<table>
<thead>
<tr>
<th><strong>Title</strong></th>
<th>Privacy, boundaries and smart homes for health: An ethnographic study</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Authors(s)</strong></td>
<td>Burrows, Alison; Coyle, David; Gooberman-Hill, Rachael</td>
</tr>
<tr>
<td><strong>Publication date</strong></td>
<td>2018-03</td>
</tr>
<tr>
<td><strong>Publication information</strong></td>
<td>Health &amp; Place, 50 : 112-118</td>
</tr>
<tr>
<td><strong>Publisher</strong></td>
<td>Elsevier</td>
</tr>
<tr>
<td><strong>Item record/more information</strong></td>
<td><a href="http://hdl.handle.net/10197/9714">http://hdl.handle.net/10197/9714</a></td>
</tr>
<tr>
<td><strong>Publisher's version (DOI)</strong></td>
<td>10.1016/j.healthplace.2018.01.006</td>
</tr>
</tbody>
</table>
Privacy, boundaries and smart homes for health: An ethnographic study

Alison Burrows\textsuperscript{a,b}, David Coyle\textsuperscript{b}, Rachael Gooberman-Hill\textsuperscript{c}

\textsuperscript{a} SPHERE-IRC, University of Bristol, UK
\textsuperscript{b} School of Computer Science, University College Dublin, Ireland
\textsuperscript{c} School of Clinical Sciences, University of Bristol, UK

\textbf{A R T I C L E  I N F O}

\textbf{Keywords:}
Smart home
Ethnography
Privacy
Boundary work
Borders

\textbf{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.

\section{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, 2006; 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 Research 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 reconfirm 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
agreed to take part. Whenever possible, all residents in each household were invited to participate. The sample comprised a socially diverse group of 19 people. These were 8 men and 11 women, with ages ranging from 19 to 77 (median age: 51). The sample included people who reported living with no long-term health conditions as well as people who had one or more long-term health conditions. More details are provided in the Findings section, in Table 1 and 2.

2.2. Data collection

Data were collected by AB, who used a variety of qualitative methods. Data were collected in participants' homes, through interviews, technology tours and cultural probes.

2.2.1. Interviews

Semi-structured interviews were conducted to explore issues pertaining to the home, technology, and health, as well as the interrelationships between these three areas. For instance, participants were asked if their or another resident’s health conditions had precipitated changes to their home and, if so, how this had affected their feelings towards their home. The researcher encouraged participants to talk about experiences that were meaningful to them. All 19 participants were interviewed, over one or more home visits. These interviews were audio-recorded and subsequently transcribed.

2.2.2. Technology tour

Participants were asked to give the researcher a tour of their home, to show and discuss the technology present in each room. The Technology Tour is a technique that aims to elicit real life examples of people's experiences of domestic technology (Baillie and Benyon, 2001). This walking tour of the home also enabled the researcher to observe how people had integrated technology into their homes and into their daily lives. These tours took place after the first interview, either during the same visit or during a subsequent visit. They were audio-recorded and later transcribed; some photographs were taken by the researcher, when appropriate and when participants had given prior written consent for this.

2.2.3. Cultural probe

After the initial interviews and technology tour, participants were invited to use cultural probes to self-document aspects of their health and technology use in daily life. Cultural Probes are a technique pioneered by Gaver et al. (1999), which we adapted for the purpose of this study and to explore themes emerging from the ethnographic interviews. The cultural probes that we offered our participants contained a body map, a diary activity, and photo elicitation prompts along with a digital camera. Responses to the cultural probes varied and 10 participants returned completed elements of the packs. The researcher conducted a follow-up interview with these participants, to discuss the materials produced.

2.2.4. Field notes

The researcher wrote down her observations during and immediately after each visit. These field notes focused on recording information beyond what was captured in the audio-recordings, including but not limited to descriptions of the domestic environment, the types of technology shown, and participants' behaviours. These notes were used to interpret the tone and meaning of transcribed conversations.

