

Smart2: Self Management Supported by Assistive Rehabilitative and Telecare Technologies (Grant Reference EP/F002815/1)

Mid Term Report

The SMART2 project (Self Management supported by Assistive, Rehabilitative and Telecare technologies) is a joint project being conducted by the SMART Consortium (www.thesmartconsortium.org). The project started on January 1st 2008 and will be completed on 31st December 2011. It is funded by the Engineering and Physical Science Research Council, through the EQUAL (extending quality life of older and disabled people) programme.

This progress report of the last two years is based on a series of e-bulletins which are on the SMART project website (www.thesmartconsortium.org) The purpose of the e-bulletins is to provide regular updates on project progress to anyone who accesses the project website.

This report is set out in two main sections. This first describes the research team, what the project set out to achieve, outcomes to date and plans for the remaining two years. The second section gives a brief summary of the work that has underpinned prototype development and lists our dissemination products.

Report Section One

The research team

The SMART Rehabilitation Consortium involves researchers from Sheffield Hallam University, University of Sheffield, University of Ulster and University of Bath together with partners from health care, patient advocacy groups and industry. Consortium researchers are from a range of disciplines, including informatics, engineering, medical physics, user-centred design, occupational therapy, physiotherapy and psychology. The Consortium includes both senior academics and early stage researchers.

The SMART2 project is concerned with people with three common long term conditions, namely chronic pain, stroke and congestive heart failure, and how they might be helped to successfully manage their condition by using commonly encountered technologies that are configured together into a personalised system.

Background

People with long term health conditions use a significant proportion of all appointments with GPs, with outpatient clinics and inpatient hospital bed days. This is because many people with long term conditions can be locked in a cycle of frequent hospital admission due to exacerbations of their illness, even though much of this is avoidable with effective and timely interventions. Self management is key to avoiding this negative cycle, thereby improving the health and quality of life of people with long term conditions, whilst at the same time reducing the burden on healthcare. Computer-based technology has significant potential to assist with the facilitation of behavioural change which is necessary for successful self management. However, to engage with the user, devices for self management need to be informative, engaging and persuasive and above all, personalised to meet the specific requirements of the individual.

Research aims and objectives

The aim of the SMART2 project is to deepen understanding of the potential for technology to support self management of long term conditions. This includes the extent of behavioural change that use of the technology might encourage on the part of the individual user. We

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are creating user-centred designs for technology and using these to construct a *Personalised Self Management System* for evaluation in practice in the fourth year of the project.

Self management involves problem solving, taking decisions, locating and using resources, partnership working between the professional and the person, making an action plan and taking action. An early decision was taken to focus upon two main aspects of self management for this study, namely: supporting the individual to make an action plan to improve and increase physical activity; and motivating them to undertake this plan, thereby working towards an identified personal goal. The differing interpretation of self management for each of the three conditions was an added complexity; for example, following stroke, prescribed exercises need to be continued over a protracted period of time to improve function and consequent participation.

For all three conditions, the individual's ability to self manage can be assisted by tailored education. We agreed that an education component would be included in the prototype device for all three conditions so that the technology would be informative, personalised and persuasive.

The research we are engaged in is innovative in that we are moving beyond the construction of technology to exploring the efficacy of the resulting devices and specifically whether they facilitate the behaviour change necessary for self management. This involves researching fundamental issues, such as:

- How can information on changes in function of people with long term conditions be collated and fed back to them in meaningful and usable ways so that they might understand their condition?
- How can information, remote from a health service practitioner, present ways that might promote health behaviour change?
- How can a Personalised Self Management System allow people to adjust their life goals to accommodate and aid acceptance of their condition?

Three animated scenarios (Mary's story, Albert's story and Daniel's story) can be viewed on the project website. These were formulated in the first year of the project and give a flavour of how such a system might be implemented and experienced by the user. Their purpose has been to stimulate further discussion within the research team and also to encourage discussion at conferences and other forums.

Accessing the necessary external approval

The main challenge during the first few months of the project was obtaining the necessary ethical and governance approval which would allow us to consult with people who may be NHS patients, as well as with staff employed by health services. This was followed by successful applications for site-specific ethical approval which meant that we could approach and recruit health service staff and patients from identified services.

We also had to establish a project agreement across the four participating universities.

