

The Shifting Sands of Labour: Changes in Shared Care Work with a Smart Home Health System

Ewan Soubutts

University of Bristol, Bristol, UK, e.soubutts@bristol.ac.uk

Elaine Czech

University of Bristol, Bristol, UK, elaine.czech@bristol.ac.uk

Amid Ayobi

University College London, London, UK, a.ayobi@ucl.ac.uk

Rachel Eardley

University of Bristol, Bristol, UK, r.eardley@bristol.ac.uk

Kirsten Cater

University of Bristol, Bristol, UK, kirsten.cater@bristol.ac.uk

Aisling Ann O’Kane

University of Bristol, Bristol, UK, a.okane@bristol.ac.uk

Whilst the use of smart home systems has shown promise in recent years supporting older people’s activities at home, there is more evidence needed to understand how these systems impact the type and the amount of shared care in the home. It is important to understand care recipients and caregivers’ labour is changed with the introduction of a smart home system to efficiently and effectively support an increasingly aging population with technology. Five older households (8 participants) were interviewed before, immediately after and three months after receiving a Smart Home Health System (SHHS). We provide an identification and documentation of critical incidents and barriers that increased inter-household care work and prevented the SHHS from being successfully accepted within homes. Findings are framed within the growing body of work on smart homes for health and care, and we provide implications for designing future systems for shared home care needs.

CCS CONCEPTS • **Human-centered computing** ~ **Collaborative and social computing** ~ Empirical studies in collaborative and social computing

Additional Keywords and Phrases: Smart homes, shared care, health, labour, work

ACM Reference Format:

First Author’s Name, Initials, and Last Name, Second Author’s Name, Initials, and Last Name, and Third Author’s Name, Initials, and Last Name. 2018. The Title of the Paper: ACM Conference Proceedings Manuscript Submission Template: This is the subtitle

of the paper, this document both explains and embodies the submission format for authors using Word. In Woodstock '18: ACM Symposium on Neural Gaze Detection, June 03–05, 2018, Woodstock, NY. ACM, New York, NY, USA, 10 pages. NOTE: This block will be automatically generated when manuscripts are processed after acceptance.

1 INTRODUCTION

The proportion of older adults in the UK who are aging into older adulthood has increased exponentially in the past decade [103]. Supporting aging in place is cited by the World Health Organisation as a staple for providing increased support to the growing proportion of the world's population who are living for longer into older age [100]. As older people are living longer, the requirement for a higher level of care has increased in proportion to this [47,70]. However, the ability to live independently with a high quality of life mostly considers an individual's physical wellbeing and expected years of life remaining unburdened by disease, and does not typically consider their social support networks [60]. For those who live alone and have fewer close social connections, formal care (where a person pays for the time of another to care for them), is often the only option available [29]. However, informal care (where a person is cared for by a friend, family member or other close relation) is the most common type of care provided for older adults in the UK [70].

These informal caregivers (who are often younger and of working age), must make sacrifices from their own lives and livelihoods, cutting into their working and personal time to provide care, usually for an older relative [47]. This also carries the emotional burden of being called upon at almost any time to provide for the person they are caring for [29]. For those caring for older adults, such as an informal caregiver, the burden of caring is often unpaid. For the year 2020/21, the UK's Family Resources Survey, commissioned by the UK government estimated that 4.2 million people (around 6% of the population) were providing informal care for another, of which around 10% are of working age and disproportionately 1.5 times more likely to be from a black or minority ethnic community [18].

Providing informal care together in a home requires collaborative effort [78], time, commitment, and cost [74], which can potentially be supported through technology. The smart home healthcare research domain has looked at aging and the impact that technologies have on older and vulnerable adults [10,113] as they age in place (living "independently, and comfortably, regardless of age, income, or ability level" (p.642) [92]). However, smart home technology is mostly designed with a single individual user in mind, and not how the people around them will make use of or appropriate those devices in the home [17,111,115]. Whilst in recent years, studies within HCI have dealt with concepts such as the household care network [112] and multi-resident home [89] additional consideration is still needed for how laborious care work is accomplished with the addition of smart home technology and how this changes the way caregiving work is enacted.