2.3. Data analysis

Data sets for each participant consisted of multiple data sources in various formats, including interview transcripts, completed or part completed maps and diagrams, photos taken by the participants or by the researcher with participants' consent, and field notes. Data were anonymised by AB and the principles and procedures of thematic analysis (Braun and Clarke, 2006) were used to analyse these data as a whole. AB and RGH independently read, re-read and coded five interview transcripts. Both these lists of codes were compared and a consensus about the coding frame was reached by the team. The rest of the data set was then coded according to this frame, which was refined as data collection and analysis progressed. Once coded, data were grouped into higher-order themes. In this article, we present the findings that relate to home, borders and boundary work, with a particular focus on experiences of healthcare and technology in this context. All names are pseudonyms.

3. Findings

Of the 15 households that took part, 4 households had experience of telecare systems including wrist-worn alarms (2 cases), pendant alarms (1 case), pull-cord alarms (4 cases), motion and door sensors in the home (1 case) and in the common areas of their residential unit (2 cases); all these devices were linked to a base unit connected to a telephone line in participants’ homes. Four other households had experience of smart energy systems, which monitored domestic energy consumption but not health; these systems included gas and electricity smart meters, plugs to monitor energy consumption of up to five appliances, and a touch screen tablet to view energy and gas usage. The remaining seven households reported no previous experience of dedicated healthcare technologies or smart home technologies. Table 1 lists the different types of household, including their experience of technology, their occupancy and housing status.

<table>
<thead>
<tr>
<th>Table 1 Summary of households.</th>
<th>House occupancy</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Living alone (1 occupant)</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>Living with partner (2 occupants)</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>Living with child (2 occupants)</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Living with housemate (2 occupants)</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Living with partner and children (3 or more occupants)</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Experience of technology</td>
<td>Number</td>
<td>Housing status</td>
</tr>
<tr>
<td>Experience of telecare</td>
<td>4</td>
<td>Own house or flat</td>
</tr>
<tr>
<td>Experience of home sensors</td>
<td>4</td>
<td>Privately rented</td>
</tr>
<tr>
<td>Other</td>
<td>7</td>
<td>Local authority</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Sheltered housing (with resident warden)</td>
</tr>
</tbody>
</table>

Regarding housing status, 6 of the properties were owned by the residents, 2 were privately rented, 5 were local authority housing, and 2 were flats (apartments) in sheltered housing with an on-site warden. Almost universally (18 out of 19 responses), the participants felt that where they lived was ‘home’. This feeling was created by social factors (e.g. family, friends, a support system), the area where they lived (e.g. schools, shops), and physical factors (e.g. warmth, their belongings, the look of the home). The participant who felt that his current residence (a flat in sheltered accommodation) was not his home had lived there for three years, having had to move for financial reasons after his wife died. He attributed this feeling to being on his own and not having a local support system.

In terms of health conditions, this sample ranged from participants who reported living with no long-term health conditions to participants who reported living with several long-term health conditions (see Table 2).
Table 2
Summary of reported health conditions and impairments.

<table>
<thead>
<tr>
<th>Health conditions/impairments</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>No long-term health conditions/impairments</td>
<td>7</td>
</tr>
<tr>
<td>Single long-term health condition/impairments</td>
<td>6</td>
</tr>
<tr>
<td>Multiple long-term health conditions/impairments</td>
<td>6</td>
</tr>
<tr>
<td>Chronic pain</td>
<td>5</td>
</tr>
<tr>
<td>Heart disease</td>
<td>2</td>
</tr>
<tr>
<td>High blood pressure</td>
<td>2</td>
</tr>
<tr>
<td>Learning disabilities</td>
<td>2</td>
</tr>
<tr>
<td>Neurological conditions (stroke, severe migraines)</td>
<td>2</td>
</tr>
<tr>
<td>Arthritis</td>
<td>1</td>
</tr>
<tr>
<td>Asthma</td>
<td>1</td>
</tr>
<tr>
<td>Cancer</td>
<td>1</td>
</tr>
<tr>
<td>Hearing impairment</td>
<td>1</td>
</tr>
<tr>
<td>Mental health problems</td>
<td>1</td>
</tr>
</tbody>
</table>

