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Citation:

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DRS2016

Design + Research + Society

Future-Focused Thinking

50

2016 Design Research Society
50th Anniversary Conference
27-30 June 2016, Brighton, UK

A Design Primer for the Domestication of Health Technologies

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Abstract: As the population ages and places increasing pressures on health services there is widespread acceptance that we have to radically rethink how care is delivered. There is a growing body of research that focuses on telehealth to support self-care and a shift of traditional care from hospital to the home environ. This paper explores the culture and practice of health interventions that have previously resided within the domain of the hospital and the implications of this shift when they infiltrate the private space of the home. Research undertaken by the authors using a critical artefact methodology highlights collaborative approaches between design and health are critical to both understand these two disparate environments and that careful consideration is required when developing appropriate new landscapes and paradigms for care. This presents opportunity for design both in developing solutions but also within creative research approaches to understand the complexity of the challenges.

Keywords: Design methodology, Tele-health, Co-design, User-centred.

1. Introduction

There is a significant body of research concerned with healthcare practices and services as well as technological developments to support. Much of this has been conducted and disseminated by academics within the field of health, engineering and HCI. While there has been growing interest in the potential of design and the relevant underpinning research, that can draw on a tradition of creative and divergent thinking to address these fundamental and yet practical challenges to our societies' health, there is a need for more design focused research to realise this.

This paper will present an overview of the context that is shaping change in healthcare practices. Providing a technological summary within healthcare it will highlight some of the challenges as to why many of the technological developments to date have been rejected by

potential users. This summary will begin to unpick the complexities of how the hospital and domestic environment can become a hybrid space and then notate the importance of engaging users to both understand and collaboratively develop solutions. The paper then shares research undertaken by the authors utilising a critical artefact methodology, sharing some of these findings and concludes with a summary of the key challenges for Designers within this field of research.

2. Context

The dramatic increase in average life expectancy during the 20th century ranks as one of society's greatest achievements. Increasing life expectancy is part of a major transition in human health spreading around the globe at different rates and along different pathways. However will this demographic shift be accompanied by a longer period of good health, a sustained sense of well-being, extended periods of social engagement and productivity, or will it be associated with more illness, disability, and dependency? According to the Constitution of the World Health Organisation (WHO) health is not the absence of disease but 'a state of complete physical, social and mental well-being''. Health is seen in its widest sense with an emphasis on an individual's personal resources as well as physical capabilities. However Huber et el (2011) challenge the WHO definition of health as complete wellbeing that is no longer fit for purpose given the rise of chronic disease. They propose changing the emphasis towards the ability to adapt and self manage in the face of social, physical, and emotional challenges. All countries face major challenges to ensure that their health and social systems are ready to make the most of this demographic shift to support not just extended life but our future wellbeing.

There has been growing recognition of the potential of design to transform healthcare drawing on a tradition of creative and divergent thinking to address these challenges. Challenges that are, by definition, 'wicked problems', where there is no single true answer and where design's strength lies in creatively responding to the assimilation and responding complex interdependencies.

Escalating costs of healthcare services and a shortage of personnel and facilities have put pressure on the health care system to deliver more support and treatments on an outpatient basis. While tending to health needs within the home has a long history, and a variety medical devices have been adopted in the home for many years, we are now witnessing an increasing migration of devices and emergent technologies into the home setting. However, most medical devices are designed for use by health professionals in formal healthcare settings rather than for autonomous domestic use. Consequently there are many challenges to be resolved to address the complexity demanded by the varied users within this environment.

