Making Family Care Work: Dependence, Privacy and Remote Home Monitoring Telecare Systems

John Vines¹, Stephen Lindsay⁴, Gary W. Pritchard², Mabel Lie³, David Greathead¹*, Patrick Olivier¹ and Katie Brittain²

Culture Lab,
School of Computing Science¹ / Inst. of Health & Society² / Inst. of Cellular Medicine³,
Newcastle University, UK
{john.vines; gary.pritchard; patrick.olivier; katie.brittain}@ncl.ac.uk

⁴Future Interactions Technology Lab,
Computer Science,
Swansea University,
Swansea, UK
s.c.lindsay@swansea.ac.uk

ABSTRACT
Supporting independent living for the ageing population in later life is an often-cited application area for ubiquitous computing. Telecare services such as remote monitoring systems are now coming onto the consumer market but there is little knowledge of the impact these technologies may have on relationships between family members and older relatives. We present findings from a live field trial of SHel—a telecare system that allows nominated caregivers to remotely monitor activities—in 17 older adult’s homes. Interviews were conducted with the 17 older participants and 11 of their nominated caregivers before, during and after using the system. We establish that such technologies transform existing hidden care routines between family members into care work, and the impact they have upon the sense of independence and privacy of those who are being monitored in their home.

Author Keywords
Ageing in place; home sensing; privacy; trust; older people.

ACM Classification Keywords
H.5.m [Information interfaces and presentation (e.g., HCI)]: Miscellaneous;

General Terms
Design, Human Factors.

INTRODUCTION
It is widely recognized that the World’s population is now ageing at an unprecedented rate [35]. There have been concerted efforts by governments to identify the impact this change on population structure might have on the provision of health and social care [33]. This is often driven by concerns that increases in the number of older citizens will place strain on already pressurized health and social care services [33]. As a means of offsetting this pressure, there has been a focus in recent years to support the independent living of people in their homes for longer rather than entering residential care facilities. Most of this work fits under the banner of ‘telecare’—technologies that support the remote care of people who wish to live as independently as possible in their own homes.

In this paper we examine an area of growing interest in the domain of telecare—technologies that support informal care practices between older people living in their own homes and their relatives and friends. Our research took place in the United Kingdom (UK) where informal care provided by family and friends is considered to be central to the future sustainability of care for older people [11]. These views are reflected in the UK Government’s care policy [11] and found in many other economically developed nations (such as the United States [4]). Furthermore, along with many countries where care has been traditionally provided by the state, the UK is transitioning towards consumer care products and services privately sought by older people or those that care for them. As a consequence, consumer care technologies such as wearable fall detectors [25] and remote monitoring technologies [22] are likely to become more common features of informal care practices between older people and their family members.

Prior work has explored the role of reporting sensor activity from older peoples homes into the homes of informal caregivers [10,27,26]. A barrier to the acceptance of such technologies has been the perception of privacy invasion [7] and concerns about reducing in-person contact with caregivers and family members [15]. We build upon this prior work by describing the findings from field trials of SHel (Safe Home Living), a pre-release commercial remote activity monitoring system to help relatives and friends check on older family members movements in their homes in a non-invasive (i.e., minimal impact upon the home

Permission to make digital or hard copies of all or part of this work for personal or classroom use is granted without fee provided that copies are not made or distributed for profit or commercial advantage and that copies bear this notice and the full citation on the first page. Copyrights for components of this work owned by others than ACM must be honored. Abstracting with credit is permitted. To copy otherwise, or republish, to post on servers or to redistribute to lists, requires prior specific permission and/or a fee. Request permissions from Permissions@acm.org.

UbiComp '13, September 08 - 12 2013, Zurich, Switzerland
Copyright 2013 ACM 978-1-4503-1770-2/13/09…$15.00.
http://dx.doi.org/10.1145/2493432.2493469

*Author undertook this work at Newcastle University and is now affiliated with the Defence Science and Technology Laboratory, UK.
The last 15 years has seen a wealth of research within HCI future policy on ageing for many countries [14]. Therefore there has been social care costs being one of the main driving factors for economic benefits, with claimed reductions in health and significant motivator for ageing in place, however, are the moving to residential facilities [12]. Perhaps a more homes for longer and the subsequent health benefits over preferences among older people for staying in their own [12]. Typically, arguments in favour of ageing in place cite entering residential care for as long as possible in later life [12]. Perhaps a more significant motivator for ageing in place, however, are the economic benefits, with claimed reductions in health and social care costs being one of the main driving factors for its uptake in the UK [16]. Therefore there has been significant investment in telehealth and telecare to support people living longer in their own homes in the UK [30], and such technologies are important features of current and future policy on ageing for many countries [14].

