology has been set up to handle. If a system is to sustain long-term use, it needs to specifically account for the social characteristics of its users and support the strategies that those users, wishing to change their everyday behaviours, will seek to deploy.

Individual Capacity

Barriers to active self-management including the emotional impact of illness, difficulties in exercising regularly due to symptoms, fatigue, poor communication with physician, lack of support from family, and pain (Jerant, von Friederichs-

Fitzwater & Moore, 2005). Individual confidence levels and self-efficacy are important factors for success. A system should be cautiously designed to avoid the promotion of feelings of inadequacy or anxiety in those who do not achieve a goal (Farzanfar et al. 2005).

2.3.2. Usability

Poor perceived system usefulness

Perceived usefulness is the main reason why people intend to use a system (Geffen & Straub, 2000). Simply deploying technology to automate existing work processes leads to disappointing results (Pare, 2008). For example, in a review of diabetic care websites, it was found that most systems mimicked paper-based education and few used the power of electronic technology to individualise material (Blonde & Parkin, 2006 & Glasgow; Boles, McFay, Feil & Barrera, 2003 in Franklin, Farzanfar & Thompson, 2009). Usefulness may have an impact on adherence over time. According to Consolvo, McDonald & Landay (2009) a system needs to sustain interest and support the user's personal style.

Poor perceived system ease of use

When users view a main system task as easy to perform, it has a positive influence on adoption of the technology (Geffen & Straub, 2000). Poor perceived system ease of use includes a lack of control. Users need to be able to add, edit and manipulate data so that it reflects the user's status accurately (Consolvo, McDonald & Landay, 2009).

Misalignment of system with local practices and processes.

One barrier to successful implementation is failure of the system to integrate into practitioner workflow (Garg et. al., 2005). Regarding patients' work practices, it is suggested that systems are more effective if they enhance rather than replace patient-provider interaction (Glasgow, et. al., 2004). In reality patients still need assistance from health professionals to interpret and provide a holistic review of their situation (Bodenheimer et. al., 2002).

Other factors identified in the literature, such as technological, political and project organisation risks, are outside the scope of this dissertation but their importance should not be overlooked from the overall project perspective.

2.4. Requirements Elicitation

O'Connor (2008) implemented phase two of de Rouck, Jacobs & Leys' (2008) user-centred methodology for designing e-health systems. Phase two involves assessing the particular needs of the selected patient groups through literature review, document analysis and explorative interviews with key informants. The next step, phase three, is the creation of "social" use cases, defined by de Rouck, Jacobs & Leys (2008) as virtual storylines describing the visions and expectations for the technology and user context. Output from O'Connor (2008), in the form of Patient Need Statements (Appendix 1) will form part of the input for phase three, creating social use case scenarios.

However, modelling the user context of e-health technologies is difficult due to the wide range of possible events and complexity of individual motivations. Models such as the Technology Acceptance Model (TAM) (Davis, Bagozzi, & Warshaw, 1989) are often used to identify key requirements for adoption of a system but their value in the context of e-health systems has been questioned. Wilson & Lankton (2004, 2008) suggest that the use of an e-health system is often situational and depends on its micro-relevance (the degree to which use helps the here-and-now problem). This makes behavioural intentions difficult to predict. Wilson & Lankton (2008) conclude that the predictiveness of rational models such as the Technology Acceptance Model is limited in the e-health context.

An alternative for modelling the complexity of the user context is described by Sassene & Hertzum (2008) who were investigating the reasons why users did not adopt an e-health system for asthma self-management. They argue that a health-related self-management system must acknowledge and link into the ways that users live with their disease if it is to attain long-term use. They describe the views of four asthma patients interviewed about the way they *actually* deal with their asthma and describe the notion of 'good' and 'bad' passages. The concept of good and bad passages (Moser & Law, 1998) considers the complex, multiple ways of relating to a particular illness. The theoretical notion of a passage refers to a blend of physical and psychological aspects and denotes what 'feels' good and bad to the individual in question. In the case of asthma patients studied by Sassene & Hertzum (2008), some ways of performing asthma were smooth and nice to the asthmatic, constituting a good passage. Other ways of performing asthma were unpleasant and considered to be bad passages. As an example, one participant opted to take preventive medication for his asthma because it made him feel well (a good passage) and he felt less capable when he forgot it (a bad passage). Another participant did not take preventive medication in order to avoid presenting the image of being an asthmatic. For him, this constituted a good passage, even though the consequences were an attack. All participants were found to have a persistent preference for good passages over bad but their asthma practices were performed according to an 'economy of passages.' An example of an economy of passage might be an asthma sufferer's decision that it is not worth the effort to use a peak-flow monitor on a regular basis when the consequences are only the occasional attack, it being more economical to simply take the attack medication on the few

occasions it is required. Each participant achieved economy of good passage in an individual way, dynamically adjusting to deal with their asthma in response to the practicalities of day-to-day living and subject to mood, social context, the recency of their last attack and other situational factors. Sassene & Hertzum (2008) found that users ceased to use the asthma self-management system if it were not in tune with their self-image. Reasons for non-use might include forgetting, denial, inconvenience, embarrassment and laziness and strategies for practicing asthma included trying not to get worse, coping, challenging it and taking it into consideration. The strategy was not necessarily becoming symptom free per se. In fact, an interdependent and varying combination of coping strategies was likely. They concluded that successful adoption and adherence might depend on understanding the user's self-image and linking into their variety of practices. This model is compatible with Consolvo, McDonald & Landay's (2009) argument that a system should be compatible with the user's lifestyle.

2.5. Measuring Success

As previously identified, not all self-management technologies prove effective, particularly in the long-term. Warsi et. al. (2003) concluded that it is necessary to understand the efficacy of interventions in multiple settings before devoting resources. Thus, it is important to establish the acceptance criteria of each requirement early in the design process in order to measuring system effectiveness and reduce the risks of failure.

Most Medical Informatics research strives for objective design and Randomized Controlled Trials (RCTs) without considering human and contextual factors. The theories and methods of Information Systems Research can however be useful for informing health care information technology (Chiasson, Reddyb, Kaplan & Davidson, 2007). Also the low numbers involved in trials would make RCTs impractical. According to Hesse & Shneiderman (2007), the path lies with merging the science of evidence-based medicine with the practices of user-centred research.

2.6. Application of the Research

Previous research has identified possible risks for non-adoption and non-adherence related to self-management systems but little research has been done specifically on these risks for chronic pain. This study seeks to elicit barriers to adoption and adherence relevant to pain self-management. The literature calls for a user-centred approach to designing self-management technologies. We answer this by adapting de Rouck, Jacobs & Leys' (2008) methodology to include an additional stage to analyse the risk factors and apply the findings to designing for the heterogeneity of the user group. The objective is to take account of likely causes of non-adoption, non-adherence or under-utilisation of any proposed technology in order to design a solution that better fits users' lifestyle and pain self-management practices and ultimately improves long-term effectiveness and patient outcomes.

CHAPTER 3. RESEARCH METHOD

The objective of this study is to further the work of O'Connor (2008) by taking the next step towards designing an assistive technology to support patients in self-managing chronic pain. In particular, to begin to identify a design that can sustain adherence and measurably improve patient outcomes. This chapter describes how de Rouck, Jacobs & Leys' (2008) methodology (Figure 1) is applied to our research. We begin with a brief overview of the steps taken by O'Connor (2008) and continue with an explanation of the remaining steps of the methodology and the modifications made to suit our own research needs. We finish with a discussion of the rationale for adding an additional stage to the methodology.

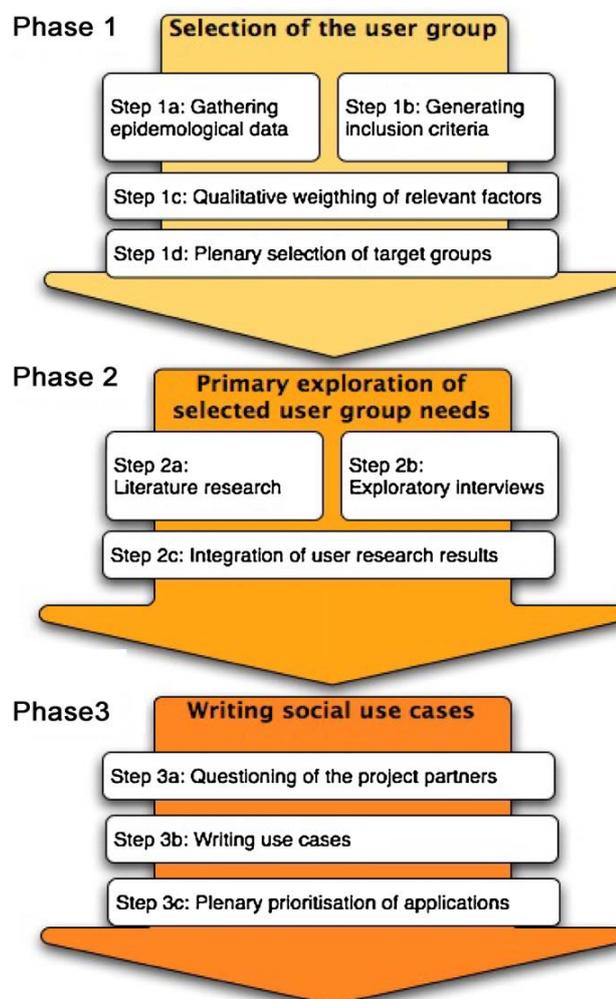


Figure 1. de Rouck, Jacobs & Leys' (2008) User Research Methodology

O'Connor (2008) based her needs elicitation study on *an interpretation* of de Rouck, Jacobs & Leys' (2008) user-centred model for incorporating user perspectives in the design and development process of e-health systems. O'Connor's partial implementation of Phase 1 of the methodology (selection of the user group) and Phase 2 (primary exploration of selected user group needs) resulted in the production of a set of Patient Need Statements.

We repeated Phase 2a, 'literature research,' as discussed in Chapter 2, to find additional information related to adherence and adoption of e-health systems and to better understand the specific issues related to use of ICTs by patients with chronic conditions. The plan was also to repeat of Phase 2b, 'exploratory interviews' using semi-structured interviews to gather data on patient demographics and physical, psychological and social information on lifestyle, self-image, social networks and how patients perform pain self-management.

The next step in the model is Phase 3, 'writing social use cases.' These 'social' use cases are written as real-life storylines, elaborating patient needs through scenarios of use. De Rouck, Jacobs & Leys' (2008) break Phase 3 down into three steps. In Step3a, 'questioning of the project partners,' project partners (stakeholders) should answer an open-ended questionnaire about their expectations for a system including, technological aspects, such as audio and video communication; ethical aspects, such as quality of care; social aspects, such as added value for patients; and legal aspects, such as privacy and protection. The application of Phase 3a to our research presents problems because there is limited access to stakeholders, including physiotherapists and psychologists, during the time period of the study. This leaves little or no scope for administering a questionnaire. To account for limited stakeholder availability, we propose to interview practitioners based on availability rather than carrying out the stakeholder questionnaire. The consequence of this approach is to reduce the statistical significance of the data that can be gathered about stakeholder expectations for the technology but semi-structured interviews have the advantage of allowing follow-up questions in response to unanticipated participant answers, they can offer richness of data over the breadth of responses from a questionnaire and the presence of a researcher can resolve any ambiguity and reduce the risk of invalid responses (Sharp, Rogers & Preece, 2007).

During Step3b, 'writing use cases,' user profiles are created and the social use cases are written. The data resulting from the questionnaire (or in our case, interviews) are combined with the information from Phase 1 and 2 to develop storylines, based on real life settings, to illustrate the daily use of the proposed application. During this phase 'Profiles' of users, based on identified patient groups, are created through group discussions. User 'profiles' are abstract representations of users (Pruitt & Grudin, 2003) derived from Contextual Inquiry (Tahir, 1997). However, de Rouck, Jacobs & Leys offer no guidance on the content of the proposed user 'profiles' or how the data should be analysed to create them and information on their creation is not freely available in the HCI literature. Cooper (1999) introduced Personas as a new way of creating user profiles (McGinn

& Kotamraju, 2008). They have the same general purpose of representing a cross-section of the selected patient group. We will substitute user profiles for Personas (Figure 2 – step 3b (i)). Our rationale for using Personas is that a great deal more information is available in the HCI literature on how to analyse the data to construct Personas, their suggested content and uses. Since we have limited access to stakeholders we are unable to create the user profiles (Personas) in a group discussion, as suggested by de Rouck, Jacobs & Leys (2008). Instead, we will validate the resulting Personas with available practitioners for authenticity.

The methodology does not consider the critical factors associated with creating ICTs to support chronic conditions, including the risks for adoption and adherence that play a critical role in the long-term effectiveness of a self-management technology; the physical and psychological strategies highlighted in our literature search; or the difficulties in modelling the complexity of e-health systems due to the wide range of possible events and problems in predicting user behaviour intentions identified by Wilson & Lankton (2008). These considerations are important to prevent the system falling into disuse and should be included as part of the user-centred design process. Franklin, Farzanfar & Thompson (2009) stress that adherence is central to effective results in e-health systems supporting chronic disease because chronic disease management involves ongoing, consistent patient participation. Therefore, identification of the factors contributing to regular use of systems is critical to achieving the desired health outcomes. The system must present a clear value proposition for adoption and utilisation by patients (Cummings, Chau & Taylor, 2008) and the more possibilities a system provides for linking into users' practices, the better chances it has of becoming part of some of these practices (Sassene & Hertzum, 2008). Understanding these practices can only be achieved by analysing and designing for chronic pain self-management strategies.

We will therefore augment the model to include an analysis of the risk factors in the domain context. The extra stage, 'Analysing risk factors,' will be carried out after 'writing personas' (as illustrated in Figure 2 - step 3b (ii)). Analysis will include understanding users' pain management practices in general and the specific risks applicable to each of our Personas, in order to take account of additional design considerations required for pain self-management. This additional stage is particularly useful for understanding behaviour in situation, such as ours, where access to stakeholder domain expertise is restricted during the writing of the social use cases. Findings from the analysis of risk factors will help reflection in the creation of richer 'social' use cases to augment the Personas and the user research results (in the form of the Patient Needs Statement, Appendix 1) produced in Step 2c by O'Connor (2008).

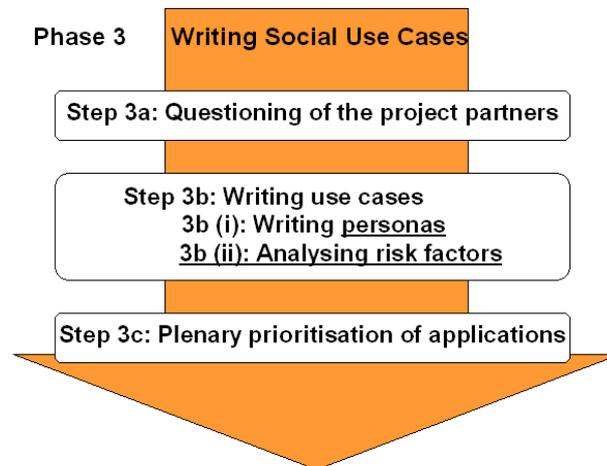


Figure 2. Modification of Phase 3 of de Rouck, Jacobs & Leys’ (2008) User Research Methodology (amendment of 3b(i): from ‘writing user profiles’ to ‘writing personas,’ addition of step 3b (ii): ‘Analysing risk factors’)

Finally, Step 3c, ‘plenary prioritisation of applications,’ requires the social use cases to be discussed with all stakeholders. They are used to set priorities for functionality and services offered by the proposed system and to identify potential strengths and weaknesses. To generate design ideas for discussion, we will evaluate existing e-health systems and review the experiences of self-management and behavioural change systems documented in the HCI literature. Based on findings and the social use cases from Step 3b, some initial designs will be created for use in semi-structured interviews with patients and clinicians. Participants will be asked to comment on the suitability of the design ideas in a pain management context. We will be unable to discuss the resulting social use cases with *all* stakeholders but it is anticipated that feedback from the interviews will partially satisfy Step 3c ‘plenary prioritisation of applications’ by providing an initial indication of system priorities for further design and development. The information will be used to make any necessary additions or amendments to the Need Statements.

CHAPTER 4. PROCEDURE

This chapter describes in detail how the study was conducted. This includes how the adapted model of de Rouck, Jacobs & Leys' (2008) methodology, as described in Chapter 3, was applied to designing an assistive technology to support patients in chronic pain self-managing, the selection of participants and how design ideas were generated based on output from the application of the methodology.

4.1. Exploratory Interviews

We had intended to repeat Step 2b of de Rouck, Jacobs & Leys' (2008) model, 'exploratory interviews' in order to gather demographic, physical, psychological and social data on lifestyle, self-image and how patients perform pain self-management. A representative sample of around ten pain patients and two clinicians were to be selected to participate in semi-structured interviews. In the event, this choice of research method was confounded by severely restricted availability of participants on both the patient and clinician side during the period of the study.