3.1. Outside, inside and letting people in

Although the telecare and energy monitoring systems in use at the time were limited to indoor use, the walking tours showed that participants did not view the natural borders of the home as so clearly delineated. Gardens and similar outdoor areas were frequently shown and discussed, because they represented prime areas for socialising, leisure, and physical activity (e.g. gardening, tai chi).

The researcher noted on her visits she was essentially crossing the natural borders of participants’ homes, which sometimes prompted them to clean or tidy up in preparation for her visit, or to segment the home tour across visits. In this way, participants could to some extent control what behaviours were visible to the researcher. This control was sometimes mediated through existing home technologies. Below, one participant describes how she and her husband had programmed their home phone to show who is calling and thus they regulated which calls they decided to take:

Margaret: This phone has on it – because we’ve put on it – the information about who is phoning in, and we’ve set it so that it tells us. When it says ‘international number,’ we know not to answer it. And when it says ‘callers withheld,’ we tend [not to answer it].

Similarly, one participant living in sheltered housing described his experience of having an on-site warden who did regular rounds to check on residents’ wellbeing, knocking on the door before each visit. This participant suggested it could be advantageous to incorporate this kind of forewarning mechanism in smart home healthcare technologies, because it would enable residents to override the system if for some reason they felt it was inappropriate.

3.2. Establishing and crossing borders within the home

Most households with multiple residents had spaces that were usually busy with various people going about routine activities, including work and leisure. Participants described strategies they used to construct and negotiate the borders necessary to allowing shared use of these spaces, such as taking turns and agreeing on daily or weekly schedules. In some situations, people’s homes afforded them the possibility to establish new borders to accommodate individual daily routines or interests:

Lloyd: This is Rose’s room, I found a few years ago that our sleep patterns were diverging, I tend to wonder around in the middle of the night and Rose doesn’t.

Rose: So he likes the radio on and the light on and…

Lloyd: Yeah, so we separated for sleeping purposes so this is Rose’s room.

Rose: As you can see, I use it as an office and a work room and all sorts of stuff, yeah.

Participants who had previous experience of energy monitoring sensors shared some examples of how these systems could cross several personal borders to make known the activities of other residents. The following excerpt illustrates one way in which the technology invaded natural borders (e.g. by making evident behaviour that happened within the home), social borders (e.g. by making evident behaviours that would otherwise have an expectation of privacy from other household members), spatial or temporal borders (e.g. by making evident behaviours that happened in the past), and ephemeral or transitory borders (e.g. by permitting other residents to make inferences about behaviour from the data):

Claire: We have [energy monitoring] sensors in my daughter’s room, on the TV and I think it was her hair straighteners. I have nothing in mine because, as you can see, I’ve got no technology in my room. We had one put on the washing machine, one on the dishwasher, the fridge – no, they didn’t do the fridge – washing machine, dishwasher, TV, her TV because we were […] watching who watched most TV. We were having a competition amongst ourselves, seeing whether she watched the most or I watched the most.

Interviewer: And what did you find?

Claire: Her cheating. [laughter]

Interviewer: How did she cheat?

Claire: Whenever I was at work and there was a school holiday or she wasn’t in school, she was watching my TV. And in the evenings she wouldn’t watch hers; she’d come down here and watch mine. So she was cheating. So we did find her fiddling the scores.

Other such participants described how visualising their household data had allowed them to know when other residents were at home, and to speculate about what activities they were doing. In contrast, a few participants described how the ability of technology to cross the natural borders of the home could be beneficial. They described how their long-term health conditions in combination with changes in their social circles had led them to feel isolated. In some instances, these participants sought to use available technology to counter these feelings. One resident of an older persons’ unit recalled that on Christmas day he set up Skype on multiple devices in the building’s common room, so the residents could get together over lunch and contact their family and friends across the world, thus virtually sharing their celebrations.