The last 15 years has seen a wealth of research within HCI and ubiquitous computing examining how technology can support independent living in the home into later life. Mynatt et al. [20] identified three key problem areas for HCI and ubiquitous computing to research to support ageing in place: i) recognizing crisis (immediate emergencies, such as someone falling in the home or predicting that the hot water boiler is about to breakdown in winter), ii) supporting everyday cognition (helping people to remember to do certain tasks and to help when tasks are interrupted), and iii) providing awareness of daily activities (monitoring people in their homes remotely and alerting carers and relatives of emergencies or times of need). HCI and ubiquitous computing research has mostly followed this lead, with examples including: monitoring for trips and falls [21]; reminder systems for medication compliance [18]; augmented environments to prompt everyday activities such as making hot drinks [23]; and sensing activity in older people’s homes so they can be remotely monitored by care teams [28], concerned relatives [27] or informal carers living in the community [10].

Our contribution to the ubiquitous computing field is a rich qualitative account of the experiences older adults and their caregivers have from living with remote monitoring technologies. Our findings address three key issues. First, we highlight how such technologies can impact upon the perceived burden of caregiving work for both groups and the sense of independence and vulnerability of those monitored. Second, we affirm and extend findings from recent studies of in home telecare systems [7,15,28] noting how older adults value opportunities to view what data is collected about their activities and granting them greater control in determining what caregivers can see. Third, while some older adults felt their privacy was being invaded, a more encompassing concern was caregivers failing to monitor at all. We conclude the paper with a set of design considerations for future systems like SHel that address these issues.

AGEING IN PLACE, FAMILY & REMOTE MONITORING
Ageing in place refers to living within one’s own community—with some level of independence—rather than entering residential care for as long as possible in later life [12]. Typically, arguments in favour of ageing in place cite preferences among older people for staying in their own homes for longer and the subsequent health benefits over moving to residential facilities [12]. Perhaps a more significant motivator for ageing in place, however, are the economic benefits, with claimed reductions in health and social care costs being one of the main driving factors for its uptake in the UK [16].

The SHEL SYSTEM
We conducted a study of a pre-release commercial pervasive monitoring system—SHel. The system was developed to be low cost and self-installed in an older person’s home by family members or other caregivers, for whom it aims to provide reassurance that their older relatives are managing to live independently within their own homes. The system is comprised of five wireless, small low-power passive infrared (PIR) sensors that connect to a central hub using the ZigBee protocol. The hub is a larger mains powered unit, which transmits data to a server via GPRS. The sensors are located at specific points of activity in the home such as food preparation, bathroom usage, relaxation, sleeping, and entering and leaving the house. Typically these correlate to rooms (such as the bedroom, bathroom, kitchen, living room and main entrance) with the intention of detecting significant activities such as getting
up in the morning, going to the toilet or preparing meals based upon the time of activation and time between entering and exiting. The sensors also measure light levels and temperature so the caregiver can tell if their relative is in a dark or cold room.

SHel is intended to be a “less than emergency” monitoring technology. This distinguishes it from most commercial telecare systems that focus on raising alarms to carers or family members in emergency situations (e.g. [28]) or provide ambient displays of activity into caregivers homes [15,20]. Instead, family members have to explicitly log into a secure web portal to view the activity logged by the system and the data recorded by the light and temperature sensors. This portal could be accessed via any standard web browser on a personal computer or mobile device. This rationale for this design decision was two-fold. First, there was a need to offset concerns about the semi-public presentation of such data in another person’s home (as noted in [7]). Second, a web-portal would provide greater access to busy caregivers who were in full-time employment, offering opportunities to access data while away from their home. Therefore, the envisaged use-case for SHel was that it would offer reassurance to family members who are concerned about their older relatives but not to the extent that warrants automated alerts about potential emergency situations.

**STUDY DESIGN**

In order to explore the experiences surrounding the installation and use of remote home monitoring telecare systems, we performed a qualitative study based upon a live field trial of SHel. In the following we describe the participants and the approach chosen to undertake data collection and analysis.

**Participants**

Our study involved recruiting 21 older adults between the ages of 66 and 91 (female n=16, male n=5) to have the SHel system installed in their homes. These participants lived in a variety of accommodation that included private residences in urban, suburban and rural areas, rented social housing and sheltered accommodation. Taken together, the study gathered views from a range of older people, including a small number who did not have children to act as caregivers in the trial. Older adults are the most diverse of any age-defined demographic and recruitment managed to reflect this diversity with respect to health, education, working lives, age, background and mobility. 4 older participants had to leave the trial due to ill health, meaning only 17 completed the trial in its entirety. As only results from those who completed the trial are presented, the majority of participants could be described as ‘active’ older adults. All of the older adult participants lived alone.