On the patient side delays with ethical approval to interview patients were encountered. From the clinician side, heavy workload and other commitments meant reduced clinician availability. It was therefore decided to analyse the data from transcripts of interviews with patients and clinicians conducted in 2008 by O'Connor instead. These data, together with one additional patient and two additional clinician interviews, were used to produce the set of Personas on which to base our understanding of users. Personas are a useful method for using empirical data to represent archetypical users when there are problems with involving the users themselves (Cooper 1999).

4.2. Participant Selection

Patient participants were selected on the existence of interview transcripts. These transcripts consisted of interviews with ten patient participants conducted in June 2008 by O'Connor (2008). The patient interviews were a sample of ten participants from the twenty-four patients who had responded to an invitation to participate. The sample of ten was selected for interview based on the ratio of 1:4 males to females (in line with COPE patient statistics²); access to a landline telephone; and availability for interview between 9th and 15th June, 2008.

The average age of the participants selected was 55 years and none was in full-time employment. The application of the above criteria resulted in the following patient participants:

² Data provided by PMC in 2008. No corresponding statistics were available for individually treated patients.

| Patient | Age | Sex | Length of time since intervention | Programme |
|----------------|------------|------------|--|------------------|
| I001 | 49 | F | 2.5 months | COPE |
| I002 | 61 | F | Ongoing – nearing end | Individual |
| I003 | 62 | F | 4 months – nearing end | Individual |
| I004 | 58 | M | 10 months | COPE |
| I005 | 64 | F | 18 months – Discharged | COPE |
| I006 | 63 | F | Ongoing – medical focus of treatment | Individual |
| I007 | 64 | F | 12 months | COPE/Individual |
| I008 | 49 | F | 18 months – Discharged | COPE |
| I009 | 31 | F | Ongoing – medical focus of treatment | Individual |
| I010 | 58 | M | Discharged | Individual |

Table 1. Patient Participant Characteristics 2008³ (O’Connor, 2008)

One further participant, who had attended a programme at a different Pain Management Clinic and was in full-time employment, responded to questions via email in June 2009.

| Patient | Age | Sex | Length of time since intervention | Programme |
|----------------|------------|------------|--|------------------|
| I027 | 44 | F | Discharged | Other |

Table 2. Patient Participant Characteristics 2009

Transcripts were also available for two senior practitioners from the Pain Management Clinic - one Clinical Specialist Physiotherapist (01A) and one Consultant Clinical Psychologist (02A). These same practitioners were interviewed again in 2009 - (Clinical Specialist Physiotherapist (P02) and Consultant Clinical Psychologist (P01)) and the interviews were transcribed. The practitioners in 2008 and 2009 were selected on the basis of availability and experience of working in the Pain Management Clinic.

³ Data as at June 2008

4.3. Writing Personas

Step 3b (i) involves writing Personas. Personas are a good foundation on which to build scenarios of use (Grudin & Pruitt (2002). They should be based on real data to avoid the inaccuracies of personal opinion and supposition (Goodwin, 2002). We required a better understanding of the needs and behaviours of our target group. This was best achieved by creating a set of Personas that collectively satisfied the wide range of goals that would have to be described in the social use case scenarios. Accordingly we constructed a set of Personas, from the transcript data, as means to deal with the complexity of needs of chronic pain users.

4.3.1. Data Analysis

The eleven patient transcripts and four clinician transcripts were analysed. Using Goodwin's (2002) methodology for identifying behaviour patterns from data, we listed the ranges of demographic and behaviour variables found in the data. We uncovered different ways in which patients managed their pain, including avoidance and coping strategies, goals and aspirations, things that interfered with a person's ability to practice pain management strategies and patients' relative degrees of success. We also looked for physical, psychological, clinical and social behaviours because these are key factors that influence pain management outcomes (P02) and we needed to understand how participants dealt with them in real-life situations. As a secondary focus, we looked at demographic variables that might be relevant to pain self-management, such as technical skills that would influence a person's ability to adopt and master an ICT, age and home environment.

Clusters of recurring patterns began to emerge across variables. Descriptions of similar behaviours were merged into the same Persona. The recurring demographic categories emerged as gender, age, employment status, children, the wider family and social circle, access to technology and experience in using technology. The behaviour categories of relevance to pain management included levels of medication and exercise plus motivation and self-efficacy. We eventually identified five Personas that we felt had distinctive characteristics and that, together, covered all the variables within the categories we had identified (Table 3). For the five characters, we wrote storylines to develop their personalities and describe their needs, goals and aspirations. These descriptions were restricted to issues that related to pain-management in order to avoid over-complicating the characters with information that would not help with the creation of the use case scenarios and would not help with communicating the design to stakeholders. As discussed by Cooper (2002), too much biography is distracting and makes the Persona less credible as an analytical tool.

| Name | Gender | Age | Employed | Children at home | Medication | | | Self-Efficacy | | | Exercise Level | | | Technology: Experience/Access | | |
|----------|--------|-----|----------|------------------|------------|-----|------|---------------|-----|------|----------------|-----|------|-------------------------------|-----|------|
| | | | | | Low | Med | High | Low | Med | High | Low | Med | High | Low | Med | High |
| Rhiannon | F | 49 | | X | | | X | | X | | X | | | | X | |
| Malc | M | 51 | | | X | | | | | X | | X | | | | X |
| John | M | 66 | | | | | X | X | | | X | | | X | | |
| Asha | F | 35 | X | | | X | | | X | | | X | | X | | |
| Ivy | F | 78 | | | X | | | | X | | | X | | X | | |

Key: X=Applicable to Persona = Not Applicable to Persona

Medication: Low/Medium/High dependency on prescribed medication.

Self-Efficacy: Low = Little belief that own effort will make a difference to outcomes. Dependency on clinicians to solve problems.
Medium = Belief that effort can influence outcome but needs encouragement and support.
High = Belief that effort can influence outcome and improve quality of life, ability to solve own self-management problems.

Exercise Level: Low = Irregular exercise pattern with exercise goals rarely achieved.
Medium = Exercises less that would like and sometimes misses a session.
High = Exercise on a regular basis with goals usually achieved.

Technology: Low = Novice with little access to pc and some experience using a mobile phone.
Medium = Intermediate level of experience using a pc and mobile phone. Access to a shared pc and requiring some assistance.
High = Expert user with high access to a pc and mobile technology. Able to sort out own technical issues.

Table 3. Summary of behaviour and demographic variables

4.3.2. Verification and Refinement

We wanted to validate the Personas to help develop trust in their accuracy. In a case study on the use of Personas during the development of an internet portal, Blomquist & Arvola (2002) discovered that there was a lack of trust in the Personas when they were built on pre-supposition rather than empirical work and when they were not developed enough.

Seeking verification was also a way of communicating our data to practitioners, who represent a key stakeholder group and an opportunity for them to comment on the data and influence the design process at an early stage.

We sought validation by consulting one Consultant Clinical Psychologist (P01) who was available to review our work. We explained that it was not our intention to create a statistically accurate representation of the pain patient population, rather to cover the full range of demographic and behavioural variables. We asked the psychologist to consider the Personas for realism and to ensure that they were not patronising in any way. We also wanted to know if any vital components of pain management strategy were missing from the descriptions or whether a particular archetype of person was absent.

Feedback was generally positive and described as, “they all ring true and are nicely put together” (P01). It was felt that one Persona, Ivy, shared many characteristics with John and did not add enough to the character set. Another, Rhiannon, was not developed enough. As a direct result of the feedback we dropped Ivy, taking characteristics across to John where they were not represented elsewhere. Rhiannon’s biography was expanded to include more information about how she managed stress and pain and her social interactions. Some other minor changes, such as more accurate terminology, were made. The four Personas are contained in Appendix 2.

After revising the Personas we reviewed the four remaining characters to check if they were all primary Personas. A primary Persona is described by Cooper (1999) as someone who’s goals have to be satisfied and cannot be satisfied with a user interface designed for any of the other Personas. The other Personas can be kept so long as they do not interfere with the primary Personas. In the review it was shown that Asha’s needs could be met by satisfying a combination of Malc and Rhiannon’s needs. This left three primary Personas, Rhiannon, John and Malc and one secondary Persona, Asha.

Validating the Personas confirmed that our understanding of our potential users and their goals was sufficiently accurate and ensured that they represented a realistic cross section of the user group. From that position, they could be trusted to form the basis of the ‘social’ use case scenarios.

4.4. Analysing Risk Factors

Before writing the ‘social’ use cases we performed the additional step of analysing the pain management practices that confound improvement in patient outcomes and the specific risks to adoption and adherence that apply to our individual Personas (step 3b (ii)). The pain management practices were based on findings from our interview with the Clinicians (P01, P02). The risk categories were based on those identified in the literature review (Chapter 2). The aim was to link into the variety of behaviours, physical and social constraints, lifestyles and attitudes uncovered during the interviews, in order to better understand how users might practice pain management and to increase the potential for designing a pain self-management system with positive patient outcomes and long-term effectiveness.

4.4.1. Pain Management Practices

In the general context of pain management practices, there are several approaches adopted by patients (P01):

Task Persistence Versus Stopping

‘Persisting’ at a task can involve a patient setting a goal and then feeling that they *have* to do it. “And to do less, or change their plans, even to adapt is somehow a defeat and letting the pain get the upper hand” (P01).

Stopping is commonly described in terms of ‘avoidance’, which has two elements, either, total avoidance of the task at all because it’s believed to be too painful or stressful; or avoiding certain things. An example of avoidance might be a patient who avoids using a beeping timer and stretching in public, in case people think they are odd. “It’s often a social thing rather than a practical thing that interferes.” (P01).

Stop rules

The COPE Manual advises that, “In order to try to avoid highs and lows of activity you need to *pace* yourself. This means doing small amounts of activity regularly...[working] out what your body can easily manage, so you know you are not overdoing something and can continue on bad days, smoothing out the highs and lows of activity”. However, people have a tendency to persist with a goal until they feel satisfied or happy or have reduced their anxiety to a certain stage. “They persist with a goal until they reach a state of some sort and that will be the rule for stopping” (P01). This can be problematic where they think, “I’ll do this until my pain is too much.”

Each of our Personas demonstrates one or more of these behaviours and the system design needs to consider the various approaches to pain management.

4.4.2. Specific Risks for Individual Personae

The risks to non-adoption and non-adherence of ICTs were considered in the context of chronic pain self-management for each Persona. Together they covered a comprehensive range of risks from different perspectives. The categories of risk reviewed were, computer skills and knowledge ranging from considerations such as ease of learning for novice users to speed and configurability for expert users; trust and privacy including anonymity and trust in the sources of information; unrealistic expectations such as limiting the expectation that a technology could be a substitute for an individual's need to participate in ongoing, consistent behavioural changes; personalisation and control ranging from system defaults so that users are not burdened with setting up the technology to a highly customisable system that can cope with unanticipated ways of using the system; individual characteristics; individual motivations including patient awareness, capacity for active self-management, individual goals including catering for those who would use the system as individuals and those who would prefer to collaborate with others; poor perceived system usefulness; and poor perceived system ease of use. Detailed analysis of the risk factors for Rhiannon, John and Malc are shown in Appendix 3 but the underlying message from all the risks considered is that the system should be designed to offer individual choice.

The results of the analysis were a detailed set of specific design considerations, beyond the level of detail contained in the Personas, for each individual. These were used to augment the social use case scenarios.

4.5. 'Social' Use Cases

During the final stage of Step 3b we wrote a set 'social' use cases that took account of individual behaviours and concerns when addressing patient needs (Appendix 4). They were based on the Patient Need Statements (Appendix 1), the Personas and the general pain management practices and risks associated with each persona. The social use cases broke down into four categories:

A. Information Seeking and Use

- General pain management related information. Includes non-personalised information about pain and specific conditions, frequently asked questions (FAQs), tips and tools.
- Requesting individualised information. This includes requesting personalised information that cannot be answered by generalised FAQs.
- Access to pain management training resources. Includes self-management education such as stretching, breathing, relaxation techniques; goal-setting and problem solving.

B. External Support and Encouragement

- Support and community. This included making contact with other pain self-management patients for social support and advice; also consideration for social issues relating to self-image and how one is perceived in the community.
- Goal sharing and collaboration. Goal sharing is intended to encourage and motivate the patient but also to involve significant others to help these significant others understand the problems that patients face in respect to self-management.
- Problem Solving. This includes finding a solution in collaboration with significant others; seeking advice from other pain-management patients; or using the system to prompt and make suggestions.

C. Skill Development

- Pacing. Including setting up and incrementing paced activities.
- Measuring Activity. Dealing with avoidance through motivation and recognition for all activity; dealing with persisting by moderating the amount of activity and encouraging breaks.
- Recording Goals and Goal Steps. This includes recording steps made towards new goals and attaining different goals from those planned.
- Scheduling. Including notification of over-scheduling and not including breaks or exercise.

D. Miscellaneous

- Set-Up and Customisation of the system to fit the patient's needs and lifestyle choices.
- Moderating. Including housekeeping activities, ensuring accurate content and system review and improvement.

The social use cases were used to help visualising the design of the system and its components.

4.6. Design Ideas – Generation and Review

A review of the HCI literature and existing e-health systems was conducted during Step 3c in order to generate design ideas that answered some of the social use cases. We then drew together all the artefacts gathered so far – the COPE manual, Patient Need Statements, Personas, risks, Social Use Case Scenarios and HCI research – and began to produce some basic designs for use during semi-structured interviews with patients and clinicians.

Sketches, together with screen prints of systems reviewed in our HCI research, were used for communicating design ideas with patients and clinicians and were a useful way of presenting tangible artefacts to participants to help them visualise the concept.

We reviewed the design ideas with two ‘graduate’ patients (I026 and I028) with a special interest in improving pain self-management provision, one of whom had prior experience in designing pain-management programmes and one practitioner (P01). Participants were selected on the basis of availability. For the reviews we conducted face-to-face, semi-structured interviews to discuss the design ideas in the context of pain management, to understand possible reasons for non-use, to discuss whether the designs would satisfy user needs and to invite suggestions to improve the designs. The gathering of qualitative data was the most appropriate method because the limited number of participants excluded the option of gathering qualitative data but also because qualitative research was more likely to yield the information about context of use that we required. Kaplan & Duchon (1988) found that qualitative data helped understand the context of the system. In their study, a questionnaire had revealed no differences in reactions to the system under investigation. Later observations and open-ended questions revealed several differences of opinion.

Feedback from the interviews resulted in modified initial design ideas and some prioritisation of functionality. We also identified new and modified Need Statements. The results are discussed in Chapter 5 ‘Findings.’

CHAPTER 5. FINDINGS

This chapter describes the main requirements for a self-management assistive technology, based on the outcome of the user research and risk analysis conducted during the application of de Rouck, Jacobs and Leys' (2008) methodology and the HCI research. It also describes the main priorities and constraints and sets out the additional needs elicited as part of the study. A means of measuring the success of the technology are also outlined.

5.1. A Tripartite Architecture

The study revealed requirements for a tripartite architecture as shown in Figure 3. The components consist of a centralised area containing accessible public information relevant to pain management, which includes access to suitable training material for those unable to attend a pain management programme; a secure and trusted member's area where pain managements patients are invited to join the social community and participate in support; and a portable assistive technology to support pain self-management skills development, such as measuring and recording activity, scheduling and pacing. Data should be transferable between the portable device and a personal computer or portal.

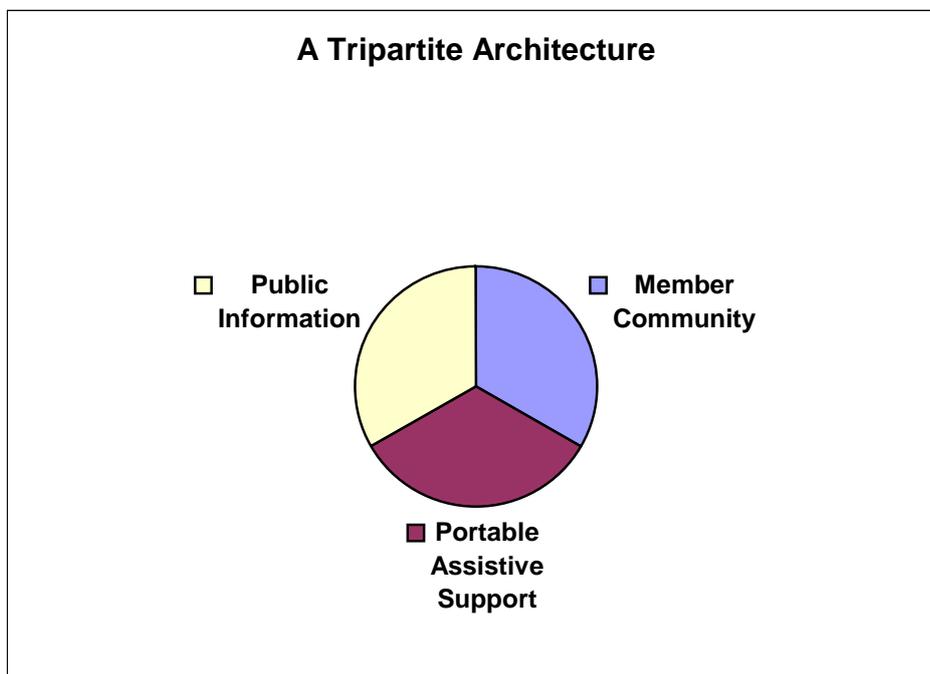


Figure 3. Pain Self-Management Technology Requirements

5.2. Results of Design and Review

The following section describes designs for each category of social use case. It includes details of initial designs based on our user research and HCI literature findings and subsequent refinements.