3.3. Boundary work and a sense of agency

In households where at least one resident was living with long-term health conditions, the home was a primary site of care. Sometimes the management of health conditions could precipitate major changes to the home and how it was used. The following excerpt, where a participant described her father’s living arrangements in the family home after he had multiple strokes, illustrates the importance of being able to engage in boundary work to manage healthcare at home:

Kim: You know, he’s on a catheter. He lives in the living room and that’s his space, and he has to share that with everyone else as we come in and out. You suddenly lose control over a lot of things, so I think it’s good to have control over […] anything that you have and you can have control over.

The physical properties of healthcare and assistive devices was an obvious factor that influenced people to engage in boundary work. There were instances of participants rendering such devices invisible or not using them, because of perceived stigmatisation associated with
them. In the following quote, a participant describes how she preferred using her own kitchen stool rather than a stool provided by her occupational therapy team, which she felt was inappropriate for her and her home:

Laura: I've got some bath seats and a grab rail in the bathroom, and I had to have rails put on both sides going up the stairs. [...] They did send a big white horrible looking stool thing to sit on in the kitchen and it was hideous! I sent it back. I can sit on my stool and I can do the cooking, so I don't have to stand up for too long.

Interviewer: Was it a special stool in any way?

Laura: Yeah, it was for elderly people. It was something that you'd find in a hospital. It was so big and clumpy, it was probably more dangerous having to pick it up and carrying it around than the one I've got out there. So that's why I sent it back. Someone else can use it rather than it being stuck in my cupboard or something.

Participants also conducted boundary work in terms of technology in general, with some people describing and demonstrating self-imposed boundaries within their homes. Several participants mentioned that their bedrooms were “no technology zones” because those spaces were intended for relaxation only, for example:

Claire: [Here's] my room. There is no technology apart from a phone charger in here, as I find my room is where I come to relax and not do technology.

Interviewer: Do you think that each room has a different identity?

Claire: For me, yes. For me, when I go to bed I read and I wind down. It's not for making my brain active; it's for me to wind down.

Some technology boundaries were more fixed and mostly delineated by the physical constraints of the technology, particularly large non-mobile technologies such as desktop computers. Even in these instances, participants had a number of strategies that permitted people to negotiate the visibility and integration of the technology within the home, such as keeping computers in cabinets that could be opened or closed depending on whether it was in use or not.

3.4. Reasoning about experiences and sharing information

All participants thought that privacy was essential, but privacy meant different things to different people. Whereas for some it meant that only they would have full access and control over what happened with the data, others saw access to the data as being more flexible. One participant who used telecare reflected on how the flow of health-related information might follow a needs-based access model, which shows how borders might become more fluid for smart home health-care technologies:

Jerry: [...] I think it's got to be in stages: generally, to your own Doctor and, as you go the next stage up if there's something wrong with you, you then go and see a specialist; at that point, the specialist asks if he can access your data. [...] Rather than it being generally open to everybody, it's then [accessed] up the chain. And as the chain drops off and you recover from whatever it is, that chain is then dropped back down to level of your GP or District Nurses looking after you. [...] Nobody is going to moan if you call out the [emergency] team and your case information has gone to A&E, they're not going to worry about that. But as soon as A&E has finished with you and when you've gone to the ward, [...] the system is funnelled back to being back to your local GP.

There were also participants who thought that certain types of information could benefit the wider community, particularly when looking beyond the individual and household levels. These participants reported being willing to share high-level and anonymised data, provided they perceived it as making a societal contribution to improving service provision and wellbeing:

Fred: From a smart home perspective, I think the thing about this project which is most interesting to me is when I'm in here, if I turn off my browser then I pretty much feel like this is my space. I'm not being monitored or read or whatever, so that's quite a nice feeling. What happens in this flat is exclusively for me only, so I think that's a positive thing. [...] I don't think it should be shared, no, but then if it's going to help with certain information...again, it's all about what's being shared, you know. I think that average data should be shared, because then you can leverage power supply – the local power company can leverage what power it needs to supply to certain areas like which parts of the city are more efficient than others; who's moving more or less? And that's beneficial, so I think that should definitely play a part.

