ABSTRACT

Current demographic and health trends mean it is becoming imperative to rethink healthcare provision worldwide. This paper introduces SPHERE, a large-scale Interdisciplinary Research Collaboration that aims to make a contribution to addressing this challenge. Specifically, SPHERE is developing a smart home system based on a common platform of non-medical/environmental sensors to address a variety of healthcare needs. In order to achieve its goal of widespread deployment, SPHERE technology must meet the requirements of its envisaged users. In this paper we present the rationale and methodology of an ethnographic study of people’s experiences of health and technology. The aim of this study was to gather rich contextual data to inform the design of meaningful and inclusive healthcare technology.

Categories and Subject Descriptors

H.5.0 [Information Interfaces and Presentation]: General.

General Terms

Design, Human Factors.

Keywords

Home healthcare, sensing technologies, User-Centered Design, ethnography, technology tour, cultural probes, focus group.

1. INTRODUCTION

Across the world, the population is ageing. This has a number of implications, in particular for healthcare. A recent article in the Lancet warned that “unless health systems find effective strategies to address the problems faced by an ageing world population, the growing burden of chronic disease will greatly affect the quality of life of older people” [13]. This demographic shift, combined with the worldwide prevalence of non-communicable diseases, places unprecedented demands on public healthcare. As a result, it has been advocated that narrow biomedical solutions would be less effective than a more holistic approach that addresses people’s social and wellbeing needs but also responds to the burden placed on carers [8]. This constitutes a global challenge.

SPHERE1 (Sensor Platform for HEalthcare in a Residential Environment) is an Interdisciplinary Research Collaboration (IRC), which aims to make a contribution towards tackling this challenge. Its vision is to address a range of healthcare needs simultaneously, by employing data fusion and pattern-recognition in a common platform of non-medical networked sensors in a home environment. Ultimately, SPHERE intends to produce systems that are clinically effective and have the potential for widespread deployment.

The typology of sensors under research in SPHERE can be grouped as: indirect, for example detecting human behavior through home energy use; remote, in particular detecting human behavior through video monitoring (for details see [11]); and on-body, which includes using sensors situated on the person for monitoring purposes as well as energy harvesting and management. Individually, each sensor focuses on a dedicated data domain. However, through the integration of complementary sensors in a single platform and the application of machine learning techniques, these data have the potential to describe people’s Activities of Daily Living (ADLs) and support healthcare at home [6].

While smart home technology presents a fertile area of research for tackling current healthcare challenges [1], adoption of these systems has been notoriously slow. These technologies are often rejected or not used appropriately [7], which suggests there remains a socio-technical gap yet to be addressed by design. This paper presents the methodology of the first User-Centered Design (UCD) study within SPHERE and gives a detailed description of the various data collection techniques we used. We begin by discussing the rationale for taking an ethnographic approach to understanding initial user requirements for domestic healthcare technologies. If these technologies are to become embedded into

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1 http://www.irc-sphere.ac.uk/
people’s everyday life, their development must be informed through early and sustained user involvement.

2. UCD RESEARCH ACTIVITY
The role of the SPHERE UCD research group is to contribute to the design of meaningful and desirable technologies, thus it involves collaboration with a range of stakeholders including domestic users, care givers and healthcare professionals. Our methodology reflects the need to empower and engage these stakeholders through a participatory mindset, since we see people as experts of their own experience and, therefore, as uniquely qualified to contribute to the design process [12].

In its first year, the focus was on gaining a broad contextual understanding of people’s healthcare practices, as well as their experiences with technology. The contexts of use for this research were defined as the Self, the Home and the Community (see Figure 1).

Figure 1. UCD research contexts for SPHERE

3. HOME ETHNOGRAPHIES
Studies of technology-assisted healthcare are frequently conducted in living lab scenarios (for an overview, see [4]), which serve the purpose of evaluating systems’ clinical effectiveness. However, they represent a compromise in terms of the contextual complexity of healthcare practices. In reality, personal management of illness is neither rational, nor simply a matter of processing information [9].

In accordance with the UCD framework described in [10], the aim of the first SPHERE UCD study was to explore people’s technology- and healthcare-related behaviors in context. Specifically, the research was guided by the following objectives:

- To understand different people’s experiences of technology and healthcare, focusing in particular on their expectations, motivation, and perceived barriers.
- To map social and/or organizational contexts for technology use and healthcare.
- To gain insights into people’s information sharing behaviors relating to technology use and healthcare.
- To identify preliminary user requirements for innovative smart home and healthcare technologies.