While we were primarily interested in the experiences of the people whose homes the technology was installed in, we also wished to seek the views of the adult children or other nominated caregivers of our participants. This was important as the family members and carers of older adults are as much the intended purchasers and users of SHel as the older adults themselves. Therefore we asked the older participants to nominate caregivers to also participate in the trial. In total, caregivers for 11 of our older participants agreed to participate in interviews during the trial. The remaining 6 older participants had the system installed and their caregivers were provided with details on how to access the web portal—however, none of these caregivers agreed to take part in interviews during the study. The 11 caregivers who participated comprised of daughters (n=7), sons (n=2), a brother (n=1) and a close friend (n=1). They all took part in interviews and used SHel to remotely monitor their relative or friend’s activities via the online portal.

The geographical distance between the older adults and their nominated caregivers differed greatly from a 5-minute drive to living over 2 hours away. These factors influenced the existing communication practices between the older adults and their relatives or caregivers. Many of those who lived close to one-another would be in frequent face-to-face contact. A number of the adult children explained how they were in regular phone contact with their parent as they had concerns over their parent’s health and well-being. This contrasted with those who lived further away who explained how their contact was much less frequent—one son had not seen his mother for 4 months and spoke to her once a month on the telephone.

**Data collection and analysis**

In order to get a deeper understanding of the perceptions of the technology and the potential impact such systems may have on informal care practices between family members our approach to data collection was qualitative. Interviews were carried out two weeks before SHel was installed in the participants’ homes (pre-int.), at the time of installation (install-int.), and at the time of system removal (exit-int.). By distributing interviews over time we hoped to explore how perceptions prior to installation changed during and after use of SHel. The period of time during which SHel was installed varied between 4 and 6 weeks. Interviews used a semi-structured format with the topic guide suggesting discussion of personal background, sense of security and privacy, impressions of the system before and after installation, and thoughts about its functionality. All the interviews were recorded with the consent of participants, transcribed and checked for errors. A thematic analysis [5] was performed on the transcribed data. Textual data was summarised with open codes, which were grouped together to form themes that described the key issues emerging from the data. These are described below, with pseudonyms used in place of participant names.

**FINDINGS**

Over the course of the field-trial use of the system differed drastically among caregivers. Typical usage by caregivers was approximately 2 logins a week during the trial. One caregiver logged into the web portal an average of 5 times a week. Another did not use it at all, citing that they
unexpectedly went on holiday during the trial. In most cases however the older participants were unaware of the amount of login activity by caregivers, and therefore did not demonstrably impact on insights from these interviews.

In the remainder of the paper we focus on findings from the thematic analysis of the qualitative data, which highlighted 7 themes: motivations for using SHel; existing routines as a barrier; balancing privacy, control and risk; security of technology and caregivers; knowing who was doing the watching; vulnerability and independence; and presence and absence.

**Motivations for using SHel**

The installation and pre-trial interviews provided a means for participants to discuss their motivations for having such technology installed in their homes or for wanting to monitor their friend or relative. Some family members explicitly stated that they had concerns about the vulnerability of their elder relatives:

> “With her being on her own you just don’t know what could happen. I worry about the fact that if you haven’t rang her that day or none of us have rang her that day, could she be lying there.” (Betty’s daughter, pre-int.)

Concerns such as those addressed above appeared to be more apparent where there was greater distance between members of a dyad. A number of the caregivers not only spoke of a worry over the older participant’s health but also of their inability to act quickly in response to problems. Mary’s daughter explained her worries about her mother:

> “She’s been on her own a lot of years and I worry about her on a night time … she’s in the house on her own … it’s a big house and you know she fell last year and fractured her wrist and em, it took me twenty minutes to get there.” (Mary’s daughter, pre-int.)

In almost all instances the perceived vulnerability of older relatives was driven by concerns over them living alone and an inability to respond fast enough should there be an emergency. In some cases, concerns were escalated further by the older participants’ desires to stay in their own home rather than move into residential or warden controlled facilities. Gerry’s son described how the health problems his father faced were somewhat magnified by his desire to stay in the home he had lived in for the last 40 years:

> “He lives in an upstairs flat and I’m frightened that he’s going to at some stage possibly fall down the stairs or something or get trapped behind the front door and he’s not able to let me know.” (Gerry’s son, pre-int.)

Gerry’s son highlights the key concerns that influenced positive initial responses from caregivers towards SHel. It was less immediately clear what benefits the older participants felt would be gained from having the system in their home. Most of the participants considered themselves of excellent health and leading active lifestyles. In the initial interviews however it became clear that some participants were beginning to have concerns about their activity levels declining, and these motivated them to take part in the study. One previously very active participant reflected on changes to her health:

> “I was feeling very fragile and fed up […] I thought I’ll have a nice hot bath, get into bed and see if I could have a good sleep and so I thought right, what if I don’t get out of the bath? So I took the key out of the front door […] I left the bathroom door open. […] and I thought well I could always phone one of my neighbors or my daughter.” (Flo, pre-int.)