A. Information Seeking and Use

General Pain Management Information

Barriers to effective self-management include low-levels of literacy (Coleman & Newton, 2005) and language difficulties (I028). E-health technology has the potential to reach under-served groups by its ability to be tailored and customized to culturally and linguistically diverse users (Gibbons, 2005). The system should deliver information in a range of formats to cater for individual learning styles and capacity. The website www.healthtalkonline.org is a good example of how information can be customised to cater for individual learning style. It offers audio/visual content in addition to printable written material and information is broken down into manageable 'bite-size' chunks. Where possible, information should be made available in other languages to increase reach and access.

Requesting Individualised Information

Patient questions invite the pooling of fragments of knowledge, forming a web of collective intelligence related to the ailment and can satisfy the information needs of patients in a way that traditional health care cannot (Johnson & Ambrose, 2006). The system should be designed to encourage users to freely request advice and offer information and should allow multiple replies. The users need to be able to filter and customise the replies they see to keep content relevant.

Pain management training resources

Many groups are excluded from access to pain management training information. For example, if their condition prevents them from attending a clinic (I028). Others remain on a long waiting list before they can attend. If information is made available for view or download, patients can read it while they wait. This may also reduce the amount of training they have to digest on the intensive programme. A stepped approach could be taken to ensure that patients do not have access to any information that is best understood with specialised training (I026).

Others have difficulty remembering the exercises. Training material should be made available for use online and on handheld devices including video demonstrations of breathing, stretching and relaxation techniques plus suitable relaxation audio music tracks available for download.

Refinement of Pain Management Training Resources

After review of these features, it was decided that the teaching techniques were the highest priority. We removed the requirement for music track downloads because music is thought to be personal in taste and has been known to encourage patients to fall asleep, which is not the objective of the relaxation techniques (P01).

B. External Support and Encouragement

Support and Community

Visits to a physician can only address a portion of patient needs and cannot provide the continuous affective or social support that could result in optimal treatment outcomes (Johnson & Ambrose, 2006). In their study of the power of health online communities, Johnson & Ambrose (2006) found that sharing information and involvement with online ‘neo-tribes,’ consisting of people with the same ailment, helped patients comprehend their treatment. A virtual community can develop bonding and satisfy patient needs provided there is authentication, safety and security. Users who participate in the online social group or share goals should be able to opt-in and control with whom they share information and what information they share.

Another aspect of community is identified as public image. Avoidance is often caused by social factors such as the embarrassment of performing pain management activities in public. There are many strategies for designing a system that is sympathetic to lifestyle. Consolvo, McDonald & Landay (2009) suggest that data should be presented and collected in a way that the user can be comfortable if others see it. Measures include using symbols instead of raw data and nicknames to create anonymity. The technology should also be unobtrusive and made available without interrupting or calling attention to the user. Devices should be compact, simple to operate and preferably have fully wireless sensors (Ware et. al. 2008) Simple solutions include using standard mobile phones that users do not object to carrying (Maitland Barkhuus, Anderson, Hall, Brown, Chalmers & Muller, 2006); headphones for private listening to pain management software in public; choice of vibrate and silent modes for alerts.

Goal sharing and collaboration

Motivational and behaviour change research suggests that external and social factors influence motivation and exercise behaviour (Adams & White, 2005). For example, commitment to a goal can be enhanced if it is made public (Locke & Lantham, 2002) and information sharing makes patients accountable to each other (Johnson & Ambrose, 2006). Yet many e-health systems focus on the individual in isolation and the role of interactions between a patient and his social circle or the role of ‘same social circle’ are aspects of collaboration that are often unsupported by ICTs (Maitland & Chalmers 2006). We looked at examples of systems that used collaboration, including how the data was gathered and displayed. In a short-term

study of a prototype where activity information was shared amongst friends, Maitland, Barkhuus, Anderson, Hall, Brown, Chalmers & Muller (2006) found that sharing encouraged reflection and increased awareness and motivation towards daily activity. In a similar study, using a pedometer and mobile phone to share step activity, Consolvo et. al. (2006) found that some participants were inspired to walk more, while others reported being pleased with the support they received from their spouse and children and that walking often became a family activity.

Figure 4 shows examples of how Maitland et. al. (2006) presented information in their study. Figure 4a gives daily activity minutes for each member of the social group and Figure 4b shows accumulated minutes for one individual for the whole week.

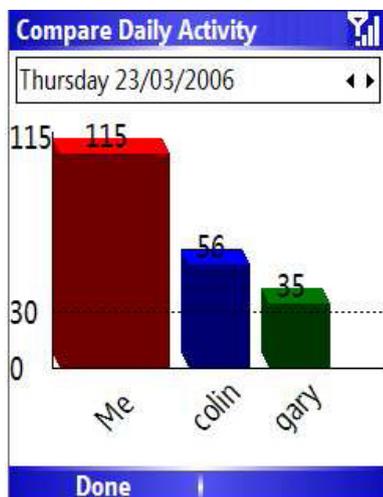


Figure 4a. Comparison of daily activity (minutes)

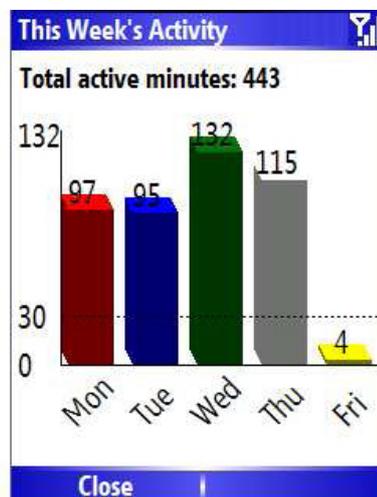


Figure 4b. Individual weekly activity (minutes) (Maitland et. al., 2006)

Refinements to Goal Sharing and Collaboration

For pain management, sharing goals is more about awareness of activity and collaborative problem solving than competition. “Competition and striving forward is not as important as keeping it low-key but getting good, accurate information all the time about how much you’ve done and where that puts you in relation to your goal.” (P01). Our design review indicated that it would be encouraging to know that everyone is making a positive effort. However, goals should not be compared in absolute numbers (e.g. Rhiannon achieved 2000 steps but Malc achieved 8000 steps) because this could create negative feelings for those who do less. Activity should be displayed in the context of individual ability, perhaps as a percentage of the goal achieved and should be moderated to avoid excesses of competition that

could lead to persisting. For example, by encouraging the user to take a break once their goal has been attained. Figure 5 gives an example display where participants in the social group can see their own statistics (e.g. 900 units attained from the target of 1000⁴) and can compare their activity to that of others as a percentage of each individual's goals but without seeing the absolute figures of other group members.

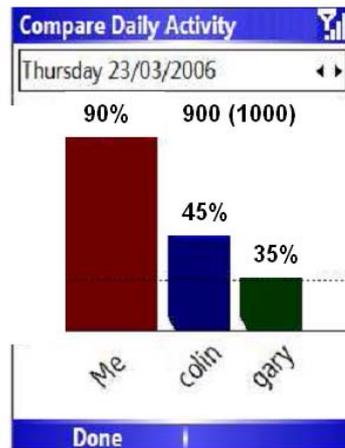


Figure 5. Percentage comparison of activity units
(adapted from Maitland et. al., 2006)

Problem Solving

Problem solving should be flexible to allow users to choose the combination of problems solving strategies. Choices should include options to solve problems collaboratively with significant others; through support from the pain management community; or individually using the assistive technology. Bodenheimer et. al. (2002) suggest that, even when a technology is available, patients need assistance from health professionals to interpret and review their situation. O'Connor (2008) also cited clinician support as a patient need during transition to self-management. During the programme patient gathered data could be useful for problem solving in collaboration between clinicians and patients, "I'd be really interested in the stats but...from a patient point of view." (P02). However, after graduation from the programme, ongoing support from clinicians can give an undermining message to self-efficacy, "Of course they can come back with their problems but I don't want them to feel...[they] need to check in with us all the time." The technology must be cautious not to encourage reliance on clinician support but encourage constructive support from significant others or 'same social circle'.

⁴ System should be flexible in the unit of measurement e.g. number of steps, number of activity minutes etc.

The technology should offer tips on how to increase physical activity, overcome barriers or improve a low self-efficacy if needed (Vandelanotte & de Bourdeaudhuij 2003). The device should be able to detect if the user consistently fails to reach goals and suggest tips on how to increase activity levels, problem solve or alter the activity. The user should be able to influence the amount and type of feedback offered.

Refinements to Problem Solving

Access to collaborative problem solving via a social forum needs to be confined to those who have learnt the concepts and jargon otherwise the experience would be unproductive (I026).

C. Skill Development

Measuring activity and Pacing

A recurring barrier to effective pain self-management is the lack of accurate awareness of activity and achievements. “Many pain patients’ lives are impoverished compared to what they used to be and that’s what they judge by... they’re often very bad at recognising their achievements,” (P01).

Increasing Awareness

The results of a study in the Netherlands (Ronda, van Assema & Brug, 2001) suggest that interventions to increase physical activity should be aimed at increasing *awareness* of personal activity levels. A system should be able to give encouraging feedback to patients about outcomes even when progress is slow (Ware et. al., 2008). Often, people do more activity than they realise and recording accumulative time spent on each category of activity was found to be motivational for those who needed raised awareness of their current activity levels (Maitland et. al. (2006). Consolvo, Klasnja, McDonald, Avrahami, Froehlich, Le Grand, Libby, Mosher & Landay (2008) investigated the effectiveness of displays as a means to improve awareness of physical activity and found that those with an awareness display maintained their physical activity levels compared to a control group, even when on holiday. Ware et. al. (2008) used movement sensors to record upper limb exercises in stroke patients and found that patients liked the being able to see progress through measurement of the smallest of changes that would otherwise be undetectable, even by clinicians, without the technology. De Oliveira & Oliver (2008) found that a ‘glanceable’ interface increased personal awareness compared to a system without a quick at-a-glance display. Figure 6a is an example of how users were able to record weekly activities and goals on a ‘glanceable’ mobile phone background (Figure 6b).



Figure 6a status after one workout. Figure 6b background screen of mobile phone after 1 week of activity. Example ‘At-a-glance’ displays. Activities are rewarded with a flower and goal achievement with a butterfly. (Consolvo et. al. 2008)

Feedback is required for status awareness to allow the user to adjust the level or direction of their effort (Locke & Lantham, 2002). The system needs to automatically capture as much data as possible, such as measurement of physical activity, to improve the accuracy of the feedback because users are bad at estimating durations and distances (P01) and are often unwilling to record data manually. With discretionary use systems, a heavy burden on manual entry would increase the chances of the technology lying unused once the novelty factor had worn off. The Shakra application (Maitland et. al., 2006) is an example prototype technology that reduces the burden on the user. It tracks the carrier of a mobile phone using fluctuation in signal strength and can infer if they are sitting, walking or travelling by car and also track the intensity of the exercise (light, moderate or vigorous).

Persisting

According to goal-setting theory, to say one is trying to achieve goal X means that one will not be satisfied unless one achieves goal X and exceeding the goal provides increased satisfaction (Locke & Lantham, 2002). The system should allow the user to set challenging goals to increase interest but should not encourage persistence until the pain is worse. The system should be designed to encourage the user to reach their goal but it should suggest taking a break once the goal is achieved and should not reward persisting beyond the goal.

Refinements to Persisting

In addition to encouraging breaks upon completion of a goal, the system should reward users for stopping before they normally would. “It would be helpful to stop the common belief that you can’t stop until you’ve finished, which normally drives them on.” (P01). The system should also allow a tolerance of around 10% to cater for unknown situations such as not knowing how long one will need to stand when waiting for a bus. Accurate timing and measurement is less important than giving people information and making people aware of distances and times. The technology should be aimed at increasing awareness rather than measuring physical activity precisely (P01).

Taking breaks and distraction

Breaks during the pacing of activities are to be encouraged but patients often find them a waste of time and do not know what to do during the break. “Something that absorbs them for the time might stop them sitting there thinking, ‘this is stupid, if I work now, I could get home earlier’.” There is also a tendency to ignore or postpone the break. Morris, Brush & Meyers (2008) investigated the use of more interactive break software solutions. Findings showed that 85% of participants preferred interactive breaks to the standard passive break reminder and a higher percentage actually took the suggested break, with no significant reduction in breaks taken over a two-week trial period. Morris, Brush & Meyers (2008) also found that participants were frustrated if the interactive content was longer than the timed break and they could not finish an activity. They recommended that videos or other interactive content should be self-contained and short enough to come to a natural end.

For a pain management application, the user needs to be able to set the timing of the break and measure in length of time or other units such as distance or number of repetitions. The type of break could include stretching and breathing activities or playing a game. Games could be collaborative, with patient sharing results to encourage more breaks (with limits designed to avoid over-use). However, content should be determinable by the user to avoid boredom, which may prompt the user to skip the breaks. Break software on a handheld device would be preferable because users would be able to move around with it, rather than sitting passively at their computer.

Distraction can detract from pain, “I know from being in a lot of pain, the only thing that really works for me is distraction. Radio only has sound but a film has sound and visuals, then you’re engaged.” (I026). The technology should be able to distract the user at appropriate times with a mixture of prompts. For example, it can be used to reduce anxiety while standing in a queue or sitting in a traffic jam to detract from stressing about how long one might have to wait in pain. A mixture of prompts including breathing, stretching and checks on posture would be required (P01) but the choice of prompts should be user determined.

Recording goals and goal steps

A goal should be challenging but believably achievable (Consolvo, Klasnja, McDonald & Landay, 2009). We considered using confidence levels to assist users in recording goals and steps that they could feel confident in achieving. For example, Coleman & Newton (2005) suggested patients modified their plan to accomplish action steps until they had a confidence level of seven or higher (on a scale of zero to 10, where 10 is extremely high confidence and zero is extremely low).

However, feedback during design refinement suggested that confidence level ratings were not always appropriate for pain management patients because setting of the ratings was subject to variance in general mood, “if they’re feeling low then everything would be a bit hard.” (P01). We therefore confined our design to more qualitative ideas such as ‘glanceable’ displays.

Full credit for activity

Consolvo, Everitt, Smith & Landay (2006) recommend that technologies to encourage physical activity should give users proper credit for activities. For example, counting all steps and counting other activities that were not the main goal. The systems should also allow manual entry or amendment of activity that was not correctly recorded.

During the review we found that for pain patients, tracking the intensity of activity is less important than accurate recording of activity. Patients may not strike the heel firmly on the ground or they may do exercises such as stretching, which does not involve much moving around, so measurement of fine movement is important. Ware et. al. (2008) in a ‘proof of concept’ project were able to achieve measurement of fine movement as well as detecting overall activity in stroke patients by using fully wireless sensors to detect upper limb and trunk movements and participants found the resultant information interesting and useful.

Pain patients also need to receive credit for progress towards social goals, such as going to a restaurant, since these are major achievements that improve quality of life. A photographic record of progress towards social goals would give a useful visual reminder of an achievement to encourage and motivate users.

Recording steps towards goals and recording different goals

Recording progress towards a goal is important, for example, “getting to the restaurant, even if they decided to turn back straight away, that’s an achievement.” (P01). Breaking down goals into steps helps with pacing and problem solving by working out how to make a goal smaller and more achievable. “Anything that breaks [a goal] down and is a bit more concrete is going to help people recognise

what they do rather than focusing on what doesn't go as well as they want.” (P01). “[Patients] work out how they're going to do each individual step or how they're going to make the goals smaller. We do that with them...but we don't do that much of it because we run out of time. I think it's the area we probably would increase”(P02).

Recording incremental achievements avoids giving the user an impression of overall failure. A system should be cautiously designed to avoid the promotion of feelings of inadequacy or anxiety in those who do not achieve a goal (Farzanfar et. al. 2005). Farzanfar et. al. (2005) evaluated an interactive health system designed that promoted moderate-intensity physical activity, such as brisk walking. They found that six participants (38%) stopped using the system once they had failed to accomplish the physical activity goals because they were concerned about the system's response if they reported an unaccomplished goal. Farzanfar et. al. (2005) suggest two precautionary design measures to mitigate this risk. Firstly, providing initial education, delivered by the system itself, to explain the likelihood that some goals may not be achieved. Secondly, ensuring that the system's tone and delivery are supportive. Consolvo, McDonald & Linday (2009) suggest using positive reinforcement through rewarding achievement without either punishing or rewarding non-achievement. Figure 7 shows examples of activities that would usefully be recorded on 'at-a-glance' displays.



Figure 7. Record of activities and goals for 'at-a-glance' display.
(Adapted from Consolvo et. al., 2008)

The icons were based on goals and activities, such as 'cardio activity' and 'strength training' proposed by Consolvo et. al. (2008). We changed the activities, based on feedback from interviews (P01, I026) to offer goals and activities more appropriate to the pain self-management domain. For example, 'cardio activity' was replaced with 'breathing exercise' and 'social activities' were added. However, the categories should be viewed as examples rather than a complete list of goals and activities. According to the literature (Consolvo et. al. 2009; Farzanfar et. al, 2005), lifestyle behaviour change technologies should be comprehensive to account for the

range of behaviours that contribute to users' desired lifestyles. The system should not artificially limit data collection and representation to the specific behaviours that the technology can sense and monitor (Consolvo et. al., (2009). Users should therefore be able to customize the display to suit individual circumstances and be able to add new categories or amend existing ones if required.