People's reported openness to sharing data varied according to their individual circumstances and views about the reasons why data might be shared. For example, participants living with long-term health conditions were more willing to consider sharing their data with researchers and practitioners if doing so would improve understanding of health conditions. For participants who lived alone and who wanted to be kept safe, sharing data was one way that they thought their safety might be enhanced. Conversely, those people who lived with a partner did not see such a need to share data because they felt they kept each other safe. People who were more familiar with smart technologies were also generally more favourable to sharing data. There was evidence that the growing ubiquity of certain technology could lead to acceptance, without a considered evaluation of personal benefits and risks. Below is an excerpt of a conversation with a participant who had previously had energy monitoring sensors in her home, as well as participated in various research and media projects:

Interviewer: In terms of when you have [your grandson] here, do you have any concerns about having the sensor technology with small children?

Sally: No, because he knows not to touch things.

Interviewer: I was thinking more in terms of privacy.

Sally: No, it wouldn't bother me.

Interviewer: Really?

Sally: No, because he's used to being filmed. He's used to being interviewed for people [laughs].

It mattered what type of data would be shared, who would be the recipients of the data, and for what purposes they wanted access to the data. Some participants reflected on their previous experiences of using self-monitoring healthcare technologies or speculated about the possibility of seeing their own health data, which was not seen as necessarily favourable. In these instances, access to such personal fine-grained data could trigger anxiety about their health status or overall wellbeing. It was apparent that participants were unclear about the concept of data and the implications of using data. In the following quotation, one participant reflects on how his experience of having home energy monitoring sensors conceptually felt different from having person-based sensors:

Dave: Well, the difference is it is monitoring not you, it's monitoring what's going on around you. It's monitoring the stuff, it's not monitoring you. And you are talking about monitoring a person, it's personal and that's the difference. And it doesn't matter how open you are with anyone.

On the surface, it seems reasonable to assume that there is a distinction between data that pertains to the individual and data that pertains to the home. However, as demonstrated earlier, much can be
inferred from environmental data to reveal human presence and activity.

4. Discussion

By exploring how technology and health affect people’s relationship with their home, this study highlights its dynamic nature as a place where people are empowered to control aspects of privacy by negotiating existing borders and boundaries. Some participants’ attempts to manage the impression they gave the researcher on her initial visits showed that front-stage performance (Goffman, 1959) does occur within the home, in this instance precipitated by an unfamiliar person crossing the natural borders (Marx, 2001) of the home. Goffman’s theory on the presentation of self is also useful to understand why healthcare or assistive devices were sometimes subjected to boundary work as described by Aarhus and Ballegaard (2010), given that such devices could be perceived as crossing social and spatial borders (Marx, 2001). We gathered several other examples of how one or more borders of the home could be crossed by interactions with technologies. This was sometimes intentional and even desired. Other times it triggered activity.

As described by Aarhus and Ballegaard (2010), given that such technology on the presentation of self is also useful to understand why healthcare or assistive devices were sometimes subjected to boundary work, the concept of boundary objects (Star and Griesemer, 1989) is best employed within studies that explore the broader ecological context of technologies, we found it to be apt to understand the role of technology features that facilitated negotiation of borders, but also the behaviours agreed among household members such as schedules or excluding the technology altogether from certain spaces. However, through analysis of people’s experiences of energy monitoring sensors, we began to uncover ways in which the current absence of appropriate boundary objects in smart home technologies has the potential to blur the boundaries between private and public in ways that can be unexpected.

