

**Pervasive healthcare in lived experience : thinking beyond the home : position paper for workshop on pervasive healthcare in the home.**

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# Pervasive Healthcare in Lived Experience: Thinking beyond the home

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## Abstract

The National Health Service (NHS) in the UK, like many other public health services worldwide, is facing a number of key challenges. Among them are an ageing population and a rising incidence of chronic health conditions. This situation requires a radical re-examination of how people manage their health and their healthcare in ways that challenge the relationship between people and healthcare services. Combining this observation with the opportunities afforded by pervasive information and communication technologies, we argue that design research should reach beyond simply locating devices and services to offer healthcare ‘in the home’ and should examine this broader agenda. Rather than focussing design discourse on the specifics of one location, we should adopt a holistic view, beginning from people’s lived experience.

In this position paper we describe the *User-Centred Healthcare Design* (UCHD) project, a 5-year collaboration between universities and NHS Trusts in South Yorkshire, UK. We suggest that new models of healthcare that re-define the institutional and social context of care are required if we are to meet the challenge of chronic illness. We describe our progress to date on the UCHD project, our commitment to placing patient experience at the centre of design, and our initial experiences of using an experience-based co-design method to improve outpatient services in a Sheffield hospital.

**Keywords-component; User Centred Healthcare Design, NHS, SY-CLAHRC, Pervasive Health, Experience**

The United Kingdom’s (UK) National Health Service (NHS) was created as part of range of welfare services created in the UK at the end of the Second World War. At that time, the primary demand for healthcare services arose from acute diseases, and the NHS was structured in a way that treated people as compliant patients, whose role was to inform clinicians of their symptoms, and the NHS focused on diagnosing and treating patients’ acute diseases. The delivery model was that services were provided through a series of discrete care episodes, involving the patient in movement between different clinicians and healthcare professionals and different departments over time. Now over sixty years old, these traditional deliverable structures and roles in the NHS are facing changed social and economic circumstances. Five specific changes can be identified:

- An ageing population who often suffer from multiple health problems rather than single illnesses, who obtain

care not only from multiple departments of the NHS but also from many different groups within and outside of the NHS (e.g. family, neighbours, social care agencies, third sector organisations).

- A rising incidence of chronic health problems, with people being required to take more responsibility for their own care in between clinic visits;
- The increasing availability of commercial products and services to assist in self-care;
- Increased expectations from patients who are used to receiving co-ordinated, responsive and customer-centred services from private sector corporations;
- Increased desire on the part of some patients to be active, interested and informed participants in decisions about, and the delivery of, their healthcare.

These socio-economic changes in the context of a public healthcare system geared to acute services means that patients often experience their healthcare as fragmented, episodic, opaque, and not matched to their expectations. In addition, the changing demographics and rise in chronic conditions challenge the long term financial sustainability of the NHS. Responding to the challenges requires fundamental rethinking about how the NHS is structured and the way services are designed and operated.

User Centred Healthcare Design (UCHD) is a 5-year project within the “South Yorkshire Collaboration for Leadership in Applied Health Research and Care” (SY-CLAHRC), funded by the National Institute for Health Research. SY-CLAHRC is a large scale research collaboration focusing on the challenges of self-care in a range of long term conditions.

UCHD brings together health researchers and managers based in the NHS with design and technology researchers at Sheffield Hallam University. Together, our aim is to develop, evaluate, and promote user-centred methods for designing user-centred healthcare services. In particular, to find ways of working within the public health system that will make possible the structural, behavioural and philosophical changes needed to meet these challenges. We work in collaboration with health researchers, healthcare providers, patients, carers and the public to investigate the impact of user-centred methods in healthcare designing, and the challenges faced in adopting such methods within established public health

systems. A key dimension in our approach is a central concern with people's lived experience [1].

### I. NEW MODELS OF HEALTHCARE

We believe that providing services to support the self management of chronic conditions requires radically new thinking about how public health services are organised and delivered, not simply the provision of technologies 'in the home'. We need to consider not only how user-centred design can support the development of technologies within existing healthcare systems, but also, how user-centred design can guide a rethinking of health services and systems towards more user-centred models.

A starting point for such thinking is the concept of the co-production of health outcomes. At the most basic level, this model focuses on the dyad of patient and physician working together to promote the patient's health. This dyad can be extended to include carers, relatives, friends and community organisations as participants in co-producing health. One radical model of healthcare delivery that builds on co-production has been termed Open Health [2]. Open Health recognises that health outcomes for an individual are not simply determined by episodic interventions by clinical services. Rather, outcomes emerge from the interaction of many different actors and forces. People are active participants in their own healthcare, drawing services and information from relatives and friends, from agencies of the state, private sector organisations and third sector bodies, and the wider cultural environment. The individual patient is also uniquely placed to consider how healthcare services fit into their lives.