According to the Royal College of Nursing (RCN) telehealth and telecare are relatively new eHealth services, the language used to describe them is still evolving and the terms used are interchangeable. Telehealth (also referred to as telemedicine) describes the remote

monitoring of physiological data that can be used by health professionals for diagnosis or disease management. Examples of telehealth devices include blood pressure monitors, pulse oximeters, spirometers, weighing scales and blood glucometers. Telehealth also covers the use of information and communication technology for remote consultation between health professionals or between a health professional and a patient e.g. providing health advice by telephone, videoconferencing to discuss a diagnosis or capturing and sending images for diagnosis. Telecare uses a combination of alarms, sensors and a variety of other equipment, usually in the home environment, to help people live more independently by monitoring for changes, warning end users or to raise an alert at a monitoring control centre. Examples of telecare devices include personal alarms, fall detectors, temperature extremes sensors, carbon monoxide detectors, flood detectors and gas detectors. Telehealth is generally concerned with preventative approaches to healthcare while telemedicine tends to have a narrower scope more focused on curative health.

Telehealth can be provided in real time 24/7 with and without feedback to the patient and this facility has generated interest in its use for people living remotely and difficult to access and older people who are high health service users. The interest in telehealth is largely economic prompted by the fact that the provision of current health services is unsustainable. The potential value of telehealth is broad and varied; for example it can offer the facility for the early detection of health problems, it can result in fewer face-to-face meetings between health professionals and patients and it has the potential environmental benefits to reduce the need for people to travel to access services. However successful implementation requires a fundamental culture change in how health services are delivered and received.

The Whole Systems Demonstrator programme (gov.uk) represents one of the most significant studies of telehealth and telecare in the United Kingdom. This randomised controlled trial (RCT) engaged over 6000 participants. Where the technologies were adopted there was a 45% reduction in mortality, a 20% reduction in emergency admissions and a 15% reduction in accidents and emergencies. However, whilst on one level these results were extremely positive a growing number of researchers have been keen to highlight that the figures reflect only those who engaged with the intervention. This pattern of non-adoption is found elsewhere. Indeed, in-spite of the fact that there has been much interest from health professionals and health services, and numerous technological developments and trials, the adoption has been slow with no clear sign of how a telehealth service might be integrated by the community within our homes.

While there is an established specialist strand of product design that has been integral to the development and innovation of medical devices within hospital settings there is much less evidence and guidance regards how design might contribute to telehealth. This paper will explore some of the challenges and opportunities for design within the context of telehealthcare within the domestic setting.

3. Barriers to adoption

Technological innovation in the context of health potentially offers users of this technology increased choice as to how and where health-care is delivered. However, as previously stated, successful implementation requires a fundamental culture change in how health services are delivered and received. The Whole Systems Demonstrator Programme is a good case in point. Whilst the potential of technology to positively impact on the lives of participants was clear, the main reason given by individuals for non-participation in the study was the perceived threat that this technology posed to identity. This is not an isolated example. Foster et al (2015) for instance reported that in their study of two linked telehealth trials that 82.9% of individuals did not accept the invitation to participate in the research.

Such findings have prompted a number of authors to explore the reasons why people choose not to adopt telecare when it may be an appropriate intervention in their circumstances. For instance, Bentley et al (2014) identified several factors relating to the design and suitability of telecare that negatively impacted upon its perception and use. For example there was a sense among the participants that having telecare would be accepting the fact that they are 'old', a fact, which people described as trying to resist. In addition they found a high volume of accidental triggering (miss-use) can lead to abandonment of the technology or perceived intrusion of the technology in people's daily lives. However one of the main conclusions emerging from the study was that design related barriers identified twenty years ago have yet to be addressed despite significant advances in technology.

Lack of user involvement in the design process has been identified as a particular issue (Hanson et al., 2010). This has been particularly problematic when designing for older people. As mentioned 'older' people are frequently targeted as the core users of telehealth services. Perceptions persist that 'older' people are less likely to use digital technologies due to lack of previous early exposure to the technologies, but this will decrease over time. Older people are a wide and diverse group, associated by only their physical age; individuals may not hold the same values as another and each person's abilities, motivations, aspirations and understandings can differ widely. Thus, not all older people have the same relationship with digital technology. Valentine et al (2011) propose that there are additional issues that result in a lack of use amongst older people; peer- opinion, cost and maintenance, previous negative experiences, lack of understanding and fundamentally a lack of perceived need.