Our findings echo previous research that has called for mechanisms that allow people to reason about their smart home data (Tolmie et al., 2016). Drawing on notions of borders (Marx, 2001) and privacy as contextual integrity (Nissenbaum, 2010), we argue that such mechanisms should meet the criteria of plasticity and robustness inherent to boundary objects (Star and Griesemer, 1989). Smart home data are likewise boundary objects given that they permeate various social worlds, within the home as well as other healthcare and institutional contexts. Our study showed that there is much work to be done even at this level, as people had diverse understanding about ‘data’ and this impacted on their views of sharing data. It was evident that the participants were more accepting of high-level data being used for a perceived greater good, whereas using more fine-grained data was more controversial even if the benefit could be more personal. If smart home healthcare technologies are perceived to be in any way threatening to the status quo of the people they aim to support, there is a risk that such technologies will be rejected. However, we found evidence that the gradual creep of technology into everyday life can lead to its passive acceptance. The challenge then becomes how to empower people to understand and reason about emerging forms of data, so they may harness relevant healthcare benefits while simultaneously continuing to engage in essential border and boundary work.

We argue that, by applying the boundary object lens to smart home data and associated management mechanisms, those data could become subject to the boundary work that happens in other healthcare domains (Aarhus and Ballegaard, 2010). Data could therefore exist on the visibility-invisibility and integration-segmentation continua, moving along them according to individual contexts over time. Supporting people to have such ownership and control over their data could become a much-needed ongoing consent measure, which would contribute to mitigating potential misuse of those data. Appropriation, which has been framed as controlling the home as well as the passage of people in and out of the home (Seamon, 1979), could extend to the data level in ways that are meaningful to the residents of the envisaged smart homes of the future. In HCI, appropriation is defined as the process by which people adopt and adapt artefacts either through customisation or by using them for new purposes (Dourish, 2003). It has gained considerable interest in studies about home healthcare technologies (Storni, 2010), alongside related concepts such as personalisation (Balaam et al., 2011; Lee et al., 2015) and bricolage (Greenhalgh et al., 2013). We suggest that further research is necessary on how to encourage data appropriation in smart home healthcare systems, which should draw on the broader literature on strategies to encourage user appropriation (MacLean et al., 1990; Henderson and Kyng, 1992; Robinson, 1993; Moran, 2002; Dix, 2007).

The use of a variety of data collection methods proved beneficial, as it allowed participants to express themselves in their own time and in ways that were meaningful to them. Through the technology tour and the cultural probes, participants were able to show examples of their technology and healthcare practices in the home context. A semi-structured approach to the interviews allowed the researcher to investigate pertinent issues consistently across participants, but also provided the opportunity to explore unanticipated issues that emerged during the study. The combination of these methods together with the regular home visits by the researcher fostered a closer researcher-participant relationship, which encouraged the disclosure of personal and sometimes sensitive experiences. One of the strengths of this study was the inductive nature of our approach, in which the importance of privacy to participants and the strategies they used to create privacy at home emerged naturally from the data. To ensure analytic rigour, a team of experienced qualitative researchers double coded the data and agreed on the final list of themes. We argue that our rigorous approach contributed to credible findings, which are likely to resonate with other research on smart homes and healthcare, and are worthy of further work. One avenue for future work is to broaden the research scope to other actors beyond the domestic end users, such as relatives, clinicians, and technicians, who usually come into play as part of smart home and healthcare infrastructures. This would allow a deeper exploration of how different social worlds intersect when such infrastructures are implemented, which would permit a broader ecological analysis in keeping with the construct of boundary objects.

In conclusion, our study has uncovered a need for mechanisms that allow people to interact more directly with data that will be collected and collated in smart homes in the not-so-distant future. Those mechanisms should allow people to control the interpretation and flow of their household data not only to overcome current limitations of smart technology, but also to support people to continue engaging in the border and boundary work that is integral to life at home. We argue that such mechanisms could foster ownership and interest in one’s own data and, consequently, play an important role in ongoing consent to use such data.

References