Open Health acknowledges this reality and seeks to provide resources, information and services within this rich environment that individuals (and those acting on their behalf) can draw on to improve health outcomes. In this model, the knowledge and expertise that contribute to health are seen as distributed, rather than being purely the preserve of the clinician. For example 'expert patients' can offer practical advice for dealing with everyday issues relating to their condition that a clinician would not be aware of [3]. Open Health seeks to shift the locus of control towards the patient so that other resources can be utilised to create a system that is both more effective and more responsive to people's needs and desires.

New technology infrastructures and new digital media offer significant possibilities to develop support Open Health models. Health 2.0 for example [4] has utilised the new technologies of social networking, mobile applications and the world-wide web to provide digital information services and support networks aiming to give patients voice and choice in the management of a range of chronic and terminal conditions, and to stimulate innovation in products and services.

When health and health services are understood in this way, we are challenged to think more deeply about our approach to designing for pervasive health. Below we discuss some of the issues of designing in this new environment. The challenges are presented at three distinct levels:

- Designing to improve existing services;

- Designing service innovations;
- Designing strategic change;

UCHD seeks to respond at all three levels.

### II. DESIGNING SERVICE IMPROVEMENT

At the level of individual services, the NHS Institute for Improvement and Innovation and has developed Experience-based design (EBD) as a method (and toolset) that can be used within the NHS to assist service improvement initiatives [5]. EBD is a participatory method that involves teams of service users, service providers and designers in a collaborative process of identifying problems with the existing service, envisioning new solutions and implementing them. EBD begins by gathering and sharing patients' and providers' experiences of health services. These stories are used by the team to map patients' journey through the service as a sequence of touchpoints, and the emotional highs and lows associated with those interactions are identified. These are then used to explore changes.

In the UCHD project, we have adopted EBD as a baseline of current 'best practice' within the NHS. We are conducting an action research project, applying EBD, to designing 'Better Outpatients Services for Older People'. The UCHD team are working with staff and older people who use the outpatients department at the Royal Hallamshire Hospital in Sheffield.

Issues that have been highlighted by the patients' groups include the quality of information provided about appointments, difficulties for carers & patients when dropping off elderly and frail patients, and the challenges for elderly patients in navigating around the hospital between departments. The project is currently at the stage of making immediate changes in the service, and making recommendations about more complex changes that could be implemented.

A key finding from the work so far is that any analysis of the service as experienced must extend beyond the physical location of the outpatients department. Service users have raised many issues about travelling to and from the clinic, arrangements for pick-up from the home, interactions between the outpatients department and general practitioners, and ways in which the department communicates with the patient at home (or to their mobile phone) before, during and after the clinic visit. It is also clear that the outpatients service does not just touch on the patients', but also on their relatives and carers who may be involved in dropping them off, or accompanying them on clinic visits. The outpatients' service is clearly not simply a service located at the hospital clinic and dealing with a tightly specified collection of patients, but is experienced by patients themselves, as well as their relatives and carers, in a wide variety of settings. The service already has pervasive properties and impacts on aspects of healthcare 'in the home'.

A second finding is concerned with the use of EBD and the definition of this project as one of 'service improvement'. The choice of these words is not accidental, but is a response to the constraints of ethical approval processes within the NHS. All research initiatives in the NHS are subject to ethical review. Typically research is concerned with evaluating the

effectiveness of treatments, often by means of double blind randomised control trials. There are important ethical issues when medicating patients in such trials and strong ethical review processes exist to ensure that patients are treated with the highest possible ethical standards. Within the NHS, the use of EBD for 'service improvement' has been agreed to be non-intrusive and therefore EBD initiatives can be approved by the chairs of ethics review committees without the need to submit a formally defined research protocol.

### III. DESIGNING SERVICE INNOVATIONS

The experience of chronic illness is not simply about physical sensations and pain in the body, but also about social experience (for example a person with diabetes feeling embarrassment when they need to inject, or being criticised for injecting in a public setting), emotional experience (the irritation of having to plan activities to accommodate a complex collection of drugs at specific times), and intellectual experience (calculating the CP units which indicate the calorific loading of a meal for a person with diabetes).

Many sufferers from long term conditions find that formal health services form only a small part of the resources that they use to look after their health and wellbeing. People with long term medical conditions are not passive recipients of care, but typically manage much of their own care, monitoring aspects of their condition, timing their drug regimes, adjusting their behaviours, and raising alerts if they notice changes in their experience.

Increasingly, many people are also interacting in on-line social networks to share experiences with other people with similar conditions, finding that people with similar experience can provide ideas and practical advice that clinical professionals are unable to give because they do not share the social and practical experiences of the patient. These networks can assist people in formulating positive identities for themselves as people with good self-management, and can provide social support to maintain physical and psychological health. These networks may also enable collective and critical political responses to conditions, raising issues about socially constructed aspects of illness and disability. Such networks can also share views and reviews about products and services that may be available in the public, private or third sector that may be useful, and can provide input to designing. Recognising these diverse aspects of the experience of chronic illness and of healthcare, we are challenged to explore a broader design space when consider how pervasive technologies can contribute to healthcare.