Flo envisaged that SHel would help avoid having to take all of these actions—albeit only if the system did not “worry them unnecessarily”. Another participant suggested that the system “would make me feel more secure”. These examples were unusual however. In most cases the primary benefit the older participants saw in having the system installed would be to placate the worries their family members might have about their health and wellbeing:

> “I think both of them [his son and daughter] probably would [use SHel] if they couldn’t get hold of me, they’d say funny he didn’t say he was going anywhere. […] that was my biggest worry when my wife died.” (Reg, install-int.)

Although the older adults saw their children and relatives as the primary beneficiaries of the system, this was also considered as having subsequent personal benefits. Some felt it would relieve them of having to tell their children what they had “been up to” during routine phone calls, or allow them to leave the home without necessarily having to inform their caregiver beforehand.

**Existing routines as a barrier to using SHel**

The majority of caregivers had existing routines for checking on their relative or friend. A number of the older adult participants explained how their family members or friends would be in frequent contact with them: “She’ll ring me and if I’m not all right she’ll… she’ll come down […] if she’s worried she’ll ring us, and if I don’t answer she’ll come” (Agatha, pre-int.). These phone calls and visits would typically be framed as social events where the caregiver would enquire about how the older participant’s day had been, what they had done, who they had seen.

It was clear that for those caregivers that had regular contact with their relative that their use of SHel would be impacted upon: “If I’m seeing him three nights a week which I do er Saturday, Sunday and Wednesday. I must impact I’ll not feel the necessity to log on, like the other nights of the week.” (Iris’s son, pre-int.). Other caregivers cited concerns over the amount of effort that might be needed to regularly check in on their relative or friend. After using the system for 4 weeks, Carole’s daughter’s initial enthusiasm had waned: “you need someone who is able to log on off and on throughout the day I suppose which is really something at the moment I can’t do you
know” (Carole’s daughter, exit-int.). Some of the older participants felt that their relative would simply not have the time to check up on them due to their busy lives: “I don’t like to interfere in my family’s life, [...] they have enough to do without looking after me.” (Agatha, pre-int.).

Balancing privacy, control and risk
Considering the wealth of prior work highlighting the privacy concerns older people have about being monitored [1,7,28] it was no surprise this was an issue in our study. In many cases privacy concerns were related to specific activities and rooms in the home:

“She’ll know when I’m in the bathroom […] she’s not looking at me in the bathroom is she? It’s just a light tells her that’s where I am, that would be the only place that I would be very self conscious about.” (Thora, pre-int.)

As was also evident in prior work on privacy and monitoring in the home [9,24], activity in and around the bathroom was referred to by a number of the participants as an area of the home they were particularly concerned about being monitored. On some occasions—as above—this concern was about their children being able to literally “see” what they are doing in the bathroom. This often came from misconceptions that the system was recording video—concerns that dissipated once the system was fully explained to participants. For others, their feelings against the system strengthened as they lived with it. Mary was not deeply concerned with the technology at the start of the study but was very critical by the trial’s end:

“I resented that it showed when I went to the bathroom. I really resented that, I thought I don’t want people to know. I mean I don’t get up in the night to go to the toilet, [...] I resented that if my daughter had got up, she could say mum went to the toilet twice last night, you know...I found it very intrusive.” (Mary, exit-int.)

During the course of the exit interview it became clearer why Mary found the technology so unsettling. She had a close relationship with her daughter, but the information she shared was very much on her terms:

“She rings up every morning and I’ll say, I did so and so ... she said, what did you do last night ... I said, well ... I did some ironing and then I said I had my meal and I watched the television for a while and then I said I read and then I went to bed [...] but I don’t have to tell her if I don’t want to.” (Mary, exit-int)

Robert raised similar concerns. He explained how there are aspects of his life he would not share with his daughter:

“I occasionally do stay overnight [at a friend’s] [...] it just crops up and I’ll say right I’m off and I certainly wouldn’t ring [daughter] to let her know that I was going ... it’s none of her business.” (Robert, install-int.)

In both Robert’s and Mary’s cases, there was a sense that this new technology could not afford the level of control they desired over who and when people could “watch” their activities. In Robert’s case, this may be remedied by being able to “sign out” of the system or turn it off. Mary would have preferred to not have it installed at all.

Others made trade-offs between privacy, control and perceived risk in favour of being monitored. Sarah explained: “[The bathroom is] where I’ve gone zonk [passed out] [...] the tablets didn’t agree with me” (Sarah, install-int). Both Sarah and her daughter found solace in SHel as it provided a means to watch for such events in the future. Sarah explained that she felt it:

“was very, very helpful to think that my daughter was in [Town], which is a good hour’s drive away isn’t it, and she could tell which room I was in and if I was in a room too long it would trigger – she would ring up anyway to see ‘what are you doing in there so long’ if it was the bathroom say” (Sarah, exit-int.).

