InTacT: Insights into Telehealth and Care Technologies

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Abstract: An ageing population, pressure on health, social care capacity and changing social roles and expectations are driving demand for innovative solutions to support independence at home for people living with long term conditions and disabilities. Digital health-technologies have been posited as one potential solution to alleviate pressures placed on existing care services, reducing overall costs and carer burden (Petersson et al. 2011). As a consequence, significant investment into telehealth and telecare has been made. However whilst advances in these technologies are moving apace, a growing body of research has suggested that significant questions still remain regarding the acceptance and ultimately adoption of these devices by end users (May et al. 2011, Greenhalgh et al. 2013).

This paper shares the findings of the initial phase of a two-year qualitative research study identifying end-users attitudes to technology in everyday life and exploring how technology might be most appropriately designed to support personal health care. Utilising a critical artefact methodology the study has focused particularly on exploring the needs of groups of individuals who are currently under-represented in this research arena including individuals from diverse ethnic communities and communities classed as being of high socio-economic need. The research has identified a number of barriers to inclusion and the need for designers to understand the broader physical and cultural contexts where health technologies are used. The paper concludes with a broader discussion of the role design in eliciting understanding and developing responses to the complex challenges facing current healthcare services.

1 The Broader Context

The World Health Organisation has described global ageing as both the 'greatest triumph and challenge of the twenty first century'. Increasing numbers of people have the opportunity to enjoy and use this extended time beyond retirement to pursue new goals, gain new skills and contribute to their families and communities. However, the extent to which individuals are able to do this will be very much

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dependent on their health. Whilst disability is not inevitable a number of common health conditions are associated with growing older including: loss of visual and hearing acuity, osteoarthritis chronic obstructive pulmonary disease and dementia. More complex health states commonly referred to as geriatric syndromes may also emerge. These are often the result of a number of underlying factors including frailty, falls, urinary incontinence and delirium (WHO 2015). Increasing frailty may occur at the same time as social networks are diminishing as a consequence of bereavement, making people increasing reliant on healthcare and placing increased pressure on existing services.

An ageing society therefore demands innovative thinking to reshape our future healthcare. Technology is considered to play a key role in changing both how and where care is delivered (Huang 2013). Most notable have been advances in telehealth and telecare technologies. Whilst terminology relating to these technologies is still evolving (RCN) it is generally accepted that telehealth refers to devices concerned with the remote monitoring of physiological data, enabling health professionals to support diagnosis and disease-management whilst Telecare comprises of systems of sensors and alarms that can detect possible problems such as smoke or gas and has the ability to alert carers or monitoring control centres should the need arise. These technologies are congruent with and support evolving paradigms of health, which place increasing responsibility on the individual to recognize and manage the symptoms of their condition (Lorig and Holman 2004).

Telehealth and telecare devices have undergone multiple iterations since their inception in the 1940s. First generation products including buzzers and pendant alarms for summoning help have been gradually augmented by second and third generations of devices which now include remote monitoring in the context of self-management approaches, with the intention of enabling individuals living with long term conditions to better manage their health. Rather than travelling to attend face-to-face appointments, placing pressure on services, telehealth can now help individuals manage their own homes and to become lay experts in their own care. At present it is estimated that 30% of the UK population have at least one chronic condition, which accounts for 70% of the total health services expenditure. The need to alleviate these costs is therefore a priority.

Given the potential of digital health technologies to increase autonomy and ease care needs significant investment in such devices has been made. Within the United Kingdom the Department of Health instigated the Whole Systems Demonstrator trial to explore the efficacy of telehealth. A similar approach was taken in North America by the Veterans Health Administration's National Home Telehealth Programme, which enrolled 50 000 patients. In Europe individual countries have developed more localized approaches. For instance in Germany the SOPHIA project has seen the widespread development and installation of multiple systems including advanced sensing and activity monitoring through the ubiquitous television set.