Greenhalgh et al (2013) present an interesting phenomenological analysis of the use and non-use of telehealth and telecare. They claim the things we use and make (technologies) are not neutral objects but embodiments of our selves and our cultural values. A familiar technology is 'ready-to-hand' and available to mediate between the individual and the world but if the technology does not 'work' as intended, it loses its phenomenological transparency and begins to interfere with the individual's relationship to the world. The material features of technologies, dimensions, shape, colour, durability, size of buttons, brightness of screen and so on, have a powerful influence on whether and how technologies

are used or not. Material features are key, since they affect what the person is capable of perceiving and doing with a technology in particular real-life situations. Phenomenology underpins the science of experience- based design, which takes the patient's 'ordinary experience' as its starting point. They conclude in their study that technologies can thus be disabling as well as enabling, disempowering as well as empowering. That the illness experiences and assisted living needs of older people are diverse and unique, hence do not lend themselves to simple or standardised technological solutions.

4. Home and hospital

If Greenhalgh's (2013) argument is placed within the historical development of technology it is possible to see that IT and computer hardware emerged within the office environment and later filtered into the domestic environment and was promoted as the 'home office'. However rather than being used for the same tasks undertaken within the work space people began to use the home computer for radically different activities (for example entertainment, music, films). IT technology was then responsible for a complete paradigm shift in the way we shop, bank, communicate and organise our travel. Technical innovation has enabled choice and flexibility and facility to access these services from the comfort of our homes. However the domestication of healthcare bring additional and more complex challenges aside from the more obvious fact that when we are ill we seek human comfort and contact. Building on ethnographical material, Dorish & Bell (2011) demonstrate how infrastructures, mobility, privacy and the domestic realm are indeed far messier than the ideal of homogeneous and orderly spheres that can be catered by seamless, calm technologies. They state it involves asking not what things people might want to use, but asking what people do and feel and how technologies then can play in a role in this.

Home has different meanings for people but it is generally agreed to be a place of comfort, security and emotional well-being. It is a private place that reflects our identity with who we choose to share. It is where we live and where most people would prefer to die.

The home and the hospital bring together very different cultural practices and environments. Architects and interior designers for some time have agreed that space has a very real impact on how we feel. More recently neuroscientists and psychologists have discussed the way aesthetics affect our decisions, emotional responses and the way we feel about ourselves. New fields are emerging such as embodied cognition, which looks specifically at the role the environment plays in developing cognitive capacity, and neuroaesthetics which examines the biological role of aesthetic experiences.

In (Gardner 2000) conventional wisdom posits that the original hospitals were more akin to 'a home' set up by churches to provide sanctuary and comfort for the poor and sick (Dainton 1961, Friedman 1987). However contemporary historians suggest that social control has been the significant feature of hospitals throughout history (Granshaw 1989, Cavallo 1991). According to Foucault's (Foucault 1994) analysis, the modern hospital is the site for the authoritarianism of medical knowledge and the perceptual extension of medical discourse -

the medical gaze. Within this framework the hospitalised individual becomes a patient, then an object, through the practices of medicine. Foucault argues that the hospital was organised as an 'examining apparatus' enabling almost constant observation of the patient. In this creation all extraneous variables such as the home environment, family, friends and usual activities were excluded, the hospital providing the ideal laboratory setting where the causes of symptoms could be isolated and the effects of treatment monitored.

The authoritarian nature of the hospital domain inevitably creates a power relationship between the patient and health professional. This is set within a context where the patient is usually weak, unsure and infirm, undressed and vulnerable. However the power balance arguably shifts when the 'patient' re establishes control within the familiarity of their own domestic environs.