For some participants concerns about being monitored in sensitive locations dissipated as they became familiar with SHel. Agatha was concerned that activity in and out of the bathroom would automatically lead to her daughter thinking she was always visiting the toilet: “I don’t want people knowing if I’m on the toilet” (Agatha, pre-int.). Having been monitored for 4 weeks Agatha changed her opinion:

“In the beginning I thought, I don’t like the idea I want to be in the bathroom like, and then I thought well what can they see? Nothing. They just know I’m there. Don’t you? And I just dismissed it like that, and that was it. I never thought about it anymore.” (Agatha, exit-int.)

It was clear Agatha valued the fact that the only information collected was an entry and exit from the bathroom. This supports the prior studies that note it is not necessarily the room but the perceived activity being inferred that is a privacy concern [28].

Security of technology and caregivers
There were more general concerns about being “watched” around the home by others. These concerns were focused around who was doing the monitoring. Some participants questioned who could have access to the information about their activity around their home. Some of these concerns were about criminals and hackers gaining access to the information viewable via the online portal:

“[This is] good for burglars and people like that isn’t it knowing when you’re out and all this sort of thing you know they, electronically there is all sorts of ways of tapping into things aren’t there.” (Gerry, install-int.)

This insight on Gerry’s part is not unrealistic—indeed, simple airwave snooping techniques might reveal information about the presence or not of someone in the home [8]. It is well known that older people in the UK have a high fear of crime—a fear that is often out of proportion with actual risk [3]—and therefore this focus on vulnerability to crime is not unexpected. Despite explanations of how access to the system was secured,
many of the older participants were deeply concerned about who could access and monitor their movements. One participant felt “anyone can steal that [password]” and “she [her daughter] wrote it down and just left it by her computer”, meaning anybody in the house could get access if they wished (Carole, install-int.). This concern was not necessarily unreasonable and at the time of the study there had been several high profile cases of data being lost or stolen from companies or public organisations.

Knowing who was doing the watching
While there were privacy related concerns about who could view their information, more surprising were concerns about periods where nobody was watching their activity. As noted earlier, some participants questioned how frequently their family members checked on their movements. 12 of the older participants had personal alarm pendants—albeit many had not used them nor felt happy wearing them—which via the press of a button call an emergency call centre to get help. These participants generally expressed a preference for this model of professional support rather than relying on their own family members:

“I think it’s very unwise to rely on just a family member being responsible for it, I think if the information goes into a central place […] somebody professionally should have hold of that information and I would say then it’s it would be their job to alert somebody” (Janet, exit-int.)

Views such as that of Janet’s were made by a number of participants (“I think it would be better if it was independent of a family member really” Mary, exit-int.). Another also felt that it was problematic to only have the one point of contact to get help from as her son and his family went away on holiday for a period during the study:

“That would be a good idea [if] you could contact somebody else you know I mean like, like now one of my sons is away he’s away for three weeks well there would be nobody to contact me then” (Daisy, exit-int.)

Most participants were very happy with their nominated caregivers monitoring their whereabouts in the home: “I am not bothered [if] they want to look at them and study them they can” (Gerry, install-int.). During exit interviews potential changes to SHel were discussed and this included the addition of access for multiple caregivers. When discussing who else could have access in the family, some participants were very hesitant to suggest alternatives. Many were highly reluctant for their in-laws to have access, knowing who was doing the watching who should not be able to monitor them:

Across the range of views it was readily apparent that many of the participants had become concerned about an increasing sense of their own vulnerability. SHel played a role in both making participants aware of their vulnerabilities and being supportive of perceived vulnerabilities. The latter emerged on occasions when participants reflected on experiences of others:

“I just feel very vulnerable I mean I’ve just heard another friend of mine she went out last week shopping and come in and found her husband dead on the floor” (Betty, exit-int.)

This very recent experience had a great impact on Betty and unsurprisingly it dominated the exit interview. It led her to reflect upon the moment she realised her husband had died suddenly in his sleep:

“He was in bed and he died in his sleep … I think you know if I was in bed and like dying and I mean I mightn’t be found until the next morning, till the next day sort of thing.” (Betty, exit-int.)

These experiences influenced Betty’s views on the value of SHel. At the start of the study she suggested she’d not be the “target” for such a system. She was, after all, very active still for her age and had a close network of friends she frequently socialised with. However, she went on to explain: “I think I possibly do feel a bit safer when it’s in because you know if anything happened in that month [it was installed], I would be found.” (Betty, exit-int.).