However in spite of this global investment, the evidence to date supporting the use of assistive technologies such as telecare and telehealth remains mixed. Whilst initial results from the UK's whole demonstrator randomised controlled trial were extremely promising with a 45% reduction in mortality rates, a 20% reduction in emergency admissions and a 15% reduction in accidents and emergencies authors of the study have emphasized the need for caution (Steventon et al. 2012). Dixon (2012)

highlighted that the trial included those with low risks, were provided with extra support and were followed up for only one year. This view was supported by subsequent studies seeking to understand the views of those who had declined to enter the trial. This research found that one of the main reasons for not participating in the study was that assistive technology was considered as a potential threat to identity and existing service use (Sanders et al. 2012, p.10). Further research is therefore required (Health Technology Strategy Board).

Low uptake of digital health technologies is not confined to high profile studies such as the Whole Systems Demonstrator Sites. In a recent article Foster et al. (2015) describe how in two linked randomized controlled trials focusing on telehealth interventions in the north of England (one for patients with depression and the other for patients raised cardiovascular disease) of the patients invited 82.9% (20,021/24,152) did not accept the study invite. The main reasons given for non-participation were telehealth related with 54.7% of decliners stating they did not have access to the skills or the use of the Internet/computers. The authors raise concerns regarding the implications of this in the context of engagement with telehealth products and services.

Much criticism has related to the patchiness of the evidence with some studies reporting positive findings whilst others do not and an overall lack of clarity exists regarding understanding of which type of technology is best suited to which condition. What is consistent however is the lack of engagement of patients and health-care professionals reflected in the low uptake of services and high-drop-out rates. A number of reasons have been proposed to account for this.

The extrinsic factors identified to account for non-adoption of telehealth include: geography, poor network coverage (Hanson et al. 2010) and affordability (Morris 2012). A meta-review and realist synthesis of existing quantitative and qualitative evidence on telehealth for chronic conditions (Salisbury et al. 2015) recognized these as contributory factors but suggested that intrinsic factors were more important, with confidence in using technology cited as the most significant construct associated with adoption. Salisbury et al. (2015) also recognized that acceptability, ease of use and integration into everyday routines were also important to patients and professionals. The meaningfulness of the technology in the broader context of the person's life was a theme explored in an earlier paper by Hanson et al. (2010), which examined factors that needed to be taken into account when designing technologies for digitally excluded older people. Although the paper does not specifically consider digital health technologies the authors highlight the need for designers to address and incorporate the values of older adults within the design process in order to ensure that the technology has meaning and currency within the person's broader habits and routines.

2 The Role of Design

The design of products is important on a number of levels. A study of community alarm services by Moray Community Health and Social Care (2009) partnership found that whilst end-users valued the service, one third of individuals only wore

their alarm button some of the time or not at all because it was perceived to be too easily activated or individuals simply forgot to wear it. Bentley et al. (2014) found that non-acceptance of telehealth and telecare related to the stigmatizing aesthetics of products, which reinforced notions of vulnerability and dependency. Participants in this study reported how the look and feel of certain items such as the pendant reinforced the stereotype of telecare as being for people *'who are old and unable to cope'*. The design of interfaces raises challenging issues, as a balance must be reached between creating an interface that compensates for age related disability and promotes ease of use whilst also ensuring that potentially stigmatising designs are avoided.

Overall the literature highlights that the reason for non-acceptance of telehealth is complex. The role of design is not and should not be confined to interface development or *'traditional notions of improving usability'*. Designers need to better understand the broader physical and social environments in which these technologies will operate and how they relate to the contexts of the lives of end users. This is necessary because according to Greenhalgh et al. (2013) the things we use and make (technologies) are not neutral objects but embodiments of ourselves and our cultural values. Where a disconnect between the technology and these cultural values emerge this impacts on the individual's relationship with the world. They conclude in their study that technologies can thus be disabling as well as enabling, disempowering as well as empowering. Illness experiences and assisted living needs of older people are diverse and unique; hence do not lend themselves to simple or standardised technological solutions.