If then the home is becoming a place for high tech 'hospital' care the domestication is contrasted with the notion of home as a place of sanctuary, familiarity and belonging. Liaschenko (1994) argued that while our modern sensibility recognises the bureaucratic power of hospitals this also renders us sensitive to a view of home as a private space, a haven from the demands of the world. The very word 'home' evokes feelings of familiarity, comfort, security, nurturance and peace. Mack (1991) claimed that home is the place where we can be ourselves, surrounded by familiar faces, furniture and sounds and the comforting rituals of everyday life. To 'go home' then is to go to a place that is different from other places.

Delivery of healthcare at home is not new. Half a century ago in the USA, house calls made up 40% of all physician–patient encounters while, by 1980, this had shrunk to 0.6% of all encounters (Brickner et al. 1975). Anthony et al (1988) argue the decline of in-home primary care may well have hurt the doctor-patient relationship but telemedicine may be offering a way back to them and our family medicine roots. However Liaschenko reveals, 'every nurse told me how being in someone's home altered practice, how the simple rules and ways of conducting oneself that are taken for granted in hospitals were irrelevant, even wrong in someone's home'. She presents the notion of moral geography and the idea of place to people's lives and the relevance of this to home care practice. If ethics is about how we treat each other and geography is a given space in which people live, she takes the moral geography of home care to be the nature and quality of the relationships necessary to sustain the person in that particular place. Therefore we must acknowledge rules of behaviour, and values inherent in specific social spaces. 'The geography' of sickness is shifting as hospitals are losing their spatial pre-eminence and the home and other community structures are becoming central in caring for the sick".

Gardener warns the ambience and safety of the home however can potentially be shattered by the invasion of illness-related technology. The invasion of the technology of acute care into the home has the potential to destroy the nurturing and therapeutic environment of home as a means of promoting health recovery. He states while care of the sick in their homes invariably and increasingly brings with it technology, this technology needs to fit into

the home environment without dominating it and transferring the anti-therapeutic culture of the hospital environment into the home. He advocates a need to develop sensitivity to the space of the home as one of sanctuary with multiple social and emotional functions that serve to increase the well being of people in health and illness. Rudick (1995) goes as far to say that the 'domestication' of health care could be morally questionable in that illnesses and treatments can make familiar domestic settings alien and confuse family roles. Dorrestijn (2012) presents an ethics of technology to establish interactions and fusions with technologies in such a way that they are experienced as one's own, not obstructing but becoming part of one's experience and performance of freedom and agency

5. Developing a co-design methodology – what are the questions?

Given the complexities described, participatory and collaborative approaches in the design of products and services which take into account the environments in which they are used is paramount. The importance of co-production in health-care contexts is increasingly being recognised. Bovaird (2007) for instance describes how services are no longer simply delivered by professional and managerial staff in public agencies but are coproduced. Traditional conceptions of service planning and management are now outdated and need to be revised to account for coproduction as an integrating mechanism and an incentive for resource mobilisation—a potential that is still greatly underestimated. Wherton et al (2015) support the notion that if 'care closer to home' is to be realised, then industry, health and social care providers must evolve ways to work with older people to co-produce useful and useable solutions.

"Design Participation," as the event was entitled, was the first international conference of the Design Research Society in 1966. In the decade preceding the conference, design participation had become a matter of mounting social and political concern with growing impact on the design disciplines. Cross suggested, 'Involving in the design process those who will be affected by its outcome, may provide a means for eliminating many potential problems at their source,' (Cross 1972). Since then there has been growing interest in participatory and collaborative design. More recently Von Hippel challenged the notion that innovations stem from manufacturers and suggests a shift from manufacturer centric to user centric design processes (Von Hippel 2005).

Within the growing body of work claiming co-design approaches there is increasing debate as to the role of the designer in Co-design. Vardouli (2015) asks 'Who Designs?', The "empowered" users? The tools and/or techniques that facilitate the process? The designer of the tools and/or techniques?. Von Hippel & Katz (2002) suggest that in user centred design 'Products are not designed by the users themselves, they contend, and move on to outline a set of principles that can be designed into an artefact in order to transfer design capability to the users'.