A number of the participants referred to SHel as analogous with other telecare devices such as emergency alarms and fall detectors. The older participants explained how these devices were often given to them by their “worried” offspring. Rarely were these technologies referred to in a positive manner. Mary felt such devices “take away your perception of independence”. Others felt they were of potential value but depended on personal circumstances at a particular moment in time. For example, Agatha disclosed how she had a wrist alarm device but rarely wore it:

“I don’t want something hanging round me arm, and I don’t want something on me wrist that people can see. Em, “what’s that on your wrist?” And I have to explain to everybody what it is, I don’t want that. […] I’m a bit independent like that, I don’t like people to think I can’t manage.” (Agatha, pre-int.)

She described how SHel was “better” as it was “not very obvious” and not something he had to wear all the time. She explained: “if I was poorly this system is more appropriate” (Agatha, exit-int.). Agatha’s story of not wanting to wear what she saw as a ‘medical’ device was repeated by many of the participants. Janet explained how she had an incident while out of the house once and: “the first thing my son says was did you have your pendant on Mam […] I just feel I’m not old enough yet (laughs)” (Janet, pre-int.). Janet went on to explain that her son felt she was particularly vulnerable but her perception of her

Vulnerability and independence
The exit interviews yielded a wide-range of views on the perceived value of the technology by the older participants.
self was different. It was a recurring theme that technologies such as fall alarms and SHel were seen to be designed to appease the concerns of children and doctors rather than those who had them in their home or wore them around their necks.

One of the main concerns was not necessarily the usefulness of the technology but rather its wider implications on the notion of care and independence. Although some of the motivating factors behind SHel are that it should enable ageing-in-place and, as such, independent living for longer and later into life, this was not always how the participants interpreted it. Mary stated she felt “it [was] just one step down from making you dependent on somebody”. She continued:

“Knowing there’s somebody watching you go from room to room is absolutely no happiness to you ... I mean seeing somebody come in and saying, it’s a lovely morning and I’ll make you a cup of coffee ... I’d rather have that” (Mary, exit-int.)

For Mary, being watched and followed as she moves around the home was as much an affront to her independence as it was an enabler. Worse, she felt such technologies would make people more socially isolated and less likely to have visits from friends, family or carers, or have fewer phone calls with her daughter. Although she does have frequent contact with her family who “keep an eye on” her, this was “different from keeping an eye on us all the way around the house” (Mary, exit-int.).

Finally, having experienced the system for several weeks some of the participants raised questions as to how the technology would be funded and who would provide it in the long term. As noted, the UK health and social service provision is going through radical changes and it is becoming more common for care and medical services to be provided by private companies. A number of the older participants were concerned about this and aware that they were becoming a common target for companies selling new health-related gadgets and services: “I think they are preying on vulnerable people and that’s what would concern me.” (Betty, exit-int.)

Presence and absence

Those participants who saw greater value in SHel often described how it made them feel “safer” during the period it was installed in their home. However, they would still explain how for the most part they forgot the technology was in their home at all: “after a couple of days they [the sensors] didn’t bother me you know.” (Betty, exit-int.); and: “Tell you the truth I mean I forget it’s there.” (Carole, exit-int.). Some participants felt the general lack of presence the technology had in their home was problematic. None of the sensors had any visual or audible alerts that signalled when they were activated or not, which confused some of the participants during the study: “... if you go into all the other rooms you don’t know whether it’s registering or not because you go into the bedroom” (Thora, exit-int.). Some participants suggested that all the sensors should have had a visual indicator that flashed when activated, like the ‘activity’ LED on the main hub:

“I think it’s quite reassuring to know that it’s working […] I think it should be visible at some point […] when I walked in the kitchen and walked past the fridge I could see out of the corner of my eye this thing [the main hub] go like that [flashing] I wasn’t aware of that in any of the other rooms but when I went in the kitchen it reassured me that it was still working” (Janet, exit-int.)

Another participant was surprised that nobody called during the period of the study to let them know “everything is fine” with the system: “I wasn’t terribly sure whether they were working or not.” (Sarah, exit-int.). In the exit interviews some participants revealed concerns about the presence and absence of not just the physical attributes of the technology in the home, but of their relatives checking them from afar. Many realised that the system was relatively useless without a motivated other to regularly check their activities.

DISCUSSION: CARE WORK AND INDEPENDENCE

Our field-trial of SHel highlighted a number of barriers to the acceptance of remote home monitoring telecare systems by this sample of older people, their caregivers and family members. Although many of the older people who completed the field trial were in good health, they were representative of the older people whose family or caregivers would purchase these “less than emergency”. Indeed, we noted how many family members had well-established routines to check up on their older relatives on a regular basis. Prior to the deployment of SHel these routines were explained to be a crucial part of their familial relationship. As noted, the considered questioning by the caregiver was entwined in phone conversations about what the older adult had been up to that day and what their plans for the rest of the week were. This questioning was rarely explicitly framed as related to health and capability—and indeed it was clear the older participants were offended on occasions when they were.