The system allows users the flexibility to record alternate goals in addition to their original goal. It should also encourage users by showing progress towards a goal, since achievement of the final goal is not as important as the progress made. "It's not necessarily whether they've achieved a goal but how competent they feel...the strategies they use." (P02). Ware et. al. (2008) displayed individual movements and movements over time using 3D animation that could be replayed on demand and participants found the history of where they were coming from useful in addition to knowing what they were trying to achieve. Users also need to be able to record how they felt during goal steps, since this is difficult to remember when looking back over historical progress. Ware et. al. (2008) found that stroke patients were keen to be able to access their diary notes from earlier stages of rehabilitation alongside their movement history. The systems should then be able to detect when users are recording many negative feelings and prompt the user to reflect on reasons why in order to help them problem solve. "[If] their weekly average is down for several weeks running, they need to think about what's happening...one really needs it linked in with a prompt...to try and help themselves in problem solving" (P01). The frequency of such prompts should be under user control. Accurate diary recording can help with problem solving. For example, the user should be able to record that they were ill as this will provide an explanation for why their progress dropped-off during a certain period. "It's useful to have moving averages as well, so people don't feel terrible if for two days they're walking less" (P01). The ability to display progress on a seven-day rolling basis would smooth periods of inactivity and avoid the risk of demoralising the user if they were forced to take a break in their goal progression.

Scheduling

Scheduling should be optional, with flexibility to record detailed or loose scheduling. The system should give the option to alert the user if they have not scheduled exercise and encourage users to take breaks.

D. Miscellaneous

Set-Up and Customisation

Users need to be able to set up their own system in a flexible manner to suit their individual needs. This includes being able to opt-in to any part of the system; add, edit and delete information; control who has access to data; and the option to use nicknames to maintain anonymity, if required, “[anonymity] may encourage more openness, [if] none of the other people really know who it is.” (I026).

Burns et. al., (2008) investigated the problem of providing assistive technologies that have to adapt to widely differing needs. They found that in order to create a personalised, user specific tool, an assistive technology should be configurable on three levels. Firstly personalisation of the ‘look and feel’ of icons and screens for the system as a whole; secondly service selection to make services, such as specific exercises, available only if relevant to individual rehabilitation needs; and finally, personalisation of the selected services, such as providing choice on whether to present instructions in a diagram or on video. Much of the configuration and personalisation can be set up before the technology is deployed in the home, with healthcare professionals able to select a suite of services specifically designed for the patient, preferably in collaboration with the patient concerned. Patients then configure the interface of the services and the system as a whole, within boundaries to avoid problems such as harsh colour schemes.

Customisation should also include patients being able to select and filter information to keep content relevant to individual interests and concerns. They also need control over the frequency and duration of interaction with the system. For example, Farzanfar et. al. (2005) found that users stopped using an automated telephone healthcare system because they were forced to listen to the same messages repeatedly and could not skip them. The technology needs the flexibility to skip sections as the user chooses.

Moderating

Practitioners are concerned about the quality of patient supplied content because experience shows that, “the advice isn’t always accurate and can be quite negative.” (P01). Yet the perspective of other patients can provide different insights from those of practitioners (I028). There should be a clear distinction between hospital provided and patient provided information. “If it’s set up from the hospital as ongoing help, we would have to be very thoughtful about what’s on it because patients will expect it to be good advice and not a mixture of anything.”(P01). Moderating should be a partnership between patients and clinicians, with patients being able to report a concern. Members of the online community should be invited to join and register their details to improve security and traceability in the user-driven content and increase trust. The system administrator should reserve the right to withdraw membership if needed.

5.3. Priorities and Constraints

Participants who reviewed the design ideas indicated that the key social use cases to be addressed by a technology included:

- Goal sharing and collaboration
- Measuring activity and pacing (including avoidance, persisting and taking breaks)
- Recording goals and goal steps

These priorities form part of the Portable Assistive Support described in the technology's architecture. General information seeking was considered a lower priority in the short-term because it is catered for by other sources such as pain management websites. A handheld device, with download capabilities, would be available for use while standing in a queue, walking or sitting down to assist with problems as they arise. For example, used to perform the breathing techniques as soon as the user becomes stressed or a mixture of breathing, stretching and checks on posture when the user is waiting in a queue. This supports Wilson & Lankton (2008) who suggest that the use of an e-health system is situational.

However, further validation and prioritisation with all stakeholders is required to satisfy step 3c of de Rouck, Jacobs & Leys' (2008) methodology, 'plenary prioritisation of applications,' which requires the social use cases to be discussed with *all* stakeholders. They are used to set priorities for functionality and services offered by the proposed system and to identify potential strengths and weaknesses. Since this step was not carried out for all stakeholders, the priorities can only be viewed as indicative at this stage.

A constraint for the system is the resources required to moderate user provided content and to strike the balance between freely user-driven content and accurate, relevant content. System users would benefit from constructive contributions from peers and mentors but experience has shown that un-moderated content can sometimes be counter-productive. "It could be a vehicle for some people to still be negative...so it must be policed but also it has to be relevant information on the site." (I028).

A system that accurately measures physical activity is constrained by technological maturity. For example, finding a technology that can accurately measure the number of steps when the wearer cannot walk solidly enough to register a step. Also being able to measure upper-body activities when sitting down and making fine movements, or registering swimming, when the user cannot wear a device. Our HCI literature search has uncovered examples of such technologies but they need to exist in a form that users would be prepared to wear or carry, particularly outside the home.

5.4. Additional Needs

As a result of the study, several additional needs to those elicited by O'Connor (2008) were identified:

A. Goal Setting and Progress Tracking

- Patients need a way to record progress towards a goal, even if the final goal has not yet been achieved.
- Patients need a way to record attainment of different goals from those set and to receive personalised feedback on that attainment.
- Patients need a way to record progress towards different goals from those that were set, even if the goal has not yet been achieved.
- Patients need a way to accurately measure and record the amount of activity they do.
- Patients need the flexibility to choose which self-management activities they record and monitor and to choose the level of detail they wish to record.

B. Information Seeking and Use

- Clinicians need a system that can assist in increasing the throughput of patients on a PMC programme without increase the amount of resources required.
- Patients need access to information while they are waiting to attend a Pain Management Programme. This information should be accessible and easy to understand without prior training.
- Patients who cannot attend a Pain Management Programme at a clinic need a way of accessing the training remotely.

C. Learning Style

- Patients need access to information in their preferred language and presented in a range of media including written, visual and audio formats.

D. Amendment to Needs Statement

Other needs identified by O'Connor (2008) were modified as shown in *italics*:

- Patients need testimonials and tips from other patients to provide them with ideas for improving their self-management skills and knowledge.

They need alternative perspectives, from trusted sources such as 'graduate' patients, to supplement the views of medical experts. This information should be provided in a flexible manner so that patients can find the information that is relevant to them personally.

5.5. Measuring the Success of the Technology

According to Adhurn, Kreslake & Phalen (2006) there is a lack of consensus on how to measure e-health outcomes for technologies supporting health behaviour change and chronic disease management. They found that stakeholders in e-health were not satisfied with the sensitivity, validity, and reliability of existing outcome measures and concluded that there is a need for improvement and formalization of evaluation standards.

Measurement of the effectiveness of e-health related technology requires a study design with a blend of scientific evidence-based testing and user-centred research (Hesse & Shneiderman 2007). Ideally a long-term study should be conducted. However, long-term clinical outcomes require follow-up years later, and few studies have been performed on e-health applications (Adhurn, Kreslake & Phalen, 2006). Successful and appropriate alternatives to Randomized Controlled Trials, which are purely objective in nature and may be too slow to keep up with technical developments, have included more subjective measurement such as patient preference and satisfaction measures under the umbrella of 'patient related outcomes,' including single arm pre-post studies and observational studies (Kline-Leidy, Beusterien, Sullivan, Richner & Muni, 2006). According to Newman, Steed & Mulligan (2004), a control group is required because measurement of changes to an individual over time are subject to attentional influences and are a weaker design than studies with a control group. Measurements of patient outcomes are potentially more practical as a study design because they fit with implementation timelines and funders' priorities and limitations (Adhurn, Kreslake & Phalen, 2006).

The technology's success should be measured primarily in terms of improvements in physical, psychological (behavioural) and medical outcomes (Adhurn, Kreslake & Phalen, 2006). Examples in improved physical outcomes include increased activity and overall fitness, psychological or behavioural improvements include a patient's greater belief in their ability to function or improve their current situation, and medical improvements include a reduced dependency on prescription medication. Demonstrated behaviour change was considered to be a good proxy measure to long-term clinical outcomes (Adhurn, Kreslake & Phalen, 2006). Other measures such as usability, adherence, patient satisfaction, and cost-effectiveness are important but only if they are coupled with improved patient outcomes. For example, a patient's confidence at being able to achieve a goal is more important than adherence to a specific goal, "It's not necessarily whether they've achieved a goal but how competent they feel...I think it's about the strategies they use." (P02). "[A patient's goals] may change as they

get more confident, so you can't measure that they're doing the goals that they've written down, it's whether they feel they have the skills to approach these goals.”(OA1).

Some relevant measures of success specific to pain self-management can be drawn from the practitioner interviews (OA1, P02). They include patient clinical outcomes such as impact on quality of life, wellbeing, symptoms and function. Any system needs to be able to provide support and measurably improve patient outcomes rather than creating dependency, “Some of the groups we had last year didn't make very big changes but really liked the support. So the risk is you provide more support but actually, in terms of pain management, nothing changes” (P02). This view is supported by the findings of Cummings, Chau & Turner (2008) that one should avoid replacing dependency on health professionals with dependency on technology. A system must also be able to measurably increase self-efficacy, “We're trying to provide them with information and a tool kit and an overall sense of meaning and direction...one of the things I am wary of is, on one hand one wants to offer ongoing help because new problems arise, old problems worsen or recur and so on and it's nice to be there for the patient, on the other hand [the risk is that] you make a patient a patient for life rather than seeing it a bit more like adult education.” (OA2).

Usability measures include usefulness, ease of use, ease of learning, and effectiveness. For example, a website is only useful if the contents are relevant to pain-management support, “it has to be relevant information on the site.” (I028). Patients' willingness to use the technology is not a measure of its effectiveness if it does not result in a corresponding improvement in outcomes.

Establishing acceptance criteria for the technology at the outset increases the chances of implementing a technology that meets user needs because the system will be designed with the agreed objectives in mind. Requirements should be assigned a fit criteria and scale of measurement. Quantifying subjective outcomes provides a benchmark against which users and stakeholders can gauge success (Robertson & Robertson, 1999). Based on the information provided by practitioners, examples of suitable measurement are included in Table 4. The table shows the element to be measured, how this is broken down into measurable criteria and a quantitative scale against which to measure success. The fit criteria and measurement scales shown are for illustration and require validation by stakeholders. Percentages and other scales (n, t, w, X/Y/Z) should be quantified.

A study that gathers a mixture of qualitative and quantitative data is required in order to elicit richer insights into the effectiveness of the system and produce the required blend of scientific, evidence-based and subjective measurements. Qualitative and quantitative evaluations provide different types of information. Structured quantitative data will provide insight into users' overall perceptions and outcomes but qualitative data will be able to explore complex dimensions of system utilization and user perceptions in more depth (Franklin, Farzanfar & Thompson, 2009).

| | Measurement | Fit Criteria | Example Scale(s) |
|---|-----------------------------|---|---|
| Physical | Increased activity | Increased amount of walking/swimming/ stretching etc | 'n' steps over 't' duration/frequency and lengths or time/frequency and duration |
| | Overall Fitness | Improvement in fitness level, endurance | Increased duration of an activity (such as sitting) or reduced recovery time after flare-up |
| | Overall Movement | Improved or maintained levels of flexibility and movement | Increased (or maintained) ability to pick up and carry items/use cutlery/tie shoe laces. Improved (or maintained) joint flexibility. |
| Psychological/ Behavioural | Self-confidence | Increase in the number of social activities | Taken up a new hobby or activity. Going to a café or restaurant with friends |
| | Optimism | Belief that actions will have positive effect | Reduction in medication for depression. Increase in positive actions taken |
| | Self-efficacy | Problem solving skills. Reduced dependency. | Reduction in number of calls to medical experts. Increased confidence rating. |
| | Improved quality of life | Ability to do activities that the individual considers to be important to them | Progress towards and achievement of social goals. Improved happiness and wellbeing ratings. Better relationship ratings with significant others. |
| Clinical | Medication | Less or no dependency on medication | Reduced by 'X' (over 't' period of time) |
| | Health Care Utilisation | Reduction in the number of visits to GP or reduced contact with PMC | Comparing number of GP visits over 't' period of time without reduction in patient outcomes |
| Usability | Usefulness | The majority of users find the system functions useful and relevant to pain management. | X % of users are satisfied with the system's usefulness and relevance after 'w' weeks and Y % will still find it useful and relevant after 't' period of time. X% still use it after 't' period of time (with corresponding improvement in physical, psychological and/or medical outcomes over 't'). |
| | Effectiveness | The majority of users find the system effective in learning, encouraging pain management activities and improving outcomes. | Use of the system results in a corresponding improvement in physical, psychological and/or medical outcomes. |
| | Ease of use | The majority of users find the system easy to use | X % of users will find the system easy to use Y % of the time |
| | Ease of learning | The majority of users find the system easy to learn | X% of users are able to learn the basics with Y amount of training. A further Z% of users are able to master the more complex functions within XX minutes of their first attempt at using the system. |
| | Personalisation and control | The system can be customised to suit individual pain-management needs and lifestyle and encourage usage | X % of the users are able to customise the system to their satisfaction. |
| n= number, t= time , w= weeks, X/Y/Z = amount | | | |

Table 4. Categories for measuring the technology's effectiveness

CHAPTER 6. DISCUSSION AND FUTURE DIRECTION

6.1. General Discussion

Chronic disease self-management requires ongoing, consistent patient participation and if a technology is to be successful in supporting this, it needs to sustain patient use over an extended period of time and deliver improvements in long-term patient outcomes. The benefits of e-health technology can only be realised if systems are designed with a detailed understanding of end-user needs (Cummings, Chau & Taylor, 2008). An understanding of the context of use is part of that process (ISO 13407). We answered these requirements by applying a user-centred approach to understanding the context for an assistive technology. The creation and application of artefacts such as Personas, risk factors and social use cases resulted in preliminary designs and additional need statements that are grounded on a deeper understanding of the pain self-management domain and its identified user group. This increases the likelihood of delivering a system that the target user group will adopt and continue to use. To test this assumption, a quantitative means of measuring patient related outcomes, based on practitioner defined effectiveness criteria, has been proposed.

The use of Personas and social use cases helped understanding of the range of individual, multiple requirements for an assistive technology and together with an analysis of the risks to adoption and adherence, provided a good foundation for design. They will be useful, going forward, as a shared basis for communication of the designs to stakeholders, developers and others (Pruitt & Grudin, 2003), especially since access to patient participants is restricted.

The key findings for a design to suit individual lifestyles and pain management practices are summarised as follows:

6.1.1. Public Information

Information that does not require special training from a medical practitioner should be made publicly available. Information must be relevant to pain management and from a trusted and reliable source. This can include general information about pain and its causes, pain self-management and useful contact details. It should have an accessible learning style, within the reach of a majority⁵ of the general public without additional training, regardless of age and education level. Measures should include presenting information in audio/visual as well as written styles. Support for different languages would be useful. Information should be presented in a staged manner to allow users to make progression through the material at a pace and level that suits them individually. It should also be flexible enough to allow users to skip or fast-forward sections that are not relevant to them,

⁵ Majority to be defined

to repeat parts of the material without having to go through all the information again and to tailor the information to their own needs, such as that relevant to their own condition. Users should be able to search, filter and bookmark information to keep it relevant to them. Information requiring training from a practitioner should be made available in the member community by invitation.

