Privacy, boundaries and smart homes for health: An ethnographic study

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A B S T R A C T

This article explores how people negotiate borders and boundaries within the home, in the context of health and the introduction of new technologies. We draw on an ethnographic study involving a socially diverse group of people, which included people with experience of telecare or smart home energy systems. Participants engaged in various strategies to regulate the borders of their home, even though new technologies have begun to change the nature of these borders. Participants managed health conditions but also their use of technology through boundary work that permitted devices to be more or less visible and integrated within the home. Findings highlight that if smart healthcare technologies are to be accepted in the home then there is a need for mechanisms that allow people to control the interpretation of data and flow of information generated about them and their households.

1. Introduction

The home is increasingly regarded as an important setting for healthcare, signalling a shift in focus from conventional clinical contexts towards patients and their community (Williams, 2002; Downing, 2008; Gale and Sultan, 2013). Assisted living technologies such as telecare and telehealth consequently gained much attention, with efforts focusing on demonstrating effectiveness and potential to deploy at scale (Greenhalgh et al., 2012; Steventon et al., 2012). Visions of 'smarter' and 'connected' healthcare services are becoming more concrete, with 'smart' systems generally understood as ubiquitous computing technologies such as mobile computing, sensors, and the Internet, which are increasingly affordable and widespread. A number of studies have begun to explore the deployment of such smart systems into real life contexts, including people's homes (Brush et al., 2011; Mennicken and Huang, 2012; Zhu et al., 2015; Tolmie et al., 2016). These technologies are capable of collating both automated and volunteered data from multiple sources (Kitchin, 2013), transforming personal borders from physical and visible to virtual and fuzzy. These are issues we take up here.

This article draws together approaches and concepts from social sciences, Human-Computer Interaction (HCI) and Computer Supported Cooperative Work (CSCW). HCI and CSCW are disciplines within computer sciences concerned with supporting people's interactions with technologies through user-centred design. As computing technology made its way into people's homes, the HCI and CSCW communities turned their attention to investigating the situated experiences of interactive technologies within the messy contexts of the home and everyday life (for a comprehensive review, see (Desjardins et al., 2015)). The deployment of smart technology in real-life contexts has contributed to a better understanding of the challenges, but also of appropriate ways of conducting such research in the home (Tolmie and Crabtree, 2008; Coughlan et al., 2013; Mitchell et al., 2015). Much of this work is underpinned by the notion that *home* is a complex and dynamic concept, whose material, cultural and social aspects have been widely discussed in the literature (Després, 1991; Marcus, 2006; Moore, 2000; Sixsmith, 1986). The home is also a place of negotiation, resistance, and oppression, which means it has a pivotal role in discussions about gender inequality (Bowlby et al., 1997; Pilkey et al., 2017). Putnam and Newton (1990) noted that there are recurring themes to research about the home, which are privacy, security, family, intimacy, comfort, and control. Although we touch on some of these themes, the primary focus of this paper is on privacy and control in the context of health and the introduction of new technologies in the home. In order to ground our subsequent discussion, we first discuss the concept of home and how it relates to these key themes.

Heidegger's (1971) writings about place and dwelling have inspired an interest from humanistic geographers and architects in the concept of *home* (Relph, 1976; Tuan, 1977; Seamon, 1979; Buttimer, 1980). Together, these authors sought to understand how people experience place and, in doing so, began to expose the

health-promoting characteristics of home. Tuan observed the importance of home as a place of recovery in times of illness and its association with nurturing experiences (Tuan, 1977). Similarly, Seamon viewed home as a place of regeneration and argued that the sense of at-easeness fostered by being at home is crucial in times of sickness (Seamon, 1979). This paved the way for the exploration of home as a therapeutic landscape for patients and family caregivers (Williams, 2002). Patients and family caregivers often favour home rather than institutional care, even if this has a disruptive effect on the experience of being at home because of the priority that healthcare takes at such times (Angus et al., 2005; Gale and Sultan, 2013) and the intrusion of healthcare technologies (Moore et al., 2010; Milligan et al., 2011; Gale and Sultan, 2013). It is worth then noting that households comprise one or more people whose attributes may differ substantially (Burrows et al., 2015), if designers are to respond to calls to develop technologies that support meaningful interactions and outcomes (Greenhalgh et al., 2013).