We were pleased to receive formal confirmation that our project has been included within the National Institute for Health Research Portfolio which means that it has met stringent quality criteria. It also means that the costs of recruiting people with long term conditions to take part in the research can be reimbursed to participating health providers.

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Working with stakeholders

The Consortium is working closely with a whole range of stakeholders including user advocacy organisations, healthcare providers, representatives from the Department of Health and industry, with the aim of ensuring maximum impact. The user advocacy organisations we are engaged with include the Stroke Association, the British Heart Foundation and the Expert Patient Programme (through an individual working with people with chronic pain). Representatives from these organisations sit on the project advisory group and provide general advice on progress and on the development of content for the Personalised Self Management System. A number of NHS Trusts are supporting us with engagement of practitioners and with user testing of the Personalised Self Management System. These are Barnsley Hospital and Primary Care Trust, Sheffield Teaching Hospitals and The Royal National Hospital for Rheumatic Diseases in Bath.

Industrial partners to date are Philips R&D and BT. We have also been approached by other potential industrial partners. Our intention is to incorporate the intellectual property we develop into a product based on the Personalised Self Management System that will be commercialised and, eventually, used both by the NHS in this country and by healthcare organisations worldwide.

Outcomes to date

The first challenge was to identify the discrete devices that might be incorporated into Personalised Self Management System. We are now working with Prototype 2, which involves a number of integrated devices and is tailored to meet the differing needs of people with each of the three long term conditions. Two versions of Prototype 2 have now been produced and are being evaluated: one for people with congestive heart failure and one for people with stroke. The System for people with chronic pain is about to be made available to the clinical team. To meet our goal of a system which can ultimately be adapted to people with a range of long term conditions, all three versions of Prototype 2 have common features.

The hardware components included in all three are as follows:

- A home hub. This is a touch screen computer for use in the home. It is the main means by which the user engages with their Personalised Self Management System and with health care practitioners who will access the System remotely. It also facilitates the primary communication conduit with the central server where user records are stored and processed.
- A mobile device with inbuilt GPS and accelerometry. This is able to communicate with and record the activity of the user and is configured to be interoperable with the home hub.

The software components on all versions of Prototype 2 include:-

- A series of screens on the interface that start with a home screen through which the user can engage in a process that enables them to check their current health status, provide a reminder of the agreed planned activities, facilitate the undertaking of planned activities and provide feedback on progress. The start up home screen is shown in Figure 1.
- A mobile device operates in a similar fashion to the home hub and upon starting presents the user with a home screen. This also includes screens to provide feedback on activity progress and an engaging means of giving a summary of activity achieved during a specified time frame.
- A library of life goals identified through our consultation work with users and evidence reviews. These include everyday activities such as going to the shops, walking the dog or undertaking household tasks. The user is assisted to select the life goals appropriate to their needs and aspirations from the library.

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- An early iteration of an educative component to be further developed in Prototype 3 so that it can be tailored to meet individual user needs.

Additionally, different hardware and software features have been included in the three condition specific versions of Prototype 2; for example:-