6.1.2. Member Community

A secure and trusted member's area is required, where pain management patients are invited to join the pain self-management community for more specialist information on skill development and participation in support groups. The information should be accessible to those who are unable to attend or unable to complete a pain management programme, as well as 'graduate' patients who wish to refresh their memory or improve their knowledge of pain management related skills. Information should be presented in different media styles for accessibility and include video demonstrations of breathing, stretching and relaxation exercise and training. Users should be able to search, filter and bookmark the information they find relevant to them. The information must be perceived as useful and offer something beyond that already available in the COPE manual and on the training programme. This offers a choice of information delivery mode for patients in the short term but may be seen as a replacement for the existing manual in the long term, provided any replacement is measured to be a success and all potential users, including inexperienced technology users, have access to the new technology. There is scope to tailor training to individual needs and to reach those who would otherwise be excluded from a pain management programme. This study did not have access to statistics on those excluded from PMC programmes but those excluded from COPE include patients who are not comfortable in a group setting, those who cannot attend weekly day-long sessions or those who are taking soporific or sedative medication (O'Connor, 2008). Others are excluded from programmes for reasons such as poor English (I028). A more detailed study on excluded groups, their demographics and how a technology might be designed to reach them is needed. Some moderating of content is required but members should be free to decide for themselves what to take from the information posted. A clear distinction should be made between practitioner provided material and patient-driven content in order to maintain trust in the information. Information provided in the member community needs to be relevant, updated regularly and should encourage regular contributions from members in order to sustain interest and encourage users to return to the site. Members of the community should be able to share personal information about goals in order to support and motivate each other in increasing their level of activity and to help each other break down goals, problem solve and increase their self-management skill levels and self-efficacy. During the programme, they may also want to share this information with clinicians to support their training. Each user should be able to control with whom they share their data. There should be an option to use nicknames to maintain anonymity if users do not wish to make their personal details public, this may encourage more openness. Users should be able to 'opt-in' to different services in the member area with no compulsion to do so.

6.1.3. Portable Assistive Support

A portable assistive technology is required to support pain self-management skill development situationally. A portable device will also allow users to walk around and stretch, which is preferable to sitting at their computer for too long during self-management activities. The device should support measuring and recording activities and goals, scheduling and pacing. Information should be transferable between the portable device and a personal computer or personal portal within the member community and act as a permanent record of progress. Members should be able to share their data with others of their choosing in order to support collaboration and problem solving. A public commitment to a goal may enhance the chances of success. For pain self-management, goal sharing and collaboration should emphasise low-key, accurate information that creates awareness about activity levels rather than encouraging competition with others. The system should not create feelings of failure if an individual fails to meet a goal. Instead, it should be able to detect if the user consistently fails to reach goals and suggest tips on how to increase activity levels, problem solve or alter the activity. The user should be able to influence the amount, frequency and type of feedback offered. Good, accurate feedback is important for status awareness, allowing the user to change the direction of effort to achieve a goal. Control over who sees their data, how much is visible and when it is shown should remain with the patients themselves. Clinicians may find the data useful in assisting patients overcome specific issues but reliance on clinicians for support should be restricted once patients have graduated from the programme to encourage self-efficacy. Users should have the option to maintain anonymity and symbolic, rather than raw data representation may encourage more honesty and openness if an individual user is sensitive about their public image. Public image extends to providing a handset that users are not embarrassed to carry around and is controllable. For example, switching alerts off if that are inconvenient or too noisy. Individual users should be able to influence how much data they record when measuring their activity and pacing in order to fit individual preferences on how accurately they wish to measure their pain management activity. Quick 'at-a-glance' displays and automatic measurement of activity will help reduce manual effort. If recording data is no burden it may sustain long-term usage. Automatic recording needs to be accurate, however, since too many errors could cause the system to be abandoned. Users also need to be able to add to and correct data to maintain its accuracy and give them full credit for their activities. Users should have the option to customise the device to their own individual preferences or to take system default options if this is their best economy of passage. Customisation includes users being able to set up their own self-management goals and activities, rather than being restricted to those offered by the system. This flexibility will help support individual strategies deployed in pursuit of pain management practices. These goals may include activity goals, social goals or psychological goals such as feeling more positive but the system must cope with adding new unanticipated ones. Progress towards goals should be recordable because positive progress, rather than goal attainment, is most important for pain self-management. Users also need to be able to record how they felt at the time of doing their activities in order to add context to the historic/trending information.

This information is useful when, for example, problems solving reasons for a reduction in activity. The option to display activity on a rolling seven-day basis would smooth breaks in goal progression and avoid demoralising the user if they missed a few days of activity. The system should alert the user that a goal has been reached but should not reward additional effort beyond the goal in order to discourage persisting. The user should be encouraged to take a break as a reward for achieving a goal. A tolerance should be built in so that users can exceed their goal by around 10% since many activities cannot be timed or measured with precision. Break software is often poorly received, with many users ignoring prompts to take a break. Breaks could be made more meaningful by offering a range of short pain management related podcasts or exercises to do during a break. Such breaks should be timed to complete by the end of a timed break. The content of break material must be user-driven to avoid disinterest and should be varied to prevent boredom, which may lead to disuse. Break videos are also useful for distraction from pain when out-and-about and can be used to avoid stress when the user does not know how long they may have to wait in a queue, traffic jam or other situation beyond their control. It should be left to the user to decide how loosely or accurately they schedule activities, if at all. Alerts about missed scheduled activities or prompts to take a break may be useful to some people but will not fit all lifestyles, so their use should be discretionary. The system should be promoted as a *support tool* for pain self-management rather than a solution to the problem.

E-health systems transcend time and place and if designed well, the assistive technology has the potential to reach currently under-served sections of the chronic pain community, as well as those who have already attended a programme and need support with ongoing self-management. Firstly technology can reach groups that cannot attend a pain management programme due to inability to travel or other commitments such as caring for others, attending other medical appointments or work. For example, follow up sessions at the PMC are very poorly attended (P02). Secondly it can reach those currently excluded from programmes for reasons such as language barriers or learning difficulties. The needs of such groups require careful thought and more work is necessary to identify these groups and elicit their needs. Simply automating existing work processes would lead to disappointing results (Pare, 2008). There is scope to move beyond what the current COPE training manual offers by using the power of technology to deliver information and support in a dynamic and tailored way, thus making the programme accessible to more patients. Tailoring can include individual programmes, language translations and information in audio and visual formats as well as written. Tailored systems are valued more and this increases their long-term effectiveness (Gallant, Irizarry & Boone 2008). Reaching new groups and tailoring is intended to enhance rather than replace patient-provider interaction. Glasgow et. al. (2004) suggest that this approach makes systems more effective.

There is a delicate balance between freedom of content and control. Moderating content should be a partnership between patients and clinicians, with moderators

refraining from rigidly controlling content. Korp (2006), in a study of health promotion on the internet, suggested that information should not be quality checked scientifically. Instead, Korp recommended that people be allowed to explore and make their own judgements according to their own needs. The perspective of other patients can provide different insights from those of practitioners (I028) and should not be suppressed, “In my experience of being in Google groups, wherever there are forums or an email group, there are always discussions exploding and they ride their course, it evolves” (I026). A distinction should be drawn between misleading educational information and social material, with the former being moderated more carefully.

A constraint highlighted in our findings was the cost of moderating user-driven content. However, Johnson & Ambrose (2006) found that the collective information gathered from patients is particularly authentic because it is gathered in an unobtrusive manner. It is also preserved as a permanent record. Such information could prove useful to practitioners for research and used in improving system content, training and support for patients. The cost of moderating the system could be outweighed by the benefits if it resulted in a more effective system of relevance to more chronic pain sufferers.

We suggest that the effectiveness of a chronic pain self-management technology should be measured primarily in terms of improvements in physical, psychological (behavioral) and medical outcomes because usage of the system per se does not equate to system effectiveness (Adhurn, Kreslake & Phalen, 2006). Establishing and agreeing acceptance criteria at the outset reduces ambiguity about the objectives of the project for both stakeholders and system developers and increases the chances of creating a system that meets the agreed criteria (Robertson & Robertson, 1999). Developing a scale of measurement allows quantification of both objective and subjective effectiveness measures.

6.2. De Rouck, Jacobs and Leys’ Methodology

De Rouck, Jacobs & Leys’ (2008) methodology was useful, in the context of this study, as a focus for user-centred design. The use of semi-structured interviews in place of a stakeholder questionnaire provided an opportunity to explore interesting issues in more depth and reduced the risk of invalid responses from a questionnaire that had not been piloted (Sharp, Rogers & Preece, 2007). User profiles (Personas) were an effective method for deep analysis of the exploratory interview data and led to a better understanding of the target user group. Social use cases were a good way to quickly create scenarios that helped visualise design requirements.

We suggest that the addition of a stage to the methodology, ‘Analysing risk factors’ enhanced the process of creating social use cases by helping to break down the complexity and individuality of pain management practices, giving insight into alternative social use case scenarios fitting various individual lifestyles, self-images

and situational approaches to managing pain that may not have been otherwise elicited. This understanding can help designers create a flexible system that satisfies a broader range of needs and increases the chances of the technology delivering adherence to self-management and improved patient outcomes. This extra stage might usefully be applied to the design of other chronic self-management systems in order to promote more reflection on user behaviours and self-management practices where a complex, non-rational mixture of psychological, social, economic, lifestyle changes and treatment regimes need to be modelled. This additional step is particularly useful in providing a means of analysis when direct access to the expertise of stakeholders in group discussions is not possible.

As discussed, the methodology called for the full involvement of all project partners (stakeholders) in creating user profiles (Personas) and social use cases and for setting priorities for the functionality. If stakeholders have higher priorities elsewhere, a project cannot automatically rely on full access to stakeholders and in our case there was little or no access in the timeframe. If full involvement is to be achieved, the benefits of change need to be explained and involvement encouraged. To cater for this situation, the methodology should include a process for obtaining stakeholder 'buy-in' at a very early stage in the process. Mayhew (1999) advocates finding a 'usability champion,' described as an influential stakeholder who can play a role as change agent, helping a usability activity by providing resources and other backing.

Finally, the methodology assumes progress from one step to the next without the need for iteration. We found it necessary to continuously verify our findings and re-iterate steps based on the results of our interviews, before moving onto the next step. We suggest that the methodology should be augmented to reflect the need for validation of findings and subsequent revision of artefacts.

6.3. Methodological Concerns

In a user-centred approach, the target user group needs to be consulted at all stages of the design process. Our study necessitated face-to-face interviews with patients in order to elicit their reactions to design ideas. This represented a major challenge. It was difficult to recruit patients who were able to travel to the interview. The project was operating in a highly regulated environment (for ethical reasons in order to protect the interests of the vulnerable user population) in which access to patients was restricted and where questions required approval prior to patient interviews being conducted. During the stage of refining design ideas, only two graduate patients and one practitioner could be interviewed. Although their feedback was highly constructive and influenced the design, the low number of participants weakened the reliability of the data gathered. The data was qualitative and therefore not subject to the same requirements of statistical significance. Nevertheless, more data is required from a fully representative sample of the user population. Participants represented by the user group portrayed by our secondary

Persona, Asha, were relatively easy to recruit but our study also required feedback from harder to reach groups represented by John, Rhiannon and Malc who may have less self-efficacy, problems learning or applying pain self-management skills, who are more likely to drop-out of a self-management programme, who's needs are harder to satisfy and who are, potentially, more likely to benefit from an assistive technology. Adhurn, Kreslake & Phalen (2006) recommend the inclusion of qualitative research of the preferences and technological needs of under-served populations.

The Personas were built on empirical data from interviews with patients from COPE and individual programmes collected in 2008, plus data from one participant who attended a different programme. Our sample data therefore suffered from some of the limitations highlighted by O'Connor (2008), although we were able to include a representative in full-time employment. The limitations included a lack of control over the types of pain conditions represented, where it is unknown if there are specific needs associated with particular pain conditions that might have been overlooked. Participants were selected on the basis of availability and willingness to participate, which runs the risk of omitting harder to reach and potentially more vulnerable sections of the user population. Nonetheless, a range of conditions, disability levels and ages were represented in the sample of patients interviewed. Validation of the Personas with a practitioner, for authenticity, mitigated some of the doubts about the representative nature of the data. Ideally, validation from more than one practitioner would have been preferred but this was not possible in the circumstances. We can, nonetheless, be confident that the Personas were representative and formed a strong foundation upon which the social use cases and initial designs were based. They were a useful technique that allowed us to proceed when access to the user population was so limited.

As part of de Rouck, Jacobs and Leys' (2008) methodology, all major stakeholders should have been consulted. Involvement of stakeholders is an important part of gathering multiple perspectives in a user-centred design environment but we were only able to interview two practitioners. Garg et. al. (2005) cite failure to integrate a system into practitioner workflow as one of the risks to adoption of a health-related technology. It is therefore important that this step is undertaken as soon as possible in order to improve representation in the data, ensure that all conflicting views and requirements are elicited and that all stakeholders have an opportunity to influence design.

We based some of our designs on projects found in the HCI literature (including projects, Houston (Consolvo et. al., 2006); Shakra (Maitland et. al., 2006); TrippleBeat (de Oliveira & Oliver, 2008); SMART consortium (Ware et. al., 2008; Burns et. al., 2008; Zheng et. al., 2008) and UbiFit (Consolvo et. al., 2008)), which are from prototype studies conducted over a short timeframe (typically two to six weeks). The results were encouraging and all found activity and motivation increased. However, it should be noted that the studies were not conducted using patients with chronic pain conditions and TrippleBeat, in particular, was designed to increase the amount of running in participants. Specific tests designed to increase

activity appropriate for in those with a range of chronic pain conditions is still required. Longer-term evaluation of the effectiveness of any supportive technology is also required to evaluate usage drop-off over time, although the appropriate length of time would need to be determined as part of the study design.

6.4. Further Work

6.4.1. Validation

Many of the deliverables from this project still require validation with potential users and practitioners. This includes, exploratory interviews with patients and clinicians to validate the risks and challenges identified in the literature search; identifying all stakeholders and conducting a questionnaire to fully satisfy Phase 3a of de Rouck, Jacobs & Leys' (2008) methodology; validation of the 'social' use case scenarios to satisfy Phase 3c; validation of the additional needs identified; and validation of the acceptance criteria and method for measuring the effectiveness of the system design.

In the case of patients, it is important for the identified risks, needs and the preliminary designs to be validated with hard to reach users, such as those in employment; those who are less mobile and have difficulty attending a face-to-face interview; or those who did not complete their pain management programme, as well as those more able and/or more willing to participate in interviews. One solution to reach more patients might be to interview patients in their home or at work.

The stakeholders remain to be identified and work is required to encourage practitioners to participate in requirements gathering and validation, including explaining the benefits and aims of the project to encourage 'buy-in'. One possible solution might be to identify a stakeholder usability champion to support the project.

6.4.2. Prioritisation

Priorities for development of functionality need to be agreed with all stakeholders in accordance with step 3c of the methodology but also with potential users for a truly user-centred approach.

6.4.3. Further Iteration

Once priorities are set, the sketches and design ideas should be tested with a wider range of potential users and prototypes created from the resulting designs.

6.4.4. Outstanding Issues

Although this dissertation proposes some criteria for measuring the effectiveness of a supportive technology for chronic pain self-management and has begun to

explore the most suitable method for testing the effectiveness of the system, more work is required to find and agree all the relevant success criteria with stakeholders. Measurement of patient related outcomes may be more practical than Randomized Control Trials for e-health related technology but the precise study design is still to be determined.

Many of the patients' needs identified will require additional resources, either from medical staff or from patient volunteers or mentors. For example, the provision of social forums requires a moderator. Introduction of a new technology provides an opportunity to animate training material or to tailor it to individual needs. However, production of such material requires careful design and planning and this is likely to require additional resources. Although funding is beyond the scope of this dissertation, it remains an issue that needs to be resolved if needs are to be fully met.

CHAPTER 7. CONCLUSION

Health and social care services struggle to meet demand for treatment and rehabilitation in conditions such as chronic pain (Ware et. al, 2008). There is a growing trend towards management of long-term chronic conditions outside the clinical setting. Multidisciplinary chronic pain programmes, such as those provided by the Pain Management Clinic at University College Hospital of Neurology, offer training to patients making the transition to daily pain self-management. However, the dropout rate from these programmes is high (O' Connor, 2008⁶) and initiatives are required to improve long-term patient outcomes. Technology has the potential to assist in self-management of chronic condition but studies such as Farzanfar (2005) and Sassene & Hertzum (2008) have shown that they are not always implemented successfully and their use declines in the longer term. This reduces their effectiveness in delivering long-term improvements to patient outcomes.

Our study took the user-centred approach proposed by de Rouck, Jacobs & Leys (2008) and adapted it to include an analysis of the risks to adoption of and adherence to assistive technology in the pain management domain. In doing this we were able to make several contributions towards an assistive technology to support chronic pain self-management. Firstly we created Personas, listed risk factors and wrote social use case scenarios that took account of the varying behaviour and lifestyle strategies employed by patients in pain self-management. These supported an understanding of complex user requirements and system design requirements. They will also serve as useful artefacts for communication with project partners going forward. Secondly, we specified a three-part architecture based on the social use case categories. This consisted of accessible public information relevant to pain management; a member community for support, collaboration and participation; and a portable assistive technology to further pain self-management skill development. We also found that our participants viewed a portable assistive technology as the highest priority for further research. Thirdly, we produced a set of nine patient needs in addition to those elicited by O'Connor (2008). These related to goal setting, progress tracking, information seeking and use and learning style. Fourthly, we produced initial designs based on reflection of user requirements and geared towards satisfying the reported needs of our identified user group. The suggested designs included solutions for information seeking and use, external support and encouragement, skill development and personalisation and were supported by findings in the HCI literature. Finally, we suggested a quantitative means of measuring the technology's effectiveness in producing improved patient outcomes. Identification of relevant success factors is important because usage of a system per se is not a measure of the technology's effectiveness. Our findings suggest that a technology's effectiveness needs to be measured in terms of improvements to long-term physical, psychological and medical outcomes. Usability measurements, such as usefulness and ease of use, are relevant factors because they provide a reason for

⁶ COPE patient statistics provided by the PMC, 2008

users to take up and use the technology. However they are only important if linked to improvements in patient outcomes. It is important that measures for a system's effectiveness are established early in a project, before too many resources are committed and while it is still possible to influence the effectiveness of a design. We suggest that the system should be measured quantitatively, so that there is less ambiguity as to whether objectives have been met and proposed a set of criteria and a scale of measurement to achieve this.