So how can we develop methods and approaches to engage people in meaningful ways and elicit their understanding particularly when those individuals may be vulnerable or disenfranchised from society? The lead author has led a long-term programme of practice-

based research adopting a life span approach recognising individuals may face potential challenges at any stage of life.

Chamberlain and Roddis (2003) describe the development of vibro-acoustic furniture for therapeutic use, by children who are profoundly deaf, or both deaf and blind. Due to their circumstances, the end users (the children) could not actively participate in the research through familiar protocols such as interviews or questionnaires. Only when the design research team produced working physical prototypes could they interact and develop any meaningful sense of understanding. The prototypes allowed the children to control their own sensory experiences and establish a means of communication. The designer researchers found that the working prototypes acted as a bridge between themselves, the therapists and the children, revealing knowledge and understanding about the needs of the end user, and also as a catalyst for further research and investigation.

Figure 1   Tactile sounds system (Chamberlain) – a flexible modular vibro- acoustic system that conveys meaningful everyday sounds through vibration to people with profound sensory impairment. For recreational, therapeutic and educational use. Prototypes became the bridge to understanding user needs.

Chamberlain et al 2011, Chamberlain & Yoxall 2012 describe the challenge engaging users in familiar but what is generally considered 'taboo' subject matter. The bathroom is a space of private and intimate ritual and the research methods for developing an understanding of behaviour has to be carefully considered. Significant to the research was that older community researchers were formally recruited to the project from the outset and were engaged in every stage of the research and product development. The approach broke down the hierarchal relationship often created between designer and user, academic researcher and user and adopted a respect for the user as expert, designing 'with' these users and not just 'for' them. Secondly artefacts, prototypes, field labs and exhibition were key to the research and aided in accessing users tacit knowledge rather than them trying to verbalise the things they do intuitively.

Figure 2   Future bathroom (Chamberlain) - Designing with users. Exhibition was utilised as the focus of user workshops. Objects defined and help understand bathroom use and behaviour.

Chamberlain, Craig (2013) again positioned older people as active participants central to research. Artefacts were developed and presented not as solutions, but as vehicles through which to engage people, promote discussion, to raise questions, challenge preconceptions and generate in-depth data.
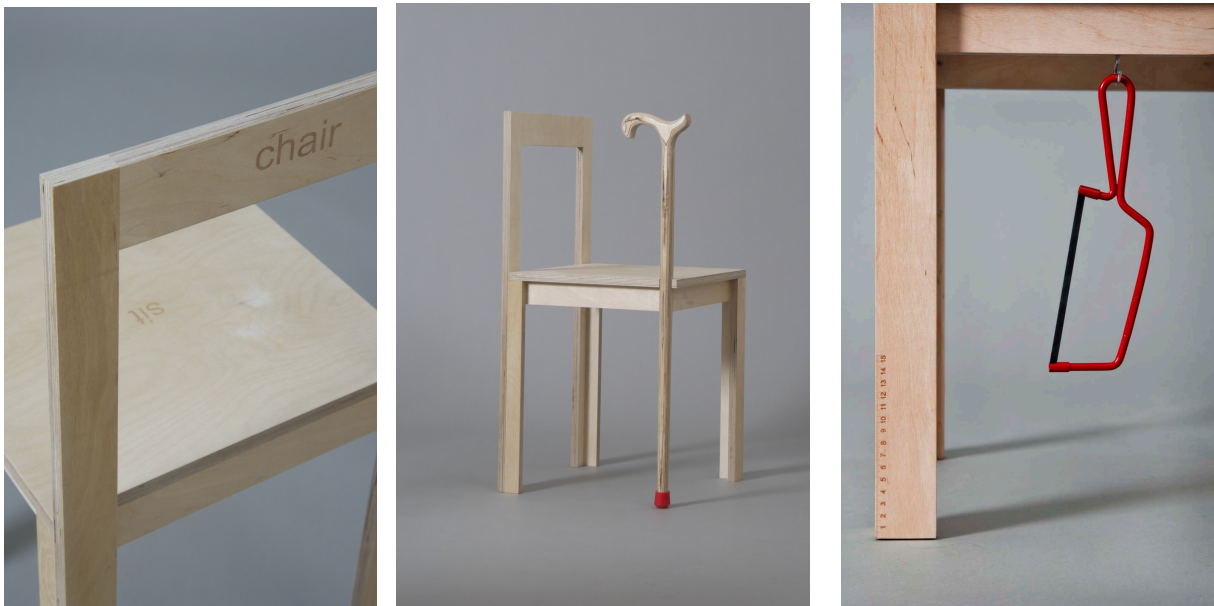