Research in the home environment poses several challenges, not least of which is the presence of multiple users who differ in various aspects that may impact upon technology and healthcare-related behaviors. We therefore intended the study sample to include people with different personal characteristics, while aiming for a balanced gender representation. The sample for this study was based on households and the only exclusion criterion was inability to give informed consent. Participants were recruited through project partners at Bristol Careline (Bristol City Council) and the Knowle West Media Centre, which has a recognized track record of community-based technology pilots and is a member of the European Network of Living Labs. The study was reviewed and approved by the University of Bristol’s Faculty of Engineering Human Research and Ethics Committee.

The sample consisted of 15 households, which included among others telecare users and households with experience of home sensors. This diverse sample contributes to achieving the SPHERE vision of producing inclusive outputs, which are usable but also desirable to as many people as reasonably possible, in a wide variety of contexts [5]. Data were elicited through a combination of traditional ethnographic methods and participatory techniques described in the design ethnography literature [3]. These included ethnographic interviews, cultural probes, and focus groups.

3.1 Data collection using mixed methods
Data collection began with interviews with participants in their homes, which were conducted in one or more home visits to suit participants’ preferences and availability. These ethnographic interviews focused on three main areas – the home, technology, and health – and the interrelationships between them. For example, participants were asked if they had made changes to their home to accommodate needs arising from health conditions and, if so, how this had affected their feelings towards their home. The interviews were semi-structured, enabling the researcher to explore common themes across participants but also allowing individual participants to talk about experiences that were meaningful to them. Where possible, participants were asked to show the researcher around their home and discuss the technology present in each room. The informal nature of this technique, known as Technology Tour [2], encourages people to share their experiences of domestic technology as they walk around each room. For the researcher, this walking tour of the home provided an opportunity to get a sense of how technology was embedded in the fabric of the home but also in people’s daily lives.

In a second phase, data were collected using cultural probes, designed to suit the purpose of this study. Participants were given a probe pack, which contained three elements that allowed them to self-document relevant experiences. The design of these elements was informed by themes emerging from the ethnographic interviews that we were interested to explore in further detail. The Map of Me (Figure 2) was intended to facilitate conversations about health and technology in relation to the context of the Self. It comprised a sheet of paper with an outline of the human body, which participants were encouraged to personalize however they wanted. Participants were asked to use the yellow dots provided to represent where on their bodies they experience pain or other health conditions; blue sticky dots were
used to indicate where on their bodies they wear or carry technology.

Figure 2. Map of Me

The other two elements did not focus on a single context, but could be used to reflect on aspects on the Self, the Home and the Community. The Map of My Day was a timeline for participants to record what they had done during the day, what technology they had used, and how their experiences could be improved. The probe kits also contained a digital camera with the following photo elicitation prompts:

- This is something I do every day.
- This is something that represents home.
- This technology looks good in my home.
- This technology doesn’t fit in with my home.
- This is something that is improved by technology.
- This is something that technology can’t do.
- This is technology that I share with someone else.
- This is something that represents my health.
- This is something that I worry about.
- This is something that reassures me.

Participants were given the freedom to express themselves through any medium (e.g. words, drawings, photos) and to share as much or as little information as they wished. This open-ended approach was intended to allow participants to share the feelings and experiences that were meaningful to them. The researcher (AB) collected the completed probe kits and conducted a follow-up interview with the participants, to discuss the materials produced.

The final phase of this study consisted of a focus group discussion of the SPHERE technology. This focus group was conducted in the SPHERE house, a two-bedroom residential property in Bristol fully instrumented with the first version of the sensor platform. This gave participants an opportunity to give their initial thoughts on the SPHERE technology, as well as raise any issues that they felt were important to consider in future iterations of the system.

4. CONCLUSION AND NEXT STEPS

This study produced rich and varied data, which are currently being analyzed using thematic analysis and design-oriented techniques. We feel that our methodology was effective in achieving the desired engagement with our participants. We found the participants chose to share information in different ways, supporting the need for a mixed methods approach to investigating people’s real life experiences. For instance, in the interview some participants stated they did not have particular healthcare needs but they subsequently shared multiple examples of health conditions on their body maps. Among other things, this allowed us to consider the importance of self-perception of need as a factor that could affect the adoption of healthcare technologies. Analysis is ongoing and findings will be reported in future work by the authors.

Upcoming activities of the UCD research group include user experience research of the SPHERE technology, through a study conducted in the SPHERE house. It is anticipated this study will continue to generate feedback for iteration of the first version of the home sensor platform and contribute to identifying opportunities for user-driven innovation, from both a technological and a service design perspective.

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6. REFERENCES