As well as contributing towards the system design, we were able to make a methodological contribution by adding a stage to de Rouck, Jacobs & Leys' (2008) user-centred methodology to analyse the risk factors that must be considered if the technology is to succeed in its context of use. Performing an analysis of risk factors is intended to create a technology that fits the way that patients practice self-management and to cater for a broader range of users in unpredictable contexts of use. We propose that this extra step is necessary in complex health systems in order to provide additional insight and reflection on the domain context and to bridge the gap between Personas and social use cases, especially where access to the knowledge of patients and practitioners is restricted. We suggest that this additional step in the methodology could successfully be applied to the design of other self-management systems where understanding diversity in user behaviours and lifestyles is critical.

Priorities for the future are to validate our findings and to elicit the views of more patients, clinicians and other stakeholders. The technology has the potential to reach new, previously hard to reach and potentially vulnerable sections of the target population who were not represented in our data. This includes those who are less mobile and find it difficult to attend an out-patient programme and those who are excluded from the current system for reasons such as language barriers. The power of technology can be used to tailor programmes to individual needs. We propose that understanding and meeting the requirements of these groups requires careful consideration and that additional research is required to elicit the needs and particular difficulties experienced by more vulnerable groups. Without doing so, there is a risk that the technology will miss an opportunity to reach out to new audiences. Changes of this nature also need to be sympathetic to local practices and processes (Garg et.al., 2005), so it is also important to reach and include the views of more stakeholders if implementation is to be successful.

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APPENDICES

Appendix 1. Patient Need Statements (2008)

Based on analysis of patient interviews and feedback on their validity and relevance to chronic pain self-management, the following patient needs were identified:

Learning Style

1. Patients need self-management information taught in a way that is compatible with their style of learning and comprehension.
2. Patients need skill instructions presented in a way that facilitates correct application in the home environment.

Goal Setting and Progress Tracking

1. Patients need a way to set goals in the home environment that is similar to the way they set them at the hospital.
2. Patients need help to create meaningful goals in the home environment.
3. Patients need sources of inspiration for their goal creation to guide self-management activities in the absence of practitioners.
4. Patients need a simple way of breaking down goals into achievable steps, and calculating increments to ensure correct pacing of activities. *There should be flexibility in the units patients can choose to work in e.g. time, distance, and number of items.*

Example:

- a. Goal is to increase exercise from 10 minutes to 30 minutes
 - b. Goal is to be able to make a particular journey on the tube
5. Patients need a simple way to store and review their progress towards their goals.
 6. Patients need to know when they have reached their goal and *be given personalised encouragement* to create new ones so that they can continue to increase fitness and everyday activities.

7. *Patients need personalised feedback and encouragement based on how they are progressing with their self-management.*
8. *Patients need to be able to review their progress with the medical practitioners at the PMC.*

Routine Development

1. Patients need assistance to set-up and maintain the routine commenced during their training to transfer this to the home environment.

Examples:

- a. Calendar
 - b. Scheduling tool
2. Patients need help to schedule their time to support habituation of particular daily pain management activities.
 3. Patients need to be able to incorporate their self-management activities within a schedule. Patients should be able to:
 - Add;
 - Change; and
 - Remove both home events and appointments within this schedule.

This schedule should enable patients to reflect on their chronic pain self-management activities and make adjustments to specific activities in response to their assessments. Furthermore, patients need personalised prompts to help them make the best assessment of the schedule changes required.

4. Patients need reminder facilities associated with these schedules to help them to remember to perform particular self-management activities. E.g. exercises or relaxation
5. Patients need a way to record or tick-off completed activities in their schedules.
6. Patients need a way to review their schedules, past and present to be able to see how they are progressing with their self-management. *This should be*

presented visually to demonstrate improvements.

7. *Patients need a straightforward way to record events that interfere with them following their plans.*
8. *In the case of flare-up patients need the facility to take stock and rewind self-management activity levels to a period in their schedule they feel better equipped to cope with while they are recovering. Furthermore, as they feel better they should be able to fast-forward to previous higher levels of activity.*

Reminders

1. Patients need help to remember to perform some activities related to chronic pain management.
2. In the case of unforeseen circumstances, patients need a way to delay any reminders to a more convenient time *to allow them to stop and take stock of the situation.*
3. Patients need to be able to easily refer to instructions for the self-management technique they need to perform if they experience difficulties remembering the specifics of it.

Examples:

- a. Exercise
- b. Mindfulness
4. Patients need to be reminded of the benefits of self-management activities for particular skills they need to carry out, particularly when they may seem unappealing to do. *This information needs to be personalised to the patient and linked to their goals*
5. Patients need help to remember the steps involved in fulfilling specific self-management activities. This assistance needs to be presented in such a way that the patient is able to perform each step and that enhances patient reflection and skill development.

Examples:

- a. CBT – ABC's, daily planners
- b. Goal setting
- c. Pacing

6. Patients need help and encouragement with rehearsal of skills, such as banishing negative thoughts, which are only used in specific situations. *These prompts should be delivered randomly.*
7. In the event of a flare-up or crisis, patients need a way to identify their personal pain triggers (as identified at the hospital) and the self-management techniques that might assist with pain relief, so that effective pre-emptive behaviour can be taken and communication assisted in the event of a visit to their GP.
8. In paced activities, patients need to be able to set alarms that prompt them to stop or take a break from a particular activity that is known to cause discomfort after a period of time.

In the event that the break has a time limit as the patient is building up their tolerance levels they need a way to be reminded when they can resume the original activity again. *Furthermore, patients need personalised inspiration as to activities they could undertake during these breaks.*

9. Patients need alarms and reminders to be adaptable to allow them to be used in public places without unnecessary attention being drawn to them.
10. *Patients need the flexibility to edit their flare-up triggers to cope with changes in their symptoms and the discovery of new techniques that assist them with addressing these triggers.*

Support

1. Patients who are experiencing difficulties making the transition to self-management at home need a way of contacting the PMC and practitioners which supplements the email or telephone mode of contact.
2. Patients, who are experiencing difficulties applying aspects of the training to the home setting, need a way to elicit and receive feedback during the initial stages of their move from guided self-management to solo self-management to provide them with the reassurance that they are implementing things correctly.
3. In the event that patients wish to seek support from other patients, they need a way of finding patients who have the same condition as them and the same requirements from the relationship. *Patients' privacy must be maintained*
4. Patients need personalised feedback and encouragement based on their progress with their goals and self-management activities.

Examples:

- a. How often they do their exercises
- b. How close they are to reaching their goal

How they have increased their pacing tolerance levels

Information

1. Patients need to be able to source information that is *comprehensive, easy to find, uses plain-English, is relevant to their stage of self-management is presented in a way that supports understanding.*
2. Patients need valid, trusted and non-commercially motivated information to address their specific medical and practical concerns, related to:
 - a. *Their initial diagnosis,*
 - b. *Prescription medicines,*
 - c. *Medical procedures,*
 - d. *Symptoms,*
 - e. *Government assistance and benefits,*
 - f. *Occupational health assistance,*
 - g. *Managing pain during major life events or situations,*
 - h. *Activities available at PMC and elsewhere for pain patients,*
 - i. *Suppliers of sanctioned home aids and services*
 - j. *Product reviews*
3. This information should be delivered by a medical institution or charity that is recognisable and trusted by patients. Additionally, information provided needs to be easy to find, and up-to-date.
4. Patients need testimonials and tips from other patients to provide them with ideas for improving their self-management skills and knowledge.
5. *Patients need information in a form that can be shared with significant others so that they too can be educated on the patient's condition to help them to cope and assist the patient.*

Appendix 2. Personas

Rhiannon

Age: 49

Gender: Female

Family: Married. 2 teenage children still at home.

A day in the life of Rhiannon:

6:30 Gets dresses and goes downstairs to prepare breakfast for the family. Despite feeling pretty groggy, she tries to get everything organised before the children wake up and start making their daily demands.

7:15 Breakfast

8:00 School run – stops at the supermarket on the way home to pick up something for today's meals.

9:00 Tidies up around the house and puts on a load of washing.

10:00 Time for a quick cup of tea before hanging out the washing. Does a few stretches whilst waiting for the kettle to boil and sits down.

10:15 Hangs out the washing and gets ready to go swimming for the first time in a while.

10:30 Receives a phone call from the school to say that her son has forgotten his football kit and could she bring it in? The journey proves stressful because she is stuck in the traffic and isn't sure when she will get to the school. Rhiannon knows that this sort of stress could cause a relapse and she will probably spend tomorrow in bed.

12:00 No longer time to go swimming. Rhiannon feels guilty for not having reminded her son to pack his kit this morning and this has added to her stress. She returns home to prepare lunch.

12:30 Lunch is eaten in between replying to emails and ringing the insurance company to chase up a claim.

13:00 Yesterday she received a phone call from a friend wanting to go shopping this afternoon. She said 'yes' but doesn't really have time to meet up with Kath, even for a coffee. She goes anyway but tries to keep the wandering round the shops to a minimum.

15:00 Rhiannon and Kath take a break from shopping for a cup of tea. Rhiannon enjoys Kath's company and Kath is happy to chat for hours. Although Kath is very supportive and sympathetic about the hassle that Rhiannon is experiencing, it's hard for her to really understand about the pain. Rhiannon found it easier to talk to other

patients on the programme about that sort of thing because you didn't have to explain it. She doesn't want to become a bore to her friends, always talking about her health and drawing attention to herself. Like today, where she knows she's been sitting down for too long and should really get up and walk around but doesn't want to draw attention to herself. So she sits tight. At home she would sometimes use a beeper as a reminder to stand up but she would never use it in a restaurant in case people thought she was weird.

16:00 Picks up the children from school. They both have homework, which she will end up helping them with.

17:30 Starts preparing supper.

19:00 Husband, Geoff, returns home and they all sit down to eat.

20:00 Geoff clears away the dishes, so Rhiannon finally finds time to start searching on the internet for accommodation for the family holiday they are arranging.

22:00 The children finally go to bed and she is able to get things organised for the next day.

11:30 Finally retires to bed but brain is still buzzing with over-activity.

Work Activities:

Full-time mum and housewife.

Household and leisure activities:

Responsible for organising the home, which includes getting the children off to school, housework and cooking, shopping and generally organising the whole family's social life. Everyone makes demands on her time and she finds it very difficult to say no.

Rhiannon rarely gets much time to sit down and relax but if she does, likes to read a magazine; nothing too taxing. Enjoys family holidays but finds them very difficult to organise and she is often too tired to do much on holiday once they arrive at their destination.

Would like to take some time out of her schedule everyday to do her exercises, breathing and stretching because she knows, if she doesn't, she will not be able to keep going and all the work will pile up. However, plans often need to be cancelled at the last minute because more important commitments arise.

Exercise regime:

Sometimes does stretching exercises and breathing while cooking or washing-up but only if she doesn't feel too bad. Rhiannon is not very good at relaxing, partly

because she feels she can't spare the time but also because she never really got the hang of the techniques she was shown.

Did try to take up swimming but there are often gaps of several weeks between sessions. She feels as if she is making no progress at all with the swimming.

Emotional:

Sometimes depressed. She does not receive the support she would like from her husband and children because they do not fully understand her condition. When things get on top of her, the family feels let down because she is prone to cancelling an activity at the last minute and spending the day in bed instead. They find this hard to accept.

Medical/physical:

Takes a lot of medication to cope with depression and pain. This makes her a bit groggy and forgetful, especially in the mornings.

Technology:

Uses a computer, especially for emailing friends and a mobile phone for texting. Has used the internet to investigate support groups for her condition. She did stay in touch with other patients on the programme for a while but the contact dwindled over time and has now stopped. She would be interested in a technology that allowed her to, read other people's success stories, for encouragement; or problems, to help her realise she is not alone in her situation; also for obtaining more information about her condition.

Goals, fears and aspirations:

Would like to reduce the medication or even stop it if possible. Would really like to learn to say 'no' more often to free up more time for herself. This would allow her to take up a relaxing hobby such as yoga. To achieve this goal she knows she will need to exercise more discipline in scheduling activities so as not to over-commit or regularly cancel. She is worried that her family may resent her if she takes time out for herself without making sure all their needs are met first.

John

Age: 66

Gender: Male

Family: Married. 2 grown-up children who live away from home. Wife is also ill and needs a lot of care at home.

A day in the life of John:

6:00 John wakes up early because of the light mornings and because the pain is often worse in the morning. This is another bad morning, the third day in a row. Decides to get up straight away because the pain gets worse if he lies in bed too long.

6:15 John thinks about doing some stretches before getting dressed but puts it off today because the pain is pretty bad. Prepares breakfast in bed for his wife, Margaret.

6:45 Helps Margaret to wash and dress and to go downstairs.

7:30 They watch breakfast TV together until John starts to stiffen up again, so he wanders out to the kitchen to do a few chores.

9:00 Margaret has a doctor's appointment, so he drives her to the surgery and waits until she has seen the doctor, before taking her home again. While he is waiting, John notices that the pain is worse today than yesterday and is a bit worried that it's gone on for so many days. He remembers being told that the breathing exercises are useful when this happens but he doesn't really remember how to do them properly.

11:00 John has some work that needs doing in the garden. He had planned to do some of it yesterday but Margaret had been too ill to leave. Today he plans to go out there for an hour or so.

11:45 He finds the gardening too much for him. He finishes after 45 minutes because he is worried he will feel much worse if he does too much today. He feels it wasn't really worth doing just 45 minutes and is discouraged by his lack of progress. Hopefully he will find the time to do some more tomorrow but often other things crop up to stop him. Reads the newspaper.

12:00 Prepares and eats lunch

13:00 This afternoon a neighbour has volunteered to look after Margaret so that John can get out to the shops to buy some basics. As he leaves, he remembers to take his camera and plans to stroll down by the river to take a few photos of the wildlife after the shopping is finished.

13:45 Receives a phone call asking him to come home early because Margaret is unwell.

16:00 Has some time to himself but cannot go out. Instead, he sits down and watches some TV.

17:45 Prepares the evening meal

19:00 Spends the rest of the evening watching TV and doing the crossword.

Work Activities:

Retired postman

Household and leisure activities:

John spends a lot of time looking after his wife, who has been ill for some time. This means he has to take on responsibility for the house and garden and they are not able to leave the house very often. Many chores are left undone because John does not want to push himself to do more than he is capable of. This is a source of disappointment and frustration.

They do not usually plan anything in advance because of the high likelihood of having to cancel at the last minute, so they tend to deal with things as they come up.

John is a keen photographer but has not been out with a camera for months. He would like to get out more often to take photographs in the countryside. More often than not, they just watch TV in the evenings but John would like to develop another hobby that doesn't involve so much sitting down.

Exercise regime:

Due to a lack of routine, John is not able to do any regular exercise. When he does, it is too painful and he has to stop. Ideally he would like to do more but finds it hard to motivate himself to keep going because it seems pointless to do such a small amount of exercise. He makes sure he does not sit too long in one place but does not practice the breathing or relaxation techniques.

Emotional:

Is often depressed because he feels his condition is getting worse and it's out of his control. He believes that a lot of the techniques taught on the course weren't applicable to his particular condition. Lacks motivation because none of the techniques seem to improve his situation.

Medical/physical:

Is in a lot of pain, especially in the morning. Takes a lot of pills for the pain and is often tired due to problems sleeping. Suffers from stiff joints and has good and bad days. On a bad day he finds it very difficult to walk and even make a cup of tea. The medication makes him forgetful.

Technology:

John has a landline and a mobile phone, which is particularly useful in medical emergencies. He is thinking about getting connected to the internet and would be interested in using a technology that can help motivate him to improve his condition, provided he receives personal hands-on training first. He doesn't see himself using the computer for everything, day and night, especially since his eyesight isn't what it used to be and he finds reading things on a screen difficult. He knows he is a bit forgetful and would always be asking for reminders on how to use a computer.

He would benefit from a technology that helped with calculating percentages and increments for pacing. When he calculated them himself, the increments were so high that he was unable to keep up with the exercises after a few increases.

He would be interested in using a computer for digital photography to extend his hobby.

He is not particularly interested in reading about other people's problems because he already has too many of his own and it would depress him. However, people's tips on staying motivated would be useful, perhaps in a monthly newsletter.

Goals, fears and aspirations:

Would like to improve his current level of fitness and find things he can enjoy doing despite the pain, especially if the activity could be shared with Margaret.

Fears that his condition will worsen to a point where he cannot cope for himself or his wife.

Malc

Age: 51

Gender: Male

Family: Married. 2 grown up sons, 1 still at university.

A day in the life of Malc:

7:30 Sat too long at the computer last night and now really feeling it. Does some stretching in the hope that it will help make him feel less stiff.