Figure 3   A selection from the Stigmas series (Chamberlain) – right to left - 'This is a chair to sit on', 'Rest of your life', 'adjustable chair'. Critical artefacts part of the engagingaging platform that present a landscape of later life posing questions not answers.

Ultimately they sought to further not just our understanding but also the understanding of all those who engaged with it. Objects and artefacts offered valuable ways to begin to understand the richness and complexity in people's lives. Central to this was the notion of exhibition as a research tool that became a meeting space that enabled this to happen.

Exhibition provided the theatre for conversation and became 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.

Figure 4   Engagingaging (Chamberlain & Craig) – Theatre for conversation – was a transnational research platform utilising exhibition as a research tool providing a forum to engage with large numbers of people across continents to explore issues of ageing

There is growing evidence of the designer shifting from a reactive product focused problem solver to that of a problem setting facilitator within co-production. Dunne & Raby (in Koskinen et al 2011) support the notion that 'Design that asks carefully crafted questions and makes us think is just as important as design that solves problems or finds answers'. Mathematician and philosopher Henri Poincare is quoted to have declared, ''The question is not, 'What is the answer?' The question is 'What is the question?''' (Licklider 1960). The challenge of participatory Design and Co-Design is developing creative and appropriate methods for meaningful engagement. Concepts such as 'communicative space,' 'the counter public' (Dentith et al, 2012) or 'discursive approach' (Cook, 2012) which are encountered in participatory methodology, underline the fact that the challenge of participation is fundamentally a challenge of communication. Although they draw on different concepts, authors continually stress how important it is that the research process opens up spaces that facilitate communication. They argue that it is crucial for research that a safe space is created in which openness; differences of opinion, conflicts, etc. are permitted. Research also shows that it is necessary to find ways of engaging with individuals and groups in ways that do not assume that individuals are able to verbally articulate and express their ideas. Rather than assuming that individuals are able to adapt and engage with the methods and experience of the researcher methods of data collection focus should build on the participants' everyday experiences. This makes it easier for individuals and groups to understand the concrete procedures, promotes confidence and encourages engagement as the research begins with what is familiar. However, it means that new methods of data collection must be developed and these should be appropriate to the concrete research situation and the research partners. In this context design and creative practice has much to be recommended. A growing body of research supports this approach and the many possibilities of using visual and performative methods of data collection have been discussed in qualitative social research with the emergence of performative social science (Jones et al. 2008), visual methods (Knoblauch et al. 2008, Pink 2014) and visual arts research methods

(Ball and Gilligan 2010). Ball and Gillingan (2010) suggest that these approaches are so successful because while many people from marginalised groups may have limited verbal communication skills, they have developed other communication strategies.