Design has much to contribute to this broader agenda and recognition of its potential to transform healthcare, drawing on a tradition of creative and divergent thinking to address these challenges has been gathering momentum. Of particular interest has been the increasing range of participatory and collaborative approaches that are being adopted to engage the end user in the design of products and services.

Within the context of telecare this is important as a number of researchers have suggested that the poor design of many devices may directly be attributed to the failure to find ways to engage end-users and to elicit understanding of their requirements. This has been difficult in telehealth and telecare since the driver for the development of the products is often from the developer and within telehealth services in hospitals '*individuals who are using the products are not usually the customer*' (Purchaser).

Hanson et al. (2010) have written extensively on the value of participatory design in the context of telehealth and telecare and the literature highlights examples of design researchers who have elicited the views of end users in order to build understanding to inform the development of telehealth and telecare products and services. The SEEDS project sought to empower older adults in developing strategies to participate in the digital economy and utilised semi-structured interviews as a way of understanding the challenges participants faced when accessing technology. Greenhalgh et al. (2013) explored what people with assisted living needs identified as being important and used ethnographic methods and cultural probes in order to elicit understanding. This study particularly highlighted the materiality of care and the value of enabling people living with chronic conditions and their carers to 'think with things'.

3 The Present Study

Insights into telehealth and care technologies (InTacT) very much draw on the value of 'thinking with things' as a method to build understanding of the factors end-users identify as being important in the design of digital health devices. The overall aim of the research is to explore the inequalities in telehealth and care technologies and identify and creatively challenge cultural (e.g. language, rituals, socio-economic) barriers to adoption.

The study explores participatory methods and approaches to engage people who are frequently under-represented in telehealth/telecare research by virtue of their age, ethnicity or socio-economic status, in meaningful ways. The focus of the first phase of the research has been to utilize a critical artefact methodology to build understanding of end-users attitudes to technology in everyday life and how it might most appropriately be adopted to support their personal healthcare.

The methodology of the present study draws on an existing body of work developed by the authors (Chamberlain and Roddis 2003, Chamberlain and Yoxall 2012, Chamberlain and Craig 2013) which uses objects and artefacts as methods to stimulate and scaffold thinking, offering valuable vehicles through which the complexities of lives can be understood. The transdisciplinary research project 'Engagingaging' exhibition provided the theatre for conversation and the medium and method for data collection and created the conduit, through which societal assumptions relating to ageing could be made visible, explored and challenged. Building on methods developed within 'Engagingaging' the principles of the traditional exhibition were distilled into a format that was more flexible, accessible and inclusive. 'Exhibition in a box' (Chamberlain and Craig 2013) took the essence of the exhibition into a suitcase, a la Duchamp that could be transported to diverse environs including the home. In doing so the home was transformed into the research arena, providing individuals with a tangible prompt to scaffold conversation.

These boxes comprised of everyday objects, photographs and textual material defined through the user-workshops undertaken in conjunction with the earlier large-scale exhibitions in 'Engagingaging'. The objects were carefully selected to code, represent and prompt further discussion on themes that had emerged from earlier research. The objects could and did combine to create objective correlatives enabling participants to express emotional responses. For example, pencil and post card prompted discussion around travel, communication, technology (analogue vs digital). The objects allowed different ways for participants to express their personal identity and creativity, prompting them to describe things they have made previously in their life and suggest new ways of doing things. The present study utilises and further tests this methodology.

The first phase of the study was undertaken in the North of England. Prior to recruitment, ethical approval was obtained, following which posters and invitations describing the research and inviting people who might be interested in taking part in a workshop/focus group exploring technology were distributed through a number of voluntary and third sector organizations. These included: Age UK, the Churches Council for Community Care and the Chinese Elders. This first phase of the research was effectively a feasibility study, focusing particularly on methods of engagement.