Our findings contrast with recent studies of reciprocal telecare systems [15], suggesting that home monitoring technologies can replace the need for these social requests for information and inadvertently caused care work. SHel became the gatekeeper to the information and therefore created streams of work for caregivers to complete. The result of these new work streams was at first doubt towards the technology by both carer and cared for. This soon changed to frustration from carers as extra work would have to be carried out to find out information that perhaps could be elicited directly from older relatives. While prior work has highlighted how telecare system might promote more social interaction between family members, SHel was perceived to reduce opportunities to engage in conversation or socialise with family members and therefore broke social
contracts between the older parent’s, their adult children, brothers, sisters or close friends.

We also observed a number of instances where the use of SHel was cited as impacting upon an individual’s independence both positively and negatively. Those that cited this negatively emphasised that the system impacted on their agency to do what they liked when they liked without a sense of being observed by their caregiver. Contrasting with these were those that felt they were not being watched enough by relatives, stating preferences for professional services to watch over them instead. Regardless of the perspective, SHel certainly altered participants’ sense of being independent.

Literature on monitoring systems has noted how their acceptance often depends upon one’s perception of their own vulnerability. For example, Melander-Wilkman et al. [19] found that older assistive technology users placed mobility and safety ahead of privacy. Similarly, Beach et al. [1] identified how those with more complex health conditions were more likely to share private information with carers and family. Our study identified similar traits among our participants—those who stated a sense of vulnerability in regards to their health felt more comfortable with SHel. In our participants’ cases however there was no apparent reason for this feeling—they were, after all, healthy and active for their age. As in Betty’s case the need to have someone to depend upon came not from personal narrative but rather the narratives of friends and the stories of others. SHel supported these narratives and indeed lead to Betty accepting the system.

Birnholtz and Jones-Round [2] address a paradox between the idea of technology supporting ageing in place and the potential side-effects of telecare systems. They argued that technologies to support care at a distance reduce potential side-effects of telecare systems. They argued that cited this negatively emphasised that the system impacted on their agency to do what they liked when they liked without a sense of being observed by their caregiver. Contrasting with these were those that felt they were not being watched enough by relatives, stating preferences for professional services to watch over them instead. Regardless of the perspective, SHel certainly altered participants’ sense of being independent.

Our study confirms findings from prior work [7,28] that has noted how the acceptance of remote home monitoring technologies by current older cohorts is dependent upon their understanding of the data being collected and how this is presented to others. Our first requirement therefore is that future systems should present the data that is collected as well as show the individual that is being monitored how this data is displayed to others.

We noted that a number of the older participants had initial misunderstandings of the type of information sensed by SHel. The lack of precise feedback on the data being collected by the system also meant many were concerned that the system was simply not operating correctly. While prior work (e.g. [10,27]) has emphasised the role of presenting visualisations remotely to carers and family members it occurs to us that it is of equal importance to have such visualisations in the homes of those being monitored. SHel would have benefitted from a simple feedback mechanism that made it clear what information was being collected and displayed what was seen by the caregiver when logging into the web-portal. Examples of such a feedback mechanisms already exist in the telecare domain—for example the “DigiSwitch” [7] allows those being monitored to view the information being collected and displayed to others. The primary use-case for the DigiSwitch was to support older people in maintaining their privacy—however, we would like to emphasise further the potential visual feedback provides to building trust in the system itself. Alongside providing individuals with a greater sense of exactly what can be seen by outsiders this also would have provided reassurance that the system is operating correctly, and enable them to raise questions about the information being represented and its accuracy.

A critical design consideration here is the physical form that this presentation is packaged in. While the participants appreciated explicit feedback on the sensors that they were operating correctly, they also greatly valued the lack of physical presence of SHel in the home. There is a theme across the telecare domain to integrate visualisations into objects such as photoframes that can switch to images of family (e.g. [7,27]). Our findings suggest instead that such screens should be concealable in some way but easily accessible when needed—for example, inside a false book or jewellery box that can be stored within the home.

2) Control over how activity is presented to others
We also noted how many older participants had concerns over the level of detail being presented in the visualisations seen by caregivers. Essentially they wished to have greater control over how their activity is presented to others.

Issues to do with providing older people more control over the information displayed to remotely monitoring caregivers has been noted in prior work [7,28]. The aforementioned DigiSwitch [7] provided older adults greater control by incorporating functions to stop and start the sending of information from specific sensors around the home. Such a feature would have befitted SHel. Taking this idea further however it appears that the participants were not only concerned with the type of data being sensed (i.e., was it video footage, was it movement data) but also with the level of detail their carers could see. This includes the
length of time information is available to view (i.e., only in real-time, for the last hour, for all time), the unit size of the information that is presented (i.e., in minutes, days, weeks) and being able to configure specific sensors to only work at specific times of the day.