In the UCHD project, we are investigating this space by working with a group of young people suffering from type 1 diabetes to re-imagine the systemic environment in which they experience their lives. Our intention is to work with this group in co-design activities to understand their experience and the experience of other people with diabetes, to imagine alternative experiences, and then develop innovative service, product and systems responses that are relevant to these people's lived experience. Starting with people's experience provides a lens through which the role of individual provisions is understood to exist within a broader ecology of products and systems. We

expect that at least some of the design proposals that are developed in this activity will involve technologies that are located 'in the home', but we posit that adopting 'in the home' as a starting point would limit the scope for innovative design.

This planned research activity is currently undergoing formal ethical review.

### IV. DESIGNING STRATEGIC CHANGE

Involving patients, service users, third sector groups and a much wider group of stakeholders in designing health services offers significant potential to promote fundamental change in the organisation and delivery of healthcare. If the kind of innovation to healthcare described here is to become a sustainable reality rather than merely an academic concept, there needs to be commensurate effort dedicated to bringing about change and development in the organisations and institutions responsible for designing and delivering healthcare. These institutions need to develop their capability in design thinking, as well as their understanding of the capabilities that may be enabled by new technologies. Changes in this broader context will impact on the environment in which pervasive systems 'in the home' will operate.

However such fundamental changes are difficult to enact in large, complex, bureaucratic and democratically accountable public organisations such as the UK NHS. Part of the challenge is to find ways for concerned professionals, designers and patient advocates to interact with the broader NHS system in designing futures. Within the UCHD project we are responding to this challenge by working in partnership with the NHS in an action research framework. The project team consists of 7 people 3 of whom are employed by the NHS and four of whom are employed by the University. On both the NHS and the university payrolls there are mix of senior academic, management and researcher positions. On the NHS side we have access to staff in charge of training and development and we deliver courses to staff. We also receive secondments of health professionals to work on UCHD projects to learn about our approach. We are also engaging with third sector groups as important participants in the wider healthcare ecology.

The partnership between academic and healthcare professionals at all levels of the planning, management, executions and dissemination of UCHD research provides evidence that this design approach can work in the NHS, and builds the common ground and shared learning that will lay the foundation for strategic change.

### V. CONSEQUENCES FOR PERVASIVE HEALTH IN THE HOME

The pervasive health programme as a technological endeavour will be a central element of the move towards open health. But the technological trajectory which pervasive health seeks to define should be steered by a deep understanding of the experience of chronic illness on the one hand, and on the other by a significant re-thinking of the space, place and politics of healthcare.

The conventional clinic has been critiqued as a space that is controlled, often owned, operated and managed by the clinician. The clinician is the source of knowledge, power and

decision making in regard to what the patient needs to do in order to achieve self-management. The patient is an outsider and is someone who is the subject of a clinical intervention based on an objective classification of a disease as expressed in the body. A narrow vision of pervasive healthcare extends the clinic into the home, and in so-doing re-defines the home as a locus for treatment, or as a centre of surveillance, which for example, monitors the patient remotely, sending back information to some centre of decisions making. Thinking of the trajectory of pervasive healthcare as one which is concerned with shifting the physical location of care runs the risk of failing to respond to the experiential quality of chronic illness, which extends over time and place and involves not only the patient but their family, friends and loved ones.

In contrast, our vision for pervasive healthcare moves away from physical location as the primary focus of design discourse, towards a focus on individuals, their experiences, practices and social relationships, in order to understand how these affect self-management of long term conditions. In so doing we seek to offer a richer understanding of the move towards pervasive healthcare as a process of reconfiguration or redistribution of key resources.

This implies changes to the ways that we approach the design of pervasive technologies in healthcare.

- Services, whether provided in the home or elsewhere should give people a greater sense of ownership of the management of their condition.
- Services should provide people with information and evidence, relevant to their condition, to help them understand their situation, to make changes to their lifestyles and build their abilities in self-management. Such information, and evidence should be presented not only as abstract scientific principles and theory but also in terms of the experiences of other people.
- Service providers and technology designers need to understand in a deeper way how people live with chronic illnesses. The support and information

networks they use, the diversity of practices, places and movements which shape their self-management, and the obstacles to self-management they face on a daily basis.

- Providers need to support people in tailoring their self-management practices to their own unique physical, personal and social situation. That is to say giving them more choice in defining their own services and products and systems.
- Service providers and technology designers should respond to this richer context by offering an ecology of systems and services relating to the person as embodied in ever changing contexts.
- This ecology should include help for people to access peer-to-peer social support sharing and caring in order to encourage sustained engagement with self-management to build positive healthy identities for themselves.

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