Studies of how technology can support individuals to monitor and manage their health conditions at home have identified a number of specific challenges, which include the acceptance of the technology (Grönvall and Kyng, 2013), the installation and effective use of the technology (Grönvall and Kyng, 2013), the integration of the technology within the physical environment (Axelrod et al., 2009) and within domestic life (Ballegaard et al., 2008). Yet people are not passive in the face of such disruptions and they engage in highly complex 'boundary work', in response to the need to create order when managing health conditions and making use of healthcare technologies at home (Aarhus and Ballegaard, 2010). Aarhus and Ballegaard propose that strategies employed to achieve this can be conceptualised on a visibility-invisibility continuum and on an integration-segmentation continuum, with positions on these continua susceptible to change over time. Other research has since reported similar findings of patients engaging in impression management (Benjamin et al., 2012; O'Kane et al., 2015), which has been interpreted through Goffman's theory about how people present themselves in everyday life (Goffman, 1959). Goffman's work is underpinned by a theatre metaphor where people are actors on various social stages, who deliver performances *front-stage* to control other people's impression of themselves and convey an appropriate or idealised version of the self. Alternatively, people can interact with others *off-stage* without performing but still managing the impression they give, or simply be themselves *backstage*.

Goffman's work lends itself to understanding privacy, which has been conceptualised as a dynamic and dialectic interpersonal boundary regulation process (Altman, 1975). This regulatory process was predicated on conscious interactions with a known audience and this has been fundamentally transformed by the emergence of technologies that are capable of remotely permeating bodily and territorial privacy (Langheinrich, 2009). This change is equally true for home-based healthcare technologies, with research showing the potential of assisted living technologies to change the porosity of the boundaries between the home and the extitution, as well as between private and public spaces (Milligan et al., 2011). One way to better understand this is to draw on the notion of personal border crossings described by Marx (2001), who proposed the following four border types: *natural borders* are those that impose restrictions on the senses, such as behaviours, physical barriers, and sealed or directed communications; *social borders* are assumed or expected from particular roles such as family members and doctors; *spatial* or *temporal borders* concern the compartmentalisation of information from different periods or domains of life; and *ephemeral* or *transitory borders* are based on the premise that by-products of interactions or communications should not be in any way preserved or interpreted. Increasingly, interactions with technology are creating lasting traces that are widely available to be searched and interpreted beyond the context in which they originated. The concept of privacy has therefore evolved in the digital

age to include contextual integrity (Nissenbaum, 2010), which advocates the flow of personal information should be contextually appropriate.

A suitable understanding of context remains a pitfall of smart systems (Yang and Newman, 2013). The processes that currently exists to infer human activity from sensor data are akin to common-sense reasoning and arguably produce informed guesses at best (Fischer et al., 2016; Tolmie et al., 2016). In addition to the challenges inherent to such uncertainty, particularly in a healthcare scenario, the threat posed to people's sense of privacy is evident. Borrowing Goffman's (1959) metaphor, living in a smart home could be a relentless front-stage performance to convey a desired impression to anyone accessing the data. There is of course considerable public interest in responsible exploitation of data, including those generated by emerging smart home technologies, to advance knowledge about various health conditions and deliver timely services (Nuffield Council on Bioethics, 2015). What is missing are mechanisms to allow people to reason about their data to produce situated accounts that are occasioned, mutually constructed between all stakeholders, socially intelligible, and morally accountable (Tolmie et al., 2016). One way to think about these mechanisms is through the construct of *boundary objects*, defined as "objects which both inhabit several intersecting social worlds and satisfy the informational requirements of each of them" ((Star, 1989) cited in (Star and Griesemer, 1989)). Their adaptable yet robust nature (Star and Griesemer, 1989) means boundary objects can bridge gaps between social worlds as well as create boundaries that may be threatened by smart home technologies. Thinking with boundary objects thus provides a broader ecological way to view the smart technology infrastructure and, for this, it is important that the detail of life within the home is first understood. Despite the significant role of boundary objects in technology adoption, there is a dearth of research seeking to understand how they work and relate to human agency (Fox, 2011). Considering these challenges and the rapidly evolving field of smart home technology, this study sought to explore people's relationship with their homes with a view to understanding how people currently manage their health and technologies to maintain the *feeling of home*.

2. Methodology

This ethnographic study was conducted within the larger SPHERE project, a five-year interdisciplinary research collaboration funded primarily by the UK Engineering and Physical Sciences Resarch Council (EPSRC) with the aim of developing a smart home platform of non-medical networked sensors to address a range of healthcare needs. The ethnographic study aimed to explore people's technology and healthcare related behaviours in context. This study received research ethics approval from the University of Bristol Engineering Faculty Research Ethics Committee. Each participant provided their written, informed consent to participation and were asked to re-confirm willingness to proceed as the study progressed, with written and oral consent.

2.1. Setting and sample

Data collection took place between July 2014 and January 2015 in a large city in the south of the UK. Potential participants were identified at public engagement activities and through project community partners, and were asked if they were willing to be contacted about the study. Those who agreed provided their names and contact details. We used purposive sampling to include households with prior experience of telecare and households that had previously used home sensing technologies that monitored energy usage but not health, in addition to households with no reported experience of telecare or smart home technologies. We approached residents of 24 households who agreed to contact and, of these, residents of 15 households