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User Centred Design and Pervasive Health: A position statement from the User Centred Healthcare Design project

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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].

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. 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 what user-centred design means 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.

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 relates to the problem of designing in this space. As the project has progressed, staff have found it difficult to get released from their duties to engage in participatory exercises, and when they are released, this can sometimes result in extra work pressure being put on their colleagues. The project team have recognised the need to support the 'technical' design activity with broader communication initiatives to promote local support and good will towards the re-design project. The 'design problem' is not simply to develop a new vision of the service, but also to develop the motivation of staff and managers (who may be only indirectly involved in the design activities) to respond positively to the potential for change. Methods for designing in this space need to be sensitive to their context of use. This is apparent in two observations.

One finding is that any analysis of the service as an experience 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, their relatives and carers in a wide variety of settings. The service already has pervasive properties.

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.

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 typically manage much of their own healthcare, monitoring aspects of their condition, timing their drug regimes, adjusting their behaviour to manage their condition, and raising alerts if they notice changes.

Increasingly, many people are 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.

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 services, products and provisions is understood to exist within a broader ecology of products and systems. This planned research activity is currently undergoing formal ethical review.

Designing Strategic Change

Involving patients, service users, third sector advocacy 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 within the UK. 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 health 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.

Conclusion

User Centred Design for Pervasive Health can mean much more than improved usability of widespread technologies being used within existing medical service structures. Bringing user-centred design to healthcare implies sustained engagement with the whole healthcare system.

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