8:00 Breakfast

8:30 Had planned to work on extending sitting times this morning but now only able to sit for 10 minutes at a time because he sat too long yesterday. Instead, he plans to go out into the garden and put up the first fence panel.

9:30 Found it difficult to take a break during the fencing because there wasn't a convenient point to stop midway. So he finished the whole panel and took a break at the end of it.

10:00 Surfing the internet.

11:00 Wanders own to the bank with the dog and picks up a newspaper at the same time.

11:30 Reads newspaper, remembering to get up and stretch every 10 minutes – couldn't manage the full 15 minutes intervals of sitting today.

13:00 Lunch

14:00 Nap

15:30 Feeling better, so going for a swim to ease the stiffness of the joints.

18:00 Returned after swimming more lengths than normal because it was going well and making him feel relaxed.

19:00 Dinner

20:00 Watching TV and listening to music.

23:00 Doing some research on the internet about tips for getting back to work.

Work Activities:

Has been off work for over 1 year due to ill-health. Used to work in Information Technology for a large telecoms company.

Household and leisure activities:

Tries to help out around the house and finds it frustrating that a lot of the jobs just don't get done. The fence has been broken for 6 months now and he resents having to pay someone to fix it when he knows he can do it himself.

Enjoys eating out and concerts. Likes foreign travel to experience different foods and local beers. To relax, he likes to listen to music or watch a DVD.

Exercise regime:

Short walks with the dog. Stretching in the morning. Tries to swim every other day but sometimes other commitments get in the way. Prone to over-doing the swimming if he has missed a day because it gives a short-term 'buzz.' Often forgets to take breaks when busy, preferring to get a job over-and-done-with but this nearly always makes him feel worse the next day.

Emotional:

Thinks that his pain is not as bad as most other people on the programme. Does not usually get depressed but can feel a little low on bad days. Isn't very keen on talking about medical problems or sharing thoughts with others, preferring to 'just get on with it.'

Feels a bit guilty that he's at home all day and not really doing anything to contribute, especially when he sees his wife struggling with things like heavy shopping. This can sometimes push him into doing too many physically demanding things.

Medical/physical:

Not on medication. Suffers from fatigue. Difficulty sitting for long periods of time.

Technology:

Tech savvy. Has internet and mobile phone. Hasn't used the internet to research his condition or to find a support network but would be interested in using practical tools that support his goals.

Goals, fears and aspirations:

Main goal is getting back to work but is concerned that he won't be able to hold down a job because he can't sit for long enough to get the work done and is usually too tired in the afternoons to do anything.

He is also concerned that a return to work would increase the burden on his wife because he would be able to do even less at home.

Asha

Age: 35

Gender: Female

Family: Lives with partner. No children.

A day in the life of Asha:

7:00 Fits in a few stretches while getting ready for work.

8:30 Arrives in the office and spends a few minutes making a cup of coffee and checking emails before the 9:00 fundraising meeting. Asha sits at the back so that people will be less aware of her stretching and moving around.

10:00 The meeting has been dragging on a while and it is starting to get painful to sit down for so long. Asha calls for a break. She doesn't feel too bad about asking because she is pretty sure that most of her colleagues would value a break too.

10:15 Meeting reconvenes.

10:45 Back to her desk to start writing her report.

11:15 The phone rings. Asha uses this as an opportunity to stand up while taking the call.

11:30 A colleague offers to make the coffee. Since she is not too busy, Asha sees this as an excuse to get up and move around, so she volunteers to take over and makes them herself. She would like to do this every time but does not want to get a reputation for dropping her work at the first opportunity.

11:45 Continues writing her report on the computer. Her company have been good about providing her with the desk and chair she needs to help her sit properly and have installed a software tool that reminds her when it is time to take a break and do a few stretches. Most of the time she does them when prompted but there are occasions when she needs to postpone the break because she is so busy.

12:30 Pops out for a sandwich. Most people eat at their desk but Asha knows if she does this, it will be difficult to get through the afternoon. Although she goes out at lunchtimes, she rarely takes the full hour because she doesn't want to be seen as different from her colleagues.

13:15 Back to report writing

14:15 The break software sends a message to her screen to stand up and stretch. She does this and switches from using her trackball to her mouse at the same time. This allows her to alternate her hand position.

15:00 Asha's manager comes over to ask how she is getting on and with a request to finish a draft of the report by the end of the day. Asha agrees because it is for an important pitch that has been brought forward.

15:15 The break software sends a message to take a break but Asha has to hit the delay button because now is not a convenient time to take a break.

19:00 Asha finally finishes the draft report and emails it to her manager. She has sat at her desk far longer than planned but at least the traffic will be a bit lighter going home and she may not have to sit in it for quite as long as usual.

20:00 Reaches home and makes a quick dinner

21:00 Sits down and relaxes in front of the TV until bedtime.

23:00 Does a few stretches before retiring and hopes that she will not suffer tomorrow for today's over-exertion.

Work Activities:

Employed as a Charity Fund-raising Assistant.

Household and leisure activities:

Does not have as much time to spend at home as she would like because she is working full-time at the moment.

She is out at least three evenings per week, either at an exercise class or meeting up with friends. On the few evenings she has in during the week, she likes to cook for her partner. At weekends they usually do things together and like to have friends over. Whenever possible they go away for the weekend but try not to travel too far away because the journey can be a bit strenuous for Asha. If they can take the train, this usually works out better because she can get up and walk about and stretch more than when travelling by car or plane. Asha likes activity weekends because it gives an adrenaline rush that calms the pain. This is something that can't be achieved with a 20 minute walk into town.

Exercise regime:

Attends yoga and pilates classes weekly. Breathing and relaxation techniques and stretching exercises each morning. Since attending the course and increasing her activity, she has found that her flare-ups are less severe and she recovers from them more quickly than before. This motivates her to continue with the exercises, even when she feels unwell.

Emotional:

Motivated to improve her condition by strengthening her body. Although she recognises that she will not actually get better, Asha also appreciates the principles behind pacing and the importance of increasing activity gradually.

Medical/physical:

Does not take medication on a regular basis but will do so when the pain is really bad. Thinks that her condition is under control and is not as bad as the majority of the people she has met on the programme.

Technology:

Uses the internet and email regularly for work and socially and is confident that she will be able to solve most technical problems, either herself or with advice from her partner or a friend.

Asha uses the internet to research medical information on her condition if there is anything she needs to know and also to look for tips and advice. Would be interested in an assistive technology for finding out more information. Although not interested in forums or chat rooms for herself, she would be interested in contributing to them if it meant she could help other people.

Goals, fears and aspirations:

Main goal is to stay fit and active and to remain in work. Asha does not plan or pace rigidly, preferring to deal with setbacks as they come. Since applying information from the programme, she has been able to get back to fitness quite quickly after flare-ups and is therefore fairly confident of her ability to deal with any setback that might arise in the future. However, she does worry that any prolonged setback would jeopardise her job.

Appendix 3. Risks for Individual Personae

Designing for Rhiannon

Risk considerations relevant to Rhiannon:

Computer skills and knowledge

Rhiannon has use of a shared computer at home and has her own mobile phone. She is fairly confident that she can work out how to do most things on a computer by herself but not if there is a technical fault. She would expect the system to be robust and not go wrong regularly.

Trust and privacy

Rhiannon would prefer to enter a members' community using a nickname rather than her real name. She does not trust giving out her personal details to people she has not met and has no control over. She would be happy to share her anonymous data provided the system had good security. Rhiannon has some concerns that members may post misleading information that could harm her. She would like to know that any material of this nature would be removed from the system for her protection.

Unrealistic Expectations

Rhiannon would like to reduce the amount of medication she takes and hopes that the contacts she makes in the members' community will be able to support her in this goal. She needs to be aware that the needs and goals of other people may not match her own and must be careful not to expect too much from others. Some of the other members will have issues of their own and may not be able to give her as much support as she needs. Others may make comments that she actually finds unhelpful. She needs to limit her expectations and be able to filter out the useful from the unhelpful or undermining.

Personalisation and Control

Rhiannon probably won't have much time to customise her own system and will rely on the default to be logical. She would like to be able to control who she shares activities and information with and would like to be able to add members of her own family as well as people from the members community. She would also like to control the types of break videos and training exercises she uses so that they will be more interesting to her personally.

Individual Characteristics

Rhiannon sometimes gets depressed by her illness and turns to medication. The medication makes her forget easily. She needs to be able to record how she is feeling at any given time and look back on it. A permanent record can help her to

understand how her feelings relate to her progress and this in turn will help her to problem solve. She also needs encouragement from a system that recognises her achievements, no matter how small.

Individual Motivations

Rhiannon needs the social support from the pain management community, who will understand what she goes through in a way that her friends and family cannot. This will help to encourage and motivate her and improve her capacity to self-manage.

Individual Goals

Rhiannon would like to reduce the amount that she does for family and friends so that she has more time for exercise and other self-management activities. She often ends up taking on more than she can cope with because she finds it difficult to say 'no.' This leads to stress and a worsening of her condition. She would find it useful to schedule all her activities and use the system to alert her when she has scheduled too much or has not done any exercise. Her family are more likely to listen if the computer alerts them to the problem.

She often finds it difficult to take a break during household chores because it takes a lot of time out of her day and she gets bored. She would like a system that gave her some useful activities to do during breaks so that she can do something constructive with her time and still benefit from resting.

When Rhiannon gets stressed, her pain worsens and she needs something to distract her. She would find it useful to have a handheld device that played something to take her mind off of her situation.

Individual Capacity

Rhiannon's family do not always give her the support she would like and they have difficulty understanding her condition. She would find it useful to be able to share information with them in the hope that they would understand her circumstances more and be a little more sympathetic. Then they would understand why she must sometimes say 'no' and she would not feel as guilty for doing so.

Poor perceived system usefulness

An online community would be useful for Rhiannon because she can make contact with others suffering from the same condition. At the moment she feels isolated because her friends and family find it difficult to understand her condition and cannot relate to what it means to live with persistent pain and constant medication. An online community would mean access to support without the problems of having to travel to meet a group when she is busy and stressed.

A handheld device would be useful to her because she does not have exclusive access to the family computer. If she had her own dedicated device, she could use it for pain self-management even if another family member was using the home pc.

Poor perceived system ease of use

Rhiannon would perceive the system to be difficult to use if it went wrong, if it lost her data or if she constantly needed to correct the data that a device automatically gathered about her activities.

Designing for John

Risk considerations relevant to John:

Computer skills and knowledge

John is inexperienced at using technology and wants some individual training to give him the confidence to use the system. If he is going to get the most out of the system he will need to learn the basic features first and only move onto more advanced features when he is confident with the fundamentals. He also needs a way to be reminded of how to use the technology after the training because his medication makes him forget easily. Without having a way to refresh his memory, he will probably not use the more complex, infrequently used features or he may not bother to use the system at all.

Trust and privacy

John is not sure about giving out his personal details over the internet because of the risk of having his identity stolen. Nonetheless, he does want to be able to access information on pain management and tips for motivation and pacing. To satisfy his need, non-confidential, non-sensitive information should be made available in a publicly accessible part of the system, without the need to register and supply personal details.

Unrealistic Expectations

John cannot do as much physical activity as he used to. Consequently he has problems motivating himself to do any activities in the belief that doing so little is not really worth doing. Prompting him to do certain activities and measuring those activities may help John to realise that he does more than he thinks but any system must be delivered on the basis of providing assistance without promising to be a solution to his medical problems.

Personalisation and Control

John needs to be in control of who sees his data and how much information he gives out. He needs to be able to enter his own personal goals but does not want the burden of too much customisation of the system. If it is too complicated to set up, he will probably not bother.

Individual Characteristics

John has problems reading a computer screen and needs to be able to adjust the text size so that he can read the finer details. He would also find it useful to be able to print out articles or his exercise record so that he does not have the pain of sitting in front of the computer screen to read them. Since his medication causes difficulties with his longer term memory, these printouts would also be useful to help him remember things like how to do certain exercises, without him having to go back onto the computer and find them again.

Individual Motivations

Patient awareness, or the lack of it, can affect motivation in patients with chronic conditions and many patients underestimate their achievements.

“I’d like us to encourage for them to use pedometers...doing things by the number of steps per day has clearly been quite successful in getting people to do their number of steps. Partly because it counts everything you’re doing” (P01).

John needs support from a system that can accurately measure the amount of physical activity he actually does and to recognise that, perhaps, he does more exercise over the course of a day or week than he realises. Fulfilling John’s needs would include a way of being able to review this activity over time, so that he can see progress. John would also benefit from being able to record non-physical achievements, including social goals such as pursuing his photographic hobby, which would help him lead a more active life and distract him from the pain he experiences.

Capacity for active self-management

John’s self-doubt is not limited to underestimating the amount of exercise he achieves. He regularly fails to achieve the goals he sets for himself and as a result, he often gives up. Recording the achievement of progress towards a goal as well as achievement of the final goal would help him recognise his progress.

John is often unable to complete his goals because of the demands of taking care of his sick wife and because of his own illness. He would easily be demotivated by a technology that showed he had regressed compared with previous days achievements. Consolvo, McDonald & Landay (2009) recommend the use of positive reinforcement to encourage change by rewarding achievement without punishing non-performance. To help him deal with a temporary interruption of his

self-management routine, he needs to be able to view his progress over a longer period of time. This will account for interruptions, which distort the picture and may demotivate.

If, however, there is a continuing lack of progress, John may need assistance in understanding the underlying reasons. Providing John with a means of recording the reasons why he has not made progress towards his goals will act as a memory aid to help him to problem solve, finding alternative ways to make goal progression:

Individual Goals

John needs a system that is flexible enough to help him record and achieve his individual goals. As well as recording the amount of exercise he does, he would like to be able to record social goals and negative feelings to give him a better overall impression of his progress. He would like to be able to share these goals with his wife but is cautious about sharing goals with people he has not met in person.

Individual Capacity

Barriers to active self-management including lack of support and feelings of inadequacy when goals are not achieved.

John does not receive much motivational support from family or friends and his wife is sick. He would benefit from motivational support from other pain patients to boost his confidence and self-efficacy but he, personally, is cautious about socialising on the internet. He does not want to use a system that is full of negative comments from people because this would make him depressed. To cater for John's needs, the content of information needs to be moderated to include only constructive and motivational information and tips on pain management. As a minimum, he needs a means by which he can select the information he sees and filter out comments that he personally finds demoralising.

Personally, he would prefer to receive automatic prompts from the system when he is having difficulty achieving a goal. These prompts would provide him with problem solving ideas for breaking down his goals or suggest alternative approaches.

Poor perceived system usefulness

John rarely refers to the COPE manual because it is too long and he does not enjoy reading large chunks of text. He does, however need reminders of its content from time-to-time. A system that simply transferred details from the COPE manual onto a computer screen, in the same format, would be no more useful than reading the Word document. John would find it more useful if it was broken down into small chunks of information where he could quickly refer to the parts he is interested in. If it could be brought to life with graphics and video demonstrations it would be more accessible.

Poor perceived system ease of use

John would not find it easy to use a complicated system with too many features. He would prefer to use a system that requires little setting up, making use of the system defaults settings rather than changing them to his personal preferences.

When measuring activity, he would prefer it if the system could automatically record his movement rather than him entering a lot of data manually. Constantly recording data manually would not represent a good economy of passage for John. He is also likely to forget to do it on a regular basis.

Designing for Malc

Risk considerations relevant to Malc:

Computer skills and knowledge

Malc is confident in using a computer and other mobile technologies and motivated to optimise his use of it. He is looking for a system that can be customised to his individual needs. Issues such as performance and efficiency are important to him because he would feel frustrated having to use a system that was slow or 'dumbed down' the functionality. Shortcuts would save him a lot of time, particularly for parts of the system that he uses regularly. He would not wish to be forced to repeat instructions that he has already understood.

Trust and privacy

Malc is happy to use the member community provided it contains useful information from trusted sources that have been computer virus checked. He is also ok with providing personal details, provided that they are secured in accordance with data protection laws. When using the member's community, he probably wouldn't bother to use a nickname because he is not too worried about other members knowing who he is and he wouldn't be putting particularly sensitive information onto the system in any case.

Unrealistic Expectations

Malc is realistic about what to expect from a self-management technology and knows that it will not cure him of his condition. However, he does expect it to be professional and offer useful tips and tools that are regularly updated. He also expects the technology to be accurate in measuring his goals and activities. If it does not meet this expectation he will be likely to give up using it. Malc needs to be made aware of the current technology limitations of devices.

Personalisation and Control

Malc needs control over the content he sees and the frequency and duration of his interaction with the system. He would like to be able to bookmark things that he finds particularly interesting or useful so that he can find them again easily. He also wants control over how he can search and filter information. Information at a superficial level would not really add to what he already knows. If he finds some information that is particularly interesting, he would like to be able to drill down to a greater depth. However, he would like a summary of content so that he can pre-select what he chooses to look at. This will save him a lot of time.

Individual Characteristics

Malc is well educated and does not have any special accessibility or technology needs related to his illness.