Building on methods developed within engagingaging the principles of the traditional exhibition were translated into a format that was more flexible, accessible and inclusive. 'Exhibition in a box' (Chamberlain & Craig 2013) distilled 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. Twelve boxes were produced and distributed for use with health specialists in collaboration with older users across Europe. 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. Key themes included mobility, hygiene, relationships, identity, communication, technology, food, art, money, recreation, safety and work and these were represented through the set of found objects that included, keys, dice, soap, pencil, watch, stone, glove, post-card, spoon. The objects could and did combine to create objective correlatives prompting and enabling participants to express emotional responses. e.g. pencil and post card prompted discussion around travel, communication, technology (analogue vs digital). The objects have allowed different ways for participants to express their personal identity and in many cases their creativity prompting them to describe things they have made previously in their life and suggest new was of doing things. Working in partnership with older people has developed a set of principles that primarily position the older person as the expert and encourages choice and decision-making. Within the first phase of the research we identified and worked with four occupational therapy departments in Universities across Europe including the Hogeschool Zuyd in the Netherlands and the Zhaw Institute in Zurich. Exhibition in a box has been utilised and evaluated during the past two years as tool for occupational therapy students in support of their engagement with the community.

Figure 5   Exhibition in distilled into a box. Objects prompting meaningful insights into daily life.

The current phase of this longitudinal enquiry is supported by the Collaboration for Leadership in Applied Health Research and Care/Yorkshire & Humberside (CLARHC/YH) funded by the National Institute for Health Research (NIHR). Exhibition in a box has been employed as a method 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 research described in more detail in (Chamberlain & Craig 2016) investigates how technology (in general) is used by people in their everyday lives and how it can be used to support their health and wellbeing.

The real strength of the approach is the objects, 'things' to which individuals can relate, no matter what the culture, language or age of participant. Whilst the objects in the box remain unchanging the associations they prompt and the stories they evoke are ever changing.

6. Conclusion

The challenges society faces in providing future healthcare suggests radical changes to the way health services are delivered and the way we engage with them are inexorable. There is recognition that this is likely to demand more self-care and a shift of care from the hospital to our home. Teleheath is widely lauded as the solution and there has been significant investment in the development of these technologies to provide infrastructure and hardware. This paradigm shift may have the potential re-establish links between patient and doctor and reduce costs in healthcare delivery, however research suggests there is a significant challenge in achieving adoption of these technologies. The reasons are complex and to be accepted and work these healthcare 'tele' tools have to fit, enhance and work concurrently with our complex lives.

The hospital is the traditional and familiar controlled domain where healthcare has and is defined and delivered. The move to a personal and private home space,' brings with it significant challenges where both the individual and health care professionals will need to work together to bring sense, understanding and common trust to these diverse cultures of practices and environs. There is evident concern the medical gaze will infiltrate our homes, the place of privacy, sanctuary and familiarity which we understand and control - therefore we must consider the moral geography as presented by Liaschenko and must acknowledge rules of behaviour and values inherent in specific social spaces.

Technology is well advanced to support the collection of health data that undoubtedly has potential to improve individuals health, for example early diagnosis. However, how this data is presented- what this data means - and who has access presents many challenges but with these opportunities.

Participatory approaches and co-design are critical to overcome these challenges. If co-design and methods of data collection is fundamentally a challenge of communication then design and creative practice can importantly play a role in engaging diverse and disenfranchised users as in the case studies described. Considered objects, artefacts, prototypes and exhibition can provide a space to facilitate communication, reflection and

ownership. Greenhalgh et al present a refreshing phenomenological perspective to technology and materials that presents rich opportunity for Design as opposed to just adopting science and engineering approaches to the challenge of telehealth. If we are to achieve higher adoption rates with potential users of telehealthcare then we must not simply develop solutions and focus research within the narrow boundaries of healthcare. Solutions will only be successful if they fit with the complexity of our lives therefore there is value in taking everyday experiences as a starting point. Design can bring a creative but focused lens to the challenge but it is not as simple as producing stylish desirable technological solutions. Delight is not just associated with the materiality and formal qualities of an object but the tasks and activities we engage with through objects. Can objects that concern ill health ever be desirable?

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