At this point in the research it was not a requirement for participants to be users of telehealth or telecare devices since the aim was to develop a broader understanding of participants' attitudes to digital products and devices. In total thirty-two socially and ethnically diverse community living older people were recruited. Individuals were invited to attend one of four workshops that were held in community venues and were facilitated by the research team. Each workshop lasted on average for two hours. The workshops began with a general introduction from the research team and an invitation for participants to share (verbally or through drawing) the images and associations that came to mind when they heard the word technology. Exhibition in a box was then introduced and participants were invited, in turn, to select and to respond to the objects it contained. Written consent was obtained to video and audio record the session and these were transcribed following the groups. This data was analysed using framework analysis (Ritchie and Spencer 1994). This enabled the development of a matrix of themes and related sub-topics from the data as well as identification of the links across themes, different participants and venues.

4 Findings and Discussion

The strength of the critical artefact methodology is that the objects transcend boundaries of culture, language and age and whilst the objects remain unchanging the associations they prompt and the stories they elicit are dynamic and ever changing. Across the various workshop/focus groups different objects elicited the same themes of conversation. Particularly powerful were the pencil and the post-card which participants linked to communication and the worldwide web and the key, which very much related to security. Four themes emerged during the exploration of the objects: digital beings in a digital world, navigating change, trust and control and conceptualisations of health.

4.1 Digital Beings in a Digital World

Digital technology was seen as part of everyday life and access to computers and the Internet as being necessary to undertake fundamental activities of daily living including the paying of bills and other transactions. Participants discussed the importance of e-mail and facebook as a way to engage with friends and maintain contact with family members. Lack of access was regarded as a form of social exclusion, '*This one sounds awfully melodramatic, but you just get to the point where you don't feel like a meaningful member of society*' (Workshop participant).

4.2 Navigating Change

Digital disconnectedness was a real concern and the rapid evolution of products, the speed of change as a consequence of in-built obsolescence of many digital devices were regarded as real challenges. Participants described how within the same

household different generations of products existed, all of which had subtle differences requiring new learning and complex negotiation. 'Learning saturation' was a term commonly used to describe participants' experiences.

> *'As you get older your ability to retain knowledge is greater than your ability to take on new knowledge therefore to use something you already have existing knowledge of and know how it works is better than giving a new fangled object that a person could reject of find stigmatising.'*

<div align="right">(Workshop participant)</div>

Even when the computer products remained the same, the operating systems and interfaces were subject to constant change. Difficulties in learning how to navigate these were identified as an issue particularly given the lack of technical support. The tangibility of the critical artefacts contained within exhibition in a box and the constancy of form was contrasted with ephemerality of technological change. The pencil in particular elicited conversations regarding learning and connectivity and individuals linked this to feelings of being 'disconnected' from environments where updating of knowledge occurs such as the workplace. Others described how these challenges of mastering new technologies and products were compounded by deterioration of physical and cognitive abilities, attributing difficulties to failing memory and deterioration of skills. This was reflective of a number of people who took part in the study,

> *'We can keep on but you don't get much towards the end....I've started to lose it…it's a bit like swimming across a river, you stretch out to the bank but you can't quite reach it…'*

<div align="right">(Workshop participant)</div>

The metaphor of 'stretching out to the bank but not reaching it' was particularly poignant and reflected the loss of locus of control, and feelings of helplessness expressed by some participants in the research. Individuals spoke of how these feelings could lead to non-engagement with the technology. The keys contained in 'exhibition in a box' - which participants linked to security - prompted much conversation. However, whilst these keys were conceptualised as solid and unproblematic the security features associated with many of the computers were seen as tricky, particularly the need to remember multiple ever changing passwords. For a number of participants who were used to mending products the unfathomability of the digital was closely linked to issues of security and trust: '*I mean if it's a lock, someone could break in as well, but still it's something you get more – it's more understandable for me… you have a key, and a lock*' (Workshop participant).