Individual Motivations

Malc's main motivation is to return to work and this sometimes drives him to do too much. He would benefit from a system that made him more aware of the amount of activity he was doing and helped him moderate this activity to avoid flare-ups and periods of inactivity due to exhaustion caused by overdoing it. Persisting is a major cause of his not making progress with increasing the length of time that he can sit because of his 'stop-start' approach.

Individual Goals

Malc's individual goals include increasing the amount of time he can sit and reducing the amount of time he sleeps during the day. He would like to be able to record these goals and the progress he is making towards them. He would also welcome suggestions from the system or from members of the support community on how he can make progress on both of these strategies because he doesn't seem to be getting anywhere on his own.

Individual Capacity

Malc has difficulty sitting at the computer screen for too long. A portable device, onto which he could download all his pain-management data, would be useful so that he can walk around at the same time.

Poor perceived system usefulness

Malc intends to return to work as soon as possible. A system would only continue to be of use if information and social community were available out of hours when he could benefit from them. If he returns to work before finishing the pain management programme, it would be useful if the technology could support the follow-up programme because he would not be able to get time-off from work to attend.

He suffers from fatigue and finds it difficult to sleep at night. It would be useful if a hand-held device could be used in his bedroom at night to help him relax before going to sleep. This may help him stay awake during the day, which is currently a barrier to his returning to work full-time. The other major obstacle to his return to work is inability to sit for long periods of time. A system that could help him time his pacing activities would help increase sitting times, which remain stubbornly static at the moment.

Poor perceived system ease of use

Malc finds most computer systems easy to work out but would be frustrated by a system that did not allow him to customise his needs. Since he is busy most of the day, he would find a system with slow response times difficult to use. Also, he does not want to be bothered to read instructions, so a system that walked him through each step of how to use it would be irritating – he needs to be able to skip over the parts he has already understood.

Appendix 4. Social Use Case Scenarios

A. Information Seeking and Use

Accessing Information

Social Use Case Scenario: Search for Resources

Malc is looking for tips and tools to help him increase the amount of time he can sit at his desk. He accesses the system from home and types in the search criteria 'sitting.' The system retrieves a list of results and Malc reads the first 10 hits. He hides some of the tips on the first page because they do not seem very relevant. Two of the comments are particularly interesting, so he bookmarks them to read again later. He then clicks on an interesting link to some pacing software that he would like to read more about and possibly download.

Social Use Case Scenario: View Resources

Malc has noticed a link to some pacing software that he thinks may be useful but wants to know more about it. He takes the 'more info' option, which tells him some basic information about the tool. He then reads a couple of reviews posted by other members, which he finds quite useful. He decides to download the software and try it out.

Social Use Case Scenario: Request Resources

Rhiannon has been struggling for a while to build an exercise regime into her daily life. She would like to join a yoga class but doesn't know of a good one in her area. Previously she had searched the site but had not found an answer to her question. She decides to ask other members if they know of any. She accesses the 'social group' section of the system using her Personal ID and takes the option to 'post a question' to members.

Social Use Case Scenario: Reply to Request for Resources

Asha has read Rhiannon's request for information on Yoga classes and may be able to help. She accesses the system and posts some contact details about yoga classes run across London. Asha is also aware of a good yoga DVD, which she uses from time-to-time and so she adds this information to her reply.

Accessing Training Resources

Social Use Case Scenario: Training Tips and Tools

Rhiannon has been feeling stressed and remembers learning that the relaxation techniques are supposed to be very useful for reducing tensions. During the programme she had been a bit cynical about this. She hadn't really paid much attention because she thought she would never get round to trying them out at home.

However, she has been getting pretty depressed about lack of progress and is willing to try anything. She needs a reminder on how to do some of the techniques, so goes to the training and techniques section of the system for some tips. The section has a short video clip demonstrating some of the relaxation techniques, so she watches this. She also enters the search criteria 'relaxation' to see if she can find any other information. The system returns some postings from other members offering tips and success stories. She reads a few of these and bookmarks the ones she thinks will be useful.

Social Use Case Scenario: Contact Details

Rhiannon needs to contact her key worker for advice, so she goes to her personal details on the system to check contact details.

B. External Support and Encouragement

Support and Community

Social Use Case Scenario: Contacting Other Members

Rhiannon would like to join the support group but is wary about the safety of this. She reads the information about the support group and discovers that other members can receive her email message without disclosure of her email address or other personal information. She decides to join the support group to see how it goes. The group is advertising a social event next Thursday and so she sends a message to the organiser to find out more about it.

Social Use Case Scenario: Avoiding Attention

At home, Rhiannon is happy to use a beeping device to moderate the amount of time she sits down without getting up and moving around. Outside the home she is only prepared to use a device that is discreet enough to fit into her handbag and does not draw attention to herself. When in restaurants or cafes she switches the device from beeping to silent/vibrate mode so that she does not draw attention to herself. At times she chooses to switch it off completely.

Goal sharing and collaboration

Social Use Case Scenario: Sharing Goals with Family

Rhiannon needs a way of sharing her goals with her family. If they can be more involved in her goals, she believes they will understand her circumstances a little more and thus be more supportive. She invites them to join in with the goal to increase the amount of walking they do. The shared experience, she thinks, will introduce some light-hearted competition. Each of them sets an individual goal

based on the number of steps they currently do and they are able to compare results on how closely they met their own target.

On Wednesdays, Rhiannon has started to swim regularly. This means she has to cut back on the amount of walking she does, in order to ensure that she does not overdo the exercise for the day. However, she wants her exercise record to accurately reflect the fact that she has achieved an alternative exercise goal. She is able to add this activity to her record chart and adjust the target number of steps she needs to reach for the day that she swam.

Social Use Case Scenario: Sharing Goals with Other Members

Malc is not very keen on creating a social circle of friends on the system but is interested in finding other people who are trying to increase the amount of time they can sit. He thinks this will motivate him to improve his pacing. He searches the member profiles to find members who share similar goals. He finds two people who have indicated that they would like to share goal information. He needs to join the social group in order to share information. He decides to join using a nickname rather than his real name. After joining he invites the two members to share goals with him. Once they have accepted, each member of their group can see how he is performing against his target and he is able to see how closely they are to reaching their goal. When he reaches his daily goal, the system alerts him to take a rest and the other members in his team can see that he has reached his target.

He prefers to start the exercise counter at the beginning of the week and watch his progress as the week goes on. He has set up the system to restart the counter again each Monday, even if he didn't achieve his goal that week.

Social Use Case Scenario: Choosing not to Share Goals

John decides that he doesn't want to share goals with other people but he is still interested in measuring how much activity he does against his own personal goals, in the hope that it will encourage him to do more. He regularly checks his progress against previous weeks using the historical information and finds it useful to be notified when he reaches his exercise goal for the week.

If his wife is particularly ill, he knows that he may not reach his target for a few days in a row, so John sets up his view to compare performance on a rolling seven-day basis to give a better indication of his overall achievement over time.

Problem solving

Social Use Case Scenario: Planning a Big Event (Collaboratively)

Rhiannon is organising the family's summer holiday and is not getting much help and support from her husband or children. From past experience she knows that the journey will be exhausting for her and she will be unfit to do anything once she arrives. She uses the planning software to help pace the holiday. It allows her

to enter information such as the duration of the holiday, the destination, mode of transport and anticipated hurdles. From this she can create an itinerary to help her identify possible obstacles such as sitting in the car for too long. The system can estimate the time required and plan the breaks. Rhiannon knows that she will not be able to sit in the car for more than two hours without taking a break but her husband is more interested in getting to their destination as quickly as possible. So she uses the route planner to suggest interesting stop off points along the route. Her aim is to make the journey part of the holiday experience and collaborating with the family should help them agree the decision. The system responds with a number of options and she asks the family to vote for their choices. They tick a number of favourites, including a slight detour to a café that is featured in the good restaurant guide.

Once they have finished, the system allows them to save their ‘virtual journey’ and to print off the itinerary.

Social Use Case Scenario: Help with Problem Solving (From Members)

Malc finds that he is always exhausted by the end of the day and is having difficulty in solving this problem. He knows that, if he is going to be able to return to work full-time, he will need to increase the amount of time he can stay alert during the day. During the programme, he found that group problem solving was a useful way of stepping back from a problem. Other group members were more objective and could suggest solutions that were not immediately obvious to him. They also understood his situation better than his own family did. So he decides to post his problem to the social group area and invite suggestions for breaking down the problem and getting round the situation. A lively debate quickly breaks out. Some of the comments are more useful than others but he does find that they help him to think through the problem. He takes from it what he finds useful and ignores the rest.

Social Use Case Scenario: Help with Problem Solving (From the System)

John is not involved in the support group, so he uses the system to prompt him when he is not achieving his goals. The system detects that he has not been recording any activity for several weeks and asks him to consider why this might be. He records that his wife has not been well and he has let his exercise slip as a result. It makes him realise that he should do more.

C. Skill Development

Pacing and Measuring Activity

Social Use Case Scenario: Create Pacing chart and Calculate Increments

Since finishing the programme, John has not been able to work out how to use percentages to calculate pacing increments. When he worked them out, the increments were so large that he just couldn't keep up with the exercise. He would like to pace some light gardening. If he pushes himself beyond about 20 minutes he feels awful the next day, so he enters 20 minutes as his current level. The system automatically calculates 20 minutes less 10% and produces a colourful chart to show his target increments. He prints off the chart to take away and study and saves the details for next time.

Social Use Case Scenario: Update Pacing Chart

Malc has been working towards his goal for a week and has been making steady increments towards his target to increase his sitting time to 45 minutes. During this time, he has been using the option to enter times, information about how he feels before and after sitting and how difficult he found the task. He does this regularly and finds the information useful because it would be very difficult to remember how he felt a few days later. Now he wants to check his progress. The display shows his progress compared to the last time the data was entered. The chart makes it easy to spot progress and the system recalculates the increments to produce a new target. He prints off the chart to take away and study and saves the details for next time.

Social Use Case Scenario: Avoidance

John has been getting demoralised because he can do so little, it doesn't seem worth trying. He has been using the scheduling and pacing tools but is not reaching his target. The system detects this and when he displays his progress, it highlights his achievements and suggests alternative tactics that he may be able to use, such as adding in some breathing techniques and stretches into his daily routine. John is interested in finding out more about stretching exercises so he takes the link for more information and watches the video. He then reads some of the testimonials about how the stretching has helped other people. He is not very interested in the suggestion to take up pilates, so deletes this from the list of suggested activities shown on the screen. He prints off his chart, which contains the suggested alternative activities.

Social Use Case Scenario: Persisting

Malc is becoming increasingly frustrated because he doesn't seem to be making fast enough progress with his goal to sit for over two hours at a time. He has a habit of overdoing it and then not being able to reach his target the next day. He goes into the pacing software and enters his times. The system returns a chart suggesting that he increase the amount of time he sits by 1 minute per day. He had been making

increments of over 5 minutes, so he decides to try the new approach to see if it will help him break through this cycle of starting and stopping and improve his stamina longer term.

Social Use Case Scenario: Taking Breaks at Home

Rhiannon should take regular breaks during her household duties but often finds that she continues with a task for too long because she simply doesn't know what to do in the breaks. Her short breaks are not long enough to achieve anything constructive like reading a book or drinking a cup of tea but if she takes longer breaks she is worried that she would never finish her chores and they would pile up. She decides to try out the break software on her handheld device while doing some ironing. Initially she sets a timer so that the device notifies her to break after a set period of time. However, she finds this annoying because she doesn't want to be interrupted in the middle of a piece of ironing. So she changes the setting on the device to start a break every time she has ironed five items. Although she has to record the completion of each item, she finds this preferable to being interrupted at the wrong time. In fact, she quite enjoys the satisfaction of 'ticking off' items as she goes.

After her fifth item, the device plays a short video of stretching exercises, which Rhiannon follows. The clip is timed to be the same duration as the break so that she can complete the whole exercise. Rhiannon has set the system to alternate between stretching, breathing and relaxation clips and to randomly play testimonials and tips.

Social Use Case Scenario: Taking Breaks when Out-and-About

Rhiannon finds it stressful if the bus she is travelling on gets stuck in heavy traffic because she has to sit in one place for too long. In these circumstances, if the pain starts to get too much, she finds that distraction is the best way of taking her mind off of things. She can use the device to play short clips such as breathing exercises to calm her down. On the bus she does not feel self-conscious using a small hand-held device with headphones because this is a commonplace activity.

Sometimes, however, when Rhiannon is outside and needs to be more discreet, it is not always appropriate to play audio/video clips during a break, or to wear headphones. Under these circumstances, she can set the system to break in with short articles to read and to play video clips, which do not require sound. Rhiannon likes to have a random choice of break video clips to avoid getting bored but personally prefers them to be relevant to pain management.

Social Use Case Scenario: Measuring Activity

John feels that he is not doing enough activity but does, in fact, underestimate the amount of walking that he does each day. By using a handheld device, he is able to capture and accurately measure the accumulative time spent moving around each day. The information can be displayed on his handheld device or uploaded and

saved to his personal portal. It reveals to him that he actually does more exercise than he thinks. He is encouraged by these results to continue with his activity.

Recording Goals and Goal Steps

Social Use Case Scenario: Recording Progress Towards Goals

John is easily discouraged when he doesn't attain the goal that he set out to achieve and this can often trigger him to give up altogether. His goal was to garden for 45 minutes but he could only manage 25 minutes. By displaying the attainment of steps towards his goals, he finds that he can assess his progress better and sees that he is making some progress towards his goal, particularly when he compares this to previous weeks.

Social Use Case: Recording Alternative/Multiple Goals

John was unable to complete his goal to garden for 45 minutes this week but instead, he tried some stretching and breathing exercises for the first time. He records these on the system and is able to display these results on his handset. He can also see that he has not made an entry for any social or psychological goals. In order to complete his activity record, he decides to add a new social goal to go out with his camera and take some photos of the local wildlife before the end of the week.

Scheduling

Social Use Case Scenario: Over Scheduling

Rhiannon has been filling her day with too many activities because she does not want to let her friends and family down by saying 'no' to their demands. It usually results in her having to spend a day in bed and she actually achieves less as a result. She decides to try out the scheduling software to see if it can help her plan her day better, and allow her to include some time for relaxation and exercise.

After putting in her planned day's activities, the schedule turns 'red' to alert her to the fact that she has planned far too much and the schedule does not include any relaxation or exercise. She shows this to her family and together they agree to cut out one or two activities they have planned for the weekend. Instead, her husband agrees to take the children swimming on his own, so that Rhiannon can use the time for her yoga DVD. She does not feel as guilty doing it this way. Showing the red alert to her family seems to de-personalise the situation and she can justify her decision to cut back on activities more easily.

D. Miscellaneous

Set-Up and Customisation

Social Use Case Scenario: Set up a Membership Account

John has been given details about the system. He decides to check it out but is a bit sceptical. He accesses the system but does not want to enter his personal details until he knows a bit more about it and what it can offer him. He finds there is a 'guest area' where he can get some basic information without registering, so he reads the information about what the system is for and what it contains. He is interested in the section on goal setting and pacing and thinks that the training material may be useful. He is not sure about the social group because he thinks this may be full of negative comments to drag his mood down. Since it is possible to access some of the member's information without having to join in the social group, he decides to give it a try and sets up a membership account. He only fills in the basic 'required' information for now and notes that this will not be given out to other members or to third parties. He only ticks the boxes to receive alerts about new information related to the parts of the site that he is interested in.

Social Use Case Scenario: Change Account Setup (Switch Off Alerts)

When Malc first set up a membership account he subscribed to email alerts notifying him of new postings on the system. However, he is finding that a lot of the postings are not relevant to him and he doesn't have time to read them anyway. He decides to change his setup details to stop the alerts for everything except those for new training material and new software tools, which he still finds very useful.

Social Use Case Scenario: Transferring Personal Records

Malc likes to keep the historical information about his goals and progress. He uploads the data from his portable device to his PC so that he can see historical trends and charts more easily. He views the charts on-screen and then prints some of them so that he does not have to sit at his computer too long to study them.

Social Use Case Scenario: Accessibility

John is having trouble reading the screen. During training he was told about 'Accessibility' but hadn't been shown how to change the settings. His own PC has not been adjusted. He sees the 'Accessibility' option clearly labelled and decides to take it. The system steps him through the procedure for adjusting text size and shows him a preview of the changes. He finds the text much easier to read and so he takes the option to accept the changes.

Moderating

Social Use Case Scenario: Report a Concern

John was reading some of the members' postings and came across one containing bad language. He would prefer not to read things like that and thinks that most other people would not be interested in seeing it either. He takes the option to report a concern so that it will be reviewed and either edited or deleted as appropriate. In the meantime, he hides the comment from view.

Social Use Case Scenario: Volunteer

Asha is interested in volunteering to keep the online community active and vibrant and is willing to contribute a few hours of her time to helping. She goes onto the system and ticks the options for the things that she doesn't mind helping with, this includes reviewing concerns reported in the system and writing a monthly newsletter. She decides that she doesn't have time to also organise social events or to become a mentor, so leaves these options unchecked.

Social Use Case Scenario: Making a suggestion

Rhiannon has a good idea that could improve the system for everyone and wants to tell others about it. She goes onto the system and takes the option to 'make a suggestion.' The representative body, responsible for maintaining and monitoring the system, reviews her suggestion.