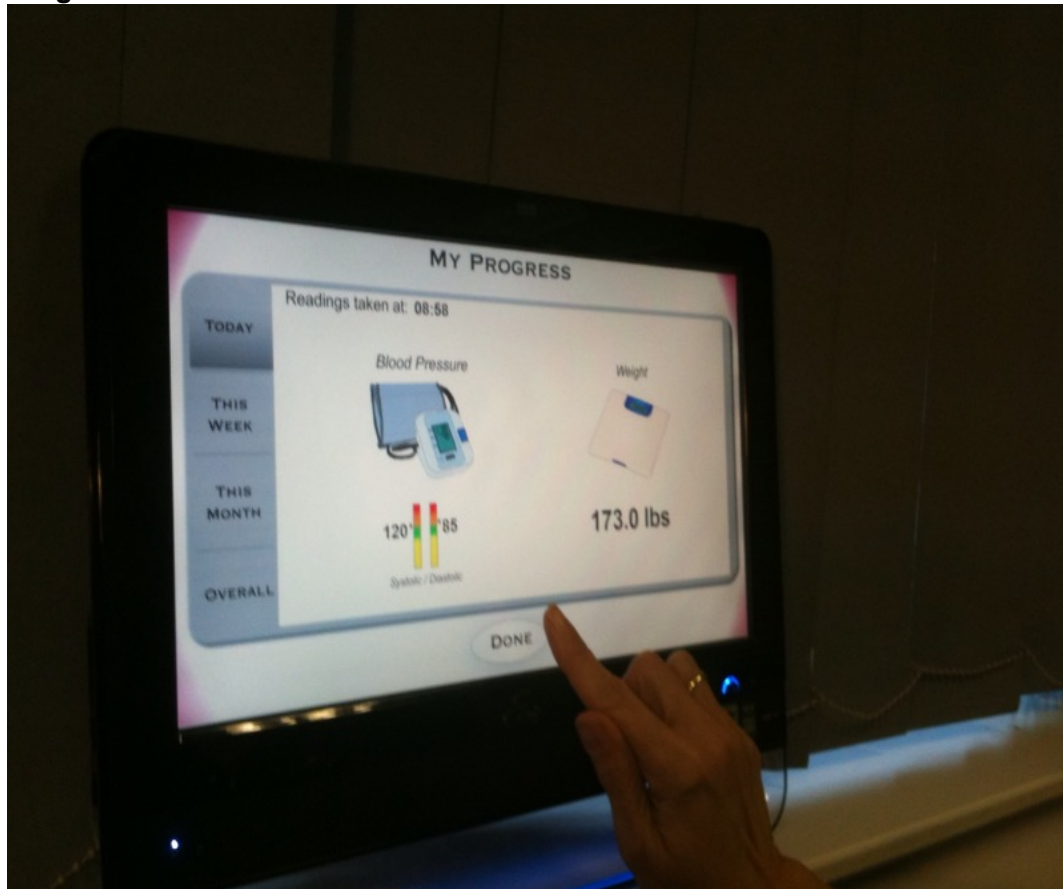
1. For congestive heart failure: Weighing scales and a blood pressure monitor are also part of the System. Fluid retention, indicated by increased weight, breathlessness and fatigue is an important indicator of deteriorating health in congestive heart failure. System feedback on the interpretation of the user's vital signs can enable them to make timely adjustments to their lifestyle as well as alerting the health professional if necessary. The customised screen interface which provides feedback to people with congestive heart failure is shown in Figure 2. The mobile device is also capable of providing feedback for people with congestive heart failure as shown in Figure 3.
2. For chronic pain: Enhanced GPS capabilities are being included to provide an accurate record of distance walked. Pacing activity is an essential element in the successful pain management with over exertion resulting in protracted exhaustion and under exertion contributing towards disengagement and poor mental health.
3. For stroke: Inclusion of additional features is proving more complex. The consequences of stroke are wide ranging and can include hemiparesis of one side of the body as well as sensory and cognitive impairment. This means that a more detailed evaluation of the home hub and mobile device is required to take into account any necessary adjustments for disability. Maintenance of balance through equal weight distribution is also important to promote good gait and avoid falls. An option appraisal is being conducted of alternative technologies to record weight distribution for inclusion in Prototype 3.

Figure 1: Home hub start up screen



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Figure 2: Progress screen on the decision support interface of the home hub for congestive heart failure



Plans for the remaining two years

Prototype 3 for each long term condition will be ready by May 2010. The components within this prototype will be highly influenced by the feedback we receive on Prototype 2, which is being obtained through the engagement of volunteer participants with stroke, congestive heart failure and chronic pain, and with health care practitioners involved with the care and rehabilitation of people with these conditions. They are currently being asked to use and critically appraise Prototype 2. Further details are provided in Section Two of this report.

Prototype 3 is certain to include an increasing amount of personalisation such as educative content that can be tailored to meet the needs of the individual user. Each prototype System will also include additional hardware. For the congestive heart failure System we may include sensor technology to monitor movement around the home and for stroke we will add technology to provide feedback on gait and balance.

The final version of the prototype will be agreed in the autumn of 2010. A year of robust clinical evaluation will follow. This will involve at least 20 people with each of the long term conditions who will be asked to use the technology for a prescribed period of time independently in their own homes and in the community. These volunteers will be asked to complete selected outcome measures before the period of testing and immediately afterwards. A number will also be interviewed about their experience of using the technology. We will then analyse the before and after data to test for any changes in health and wellbeing on the part of individuals. We will also look for common themes and differences across the interview data. If this clinical evaluation indicates that results for

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individuals and across participants are positive, we will seek support from industry to take forward prototype development so that it can be introduced to the mainstream.

Figure 3: activity record and feedback on the mobile device for congestive heart failure