4.3 Trust and Control

A theme emerging across all the workshops/focus groups in response to both the keys and to a series of 'what if?' cards, scenes of future technological scenarios was the importance of trust and reliability of products. This was seen as being particularly important in relation to health devices and existed on multiple levels including trusting devices not to break, trust in terms of where the information is

being sent, trust in relation to accuracy. Even when there was an acknowledgement that technology could be more accurate the issue was trust '*it's just the thought isn't it? I don't trust a machine*'.

One focus group discussion centred on ways of being able to access electronic health records and how this could increase transparency and lead to increased control and involvement. One person described how her digital diabetes pen, which automatically recorded the insulin dosage, enabled her to better keep track of her medication. However, the caveat for both was that this needed to occur within the context of human relationships with medical professionals where issues and concerns could be discussed. Without this relational element it was difficult to know what to trust particularly given the number of conflicting health messages.

> '*There is no technical barrier in collecting data, it is the presentation of that data. If people are able to collect and monitor data they have to be educated to what is normal. People can get data interpretation wildly wrong either by accident of design*'.
>
> (Workshop participant)

The sensory component of many of the objects prompted conversations relating to the importance of touch, and to the relational aspects of healthcare. Fears of loneliness and loss of human contact were seen as particular concerns in relation to more remote monitoring of health: *'One of the things that frightened me to death was the idea of growing old alone, but I never thought it would happen to me'* (Workshop participant).

The sensory aspect was particularly significant for participants from the Chinese community who stressed that Chinese medicine is not predicated on 'normal ranges of data' but on the feel and pallor of the skin and on the sense of touch.

4.4 Conceptualisations of Health

Ultimately discussion across the groups regarding the qualities of products that might promote the acceptance and acceptability of digital health technologies hinged on conceptualisations of what healthcare is. The 'what if?' cards effectively embodied concepts relating to self-management and a shift in the locus of control away from medical professional to the individual and the move from care being delivered in a hospital to the home. The individuals who engaged in this present study did not see this as preferable to existing systems and struggled to come to terms with this. The efficacy of many of the current medical innovations and new paradigms of health were questioned, in particular the constant bombardment of contradictory health messages. Within this the irony that technology had contributed to people leading more sedentary lives, leading to medical problems was not lost.

Participants described the importance of seeing both evolving models of healthcare and technologies in a broader societal context. World events are constantly changing and challenging our understanding of existing technologies. Increasing publicity relating to cyber-crime, terror threats played out on a global stage all impacted on the ways participants in our study related to existing home digital technologies. The importance of this should not be underestimated, '*We*

talked about trust earlier on, the world has changed in ways we are still coming to terms with' (Workshop participant).

5 Conclusion

Current literature relating to the design of telehealth and telecare has focused primarily on traditional notions of improving usability and the pursuit of stylish desirable technological solutions. An assumption has been made that designing more aesthetically appealing products will automatically increase engagement in these technologies. Early findings of this present study suggests that acceptance of digital health solutions is more complex. The present generation of health technologies are predicated on the assumption that end-users have already embraced the shift in the healthcare paradigm, which increasingly moves responsibility from the clinician and the hospital to the patient and the home. Participants in this small study raised questions regarding this and the,

> *'underpinning assumption that self-management of illness at home will occur in the same way that medical management happens in the hospital by generating, analysing and manipulating objective measures of health status'.*
>
> (Greenhalgh 2013)

Traditional qualitative research methods using structured and semi-structured interviews can preference the views of the researcher who can make assumptions about what the issues are. Exhibition in a box offered participants a space to reflect, discuss, explore and to define the real questions. The objects offered scaffolds for communication and because they were at one and the same time both concrete and abstract participants in thinking through the objects in the box were able to think outside of the box.

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