This level of configurability is important due to huge heterogeneity across older adults and the changes to caregiving needs that occur over time. At the same time, introducing an interface allowing this level of configurability could introduce more issues in terms of usability than it solves. We suggest therefore that the PIR sensor could be fitted with simple physical switches and dials affording simple manipulations of the above variables.

3) Feedback on the frequency of being monitored
A surprising finding was participants were concerned their relatives might not be monitoring them enough. Therefore, we consider providing feedback on how often and how long an individual is being monitored for is a key criteria for future telecare systems.

This could, for example, present how long it has been since the last time the caregiver logged in, or length of time they have been logged into the web portal over a defined period. Based upon the experiences of our participants, we would expect this would provide reassurance that their relatives are using the system. Crucially, design requirements 1 and 2 should also be taken into account here for the caregiver, enabling them to restrict the fidelity of the information displayed to their older relative or friend.

4) Reassuring caregivers via explicit interactions
Our fourth design consideration is to provide opportunities for explicit reassurance rather than relying primarily on non-invasive sensing. The need for explicit reassurance comes from the notion that ageing in place and being independent meant far more than just moving competently around your home. Most of the participants privileged their active social lives, and indeed on some occasions they wished to keep this out of sight from their caregivers. Wiles et al. [34] highlight how the experience of ageing in place is a complex process where the notion of the ‘home’ is in continual negotiation and extends to include wider social relations and the community of people and organizations that surround them. Ageing in place involves keeping existing social ties in tact and exploring new opportunities for socialisation [34] as was alluded to in Robert’s story.

In this case it might be inappropriate to report periods of inactivity because someone has gone out “without permission”. The capability to sign off SHel or conceal certain periods with ‘false’ activity (as suggested by [7]) would have been preferable for some of our participants. But it occurs to us that what would have been preferable in a number of cases was no passive monitoring at all and instead providing mechanisms for older individuals to disclose information that reassures the caregiver. This may be as simple as an aesthetically sensitive pendant or watch-based device that at the press of a button sends an SMS as a means to say ‘I am well’ or ‘I am having my dinner’ in ways that gives little contextual information but still support peace of mind.

5) Limiting access to data to nominated devices
Finally, both caregivers and the older adult participants related concerns about the means of accessing activity data. Older participants raised concerns about people beyond those nominated seeing the data—such as son-in-laws, co-workers of their caregiver, or grandchildren. Many were aware that monitoring was performed on computers shared by the family or from work—and in some cases did not trust family to be secure with their passwords. At the same time, for caregivers the requirement to access the online portal via a personal computer and web browser was time consuming and limited their opportunities for engagement.

A way of resolving these issues would be to limit access to the activity data to personal mobile devices of caregivers rather than shared systems. This provides opportunities to tie content more tightly to the nominated caregiver(s), while also lessening opportunities for others to accidently log on and see this information. This may also present opportunities for more spontaneous checking of activity by caregivers or push notifications of certain types of activity. Indeed, a number of consumer systems coming onto the market in 2013 include the latter functionality (e.g. [22]).

CONCLUSION
Our field-study was undertaken with a limited sample of older adults living in the North East of the UK. Future work should expand upon our study to explore the perceptions of more diverse groups of older adults, caregivers and cultural perspectives. The field trials lasted between 4 to 6 weeks and therefore use and familiarity with the system was still relatively novel at the time exit interviews were performed. However, our trials still revealed a number of key concerns and opportunities for remote home monitoring telecare systems, a category of ubicomp technology that is becoming common as a consumer product to support independent living and ageing in place. Our qualitative study suggested that, rather than supporting informal care practices, such technologies can lead to new less-social streams of care work. Such technologies also fail to acknowledge how the experience of ageing well in place extends beyond functional activity within the home and the potential impact such systems may have on the perception of ones independence. This is not to be overtly negative however, as the system was valued by many participants. We highlighted a number of considerations for the design of future telecare similar to SHel, with the aim of supporting more appropriate, sensitive and acceptable applications in the future.

ACKNOWLEDGMENTS
This research was performed as part of TSB funded project ‘SHel’ and partly supported by the TSB ALIP 3 and 4 project ‘SALT’. We thank Rob Comber and Selina Sutton for their comments and reading through drafts of this paper.
REFERENCES


7. Caine, K. et al. DigiSwitch: A device to allow older adults to monitor and direct the collection and transmission of health information collected at home. *J. of Medical Systems, 35* (5), 1181-1195.


12. FamilyLink http://www.familylink.net/


17. Magnusson, L. and Hanson, E. Ethical issues arising from a research, technology and development project to support frail Older People and their Family Carers at Home. *Housing and Social Care in the Community, 11*, 431-439.


