

## June 2008

The project is now well underway and we can now report on the activity of the first few months. We are fully staffed apart from one Research Fellow post which is currently being recruited to. NHS ethical approval to undertake our study has been granted. We have also obtained governance approval for the majority of the clinical sites where we will be collecting data. We anticipate obtaining approval from all sites in the coming weeks. We are also very pleased to have received formal confirmation that our project has been included within the National Institute for Health Research Portfolio.

As explained in the Project Background section on the website, we have divided the research programme into a series of work packages. The first work package commenced in month one of the project and extends for 12 months. It involves searching for and using existing evidence and knowledge to both inform and guide our work. A review of existing and readily available technologies that can be adapted for a Personalised Self Management System is being conducted by our partners at the University of Ulster. A review of the existing UK policy documents and current practice concerned with the promotion and adoption of technology in health and social care is being undertaken by partners at the University of Sheffield. Researchers at the University of Bath are searching for and examining literature on existing technological applications for rehabilitation and self management.

The second work package also commenced at the outset. It involves undertaking research with people who might eventually use the technology that we develop (people with chronic pain, chronic heart failure and stroke) and health service practitioners who will be involved in helping people to use the technology. Involving practitioners and end users helps to ensure that the approaches and technologies we develop are what people need, will want, and be able to use. Recruitment flyers, information and consent letters and information sheets have been devised together with lists of contacts for user and practitioner groups. Sheffield Hallam University is the clinical research site for people with stroke, University of Sheffield for people with chronic heart failure and University of Bath for people with chronic pain.

Clinical researchers at Sheffield Hallam University have already been in contact with therapists working with people with stroke through local groups of the special interest groups of the Chartered Society of Physiotherapists and College of Occupational Therapists, whereas for the other two conditions, contact with practitioners has to be established through health services and therefore needs full ethical and governance approval. An initial, successful workshop was held in April with stroke therapists and a report on the process and results is being compiled.

A "scenarios workshop" was also held in April with Consortium researchers from all four sites (clinical and informatics/engineering). The aim was to present examples of technology usage to stimulate discussion. Clinical researchers from each site presented a scenario of envisaged usage to other members of the Consortium; for example a "typical" patient (with stroke, chronic heart failure or pain), their condition and impact upon daily life, their daily routines, life before and after falling ill, and so on, and a vision of what a Personalised Self Management System might provide to the individual. The discussion highlighted both similarities and differences

between the three conditions and therefore informed the nature of the technology that might be indicated.

The third work package which has also commenced at the University of Ulster involves identifying and testing various technologies that might be included in the Personalised Self Management System (PSMS). The eventual aim is to produce an integrated System comprising of a number of different technologies for people with each of the three conditions which will deliver personalised therapy, activity monitoring, feedback, support and include a relevant library of life goals for the user to work towards. The review of technologies undertaken as part of work package one is informing the selection of a number of promising technologies for laboratory testing. The option appraisal of technologies is being informed by existing projects and web based searching, knowledge from meetings and networking with companies. Through the evidence based reviews, project meetings, and teleconferences we have already identified the need to investigate a number of technologies in the lab including 'smart shoes', GPS, gait analysis and sensors.

The fourth work package also commenced at the beginning of the project involves identifying recommended therapy to promote beneficial levels of physical activity for each of the three conditions which can be eventually incorporated into the PSMS. For example, for people with stroke this includes recommended interventions and activities to improve core stability for balance and neuromuscular coordination, activities to prevent secondary complications, stretching and strengthening exercises and repetitive task-specific training for the movement re-education. Current approaches to stroke rehabilitation have been reviewed in the context of the principles of behavioural change. International and national stroke clinical guidelines, Cochrane reviews, evidence reviews and bibliographies have been reviewed.

The review of research literature, systematic reviews and clinical guidelines to promote therapeutic levels of activity for people with chronic pain is ongoing. However, it is evident that the process of goal-directed behaviour in chronic pain requires the use of behaviour change technologies. We will focus treatment, therefore, within this area. Clinical guidelines have been consulted to identify key therapeutic interventions to maintain activity for people with chronic heart failure. A total of 267 relevant papers have been identified by applying an RCT/Systematic review filter. Care delivery procedures/protocols/care pathways and literature about behavioural change are currently being examined.

The final work package we report on here is the development of the decision support interface. The aim is to create methods of analysing information on user activity, lifestyle and self reported symptoms so that indicators are identified that can be used to inform and promote behavioural change on the part of the individual user. The emphasis of our work so far has been upon understanding the type of data which can be collected through various technologies, and the requirements of users and therapists so that they can successfully access, understand and use the data. We have the support of two PhD students who will be working on knowledge bases and the development of decision support algorithms. We are in the process of identifying relevant user data from existing and previous work for all three conditions that will contribute to our work on the decision support interface for this project.

Our next update in the early Autumn will report on the user-centred design workshops to be held over the summer months with users and health practitioners together with ongoing progress on all work packages and any other associated research activity.