This exploratory study [8] provides accounts of older adults with pre-existing chronic health conditions and their informal care networks' interactions with a smart home health system, comprised of a variety of devices that were selected by people within five separate households. We focus this exploratory research on the wider household beyond the individual for which the SHHS is setup for to explore how each home is impacted and ultimately abandons the SHHS. We contribute an empirical account of the different types of technical work and care work and how it is impacted by the introduction of a SHHS. This paper makes a novel contribution to the smart home literature through 1) identification of changes in labour enacted *within the shared household* (we use the term 'shared household' in this paper to describe people living together as well as the 'wider household' who regularly visit [48,91]) caused by the introduction of the SHHS, as well as 2) identifying novel labour types arising

from interaction with this system, such as emotional labour. We then provide implications for reducing labour cost in the shared smart home and supporting imbalances in caregiving arising from the use of this system.

2 RELATED WORK

In this section, we explore work that informed our methodological approach and research direction. We firstly discuss shared care that takes place in the smart home and lastly different types of labour that is done in the home, drawing on interdisciplinary health and care research.

2.1 Smart Home Technology and Shared Caregiving

Care is the focus of this paper's work and it is necessary to explore previous work on caregiving for older adults. HCI research within the smart home domain has conducted numerous studies with older adults to try and understand technology use patterns and how well these devices are accepted. Caregiving that takes place with others often describes a range of tasks (clinical and non-clinical) that are enacted in order to look after the older person's wellbeing. Studies such as Karlsen et al.'s describe how family caregivers often provide a range of support, from reminding older relatives to wear their telecare pendants [53], to updating their calendars [25], organising Dossette box medication [75] and general assistance with activities of daily living (ADLs) such as washing and bathing [32].

The collaborative use of smart home technology has made great waves within HCI in recent years as studies address how quality of life in the home for an older person should not be dependent on simply the use of a single technology by a single older adult, but in fact requires a network of care actors in order to support its ongoing use and acceptance within the home. Zallio et al. makes the case for those living together to share technology that will benefit the longevity of an older adult at home [115]. Others have developed frameworks for how families can modify and adapt IoT devices and everyday technology to better suit their homes [109], whilst some work has dealt with how individuals reason with and make sense of their smart home data to inform their own self-care activities [59]. Beyond the immediacy of the 'live-in' household structure, other studies have explored how neighbours, co-dwellers and 'live-out' visitors all interact with those living with smart home technology and how this either positively or negatively impacts the dynamics of households' social structures [2,28]. For shared care, considering or 're-imagining' how the home can be structured considering the relationships between people and people, but also people and things; and how often IoT objects can possess a social quality that augments care, even if these smart devices are not social actors in themselves [55,91].

2.2 Humanistic Approaches to The Smart Home

HCI research has taken a more socio-technical approach to the smart home, focusing on the impact of smart home systems and individual smart home devices (e.g. sensors) on users' everyday lives. Many recent studies have explored issues such as the privacy implications of using smart home devices in the shared space of the home [51], whereas others have looked at power relations around these devices and the impact of security when multiple residents are involved in sharing devices [37]. There has also, more recently been a turn to a more humanistic approach (which focuses on the person, or technology owner, before considering the devices used [27]). Humanistic research focuses on, for example, the relationships between people dwelling in their home and the data they own,

and how they access and interact with it [26]. Futurism and speculative design has also become a popular space to understand the smart home through embodiment [56] as well as embracing the nature of the unknown in the home through exploring human feelings towards the 'spookiness' of 'black boxes' of data within smart home technologies [33]. However, it is care that has also become a locus for exploration within HCI research here. Care research has provided greater understanding of how technology can somewhat support activities of daily living (ADLs) by those who live alone [16], how care communities use smart technology and come to understand it [14] where care relationships are built and how technology can change the dynamics of these relationships (making them more difficult or simpler) when smart devices are introduced [55]. This change in household dynamics as a result of the introduction of smart home technology is what drives the exploratory investigation in this paper that considers shared care within wider households.

2.3 Caregiving in the Diversified (Smart) Home

Having established that smart technology affects the social dynamics of care within shared homes, it is important to discuss that smart home research has also moved beyond looking at traditional family structures inside of homes (e.g. two parents and two children) and instead looked at diverse family dynamics including inter-generational renters [114], co-habitators [87] and communities (culturally diverse and queer inhabitants [81,86]). Others too have looked at shared use of technology in collaborative settings beyond the 'home' such as care homes and how this has impacted the way ADLs are conducted together [39].

For older adults with long-term chronic conditions, care work is enacted through smart home sensor devices that track disease progression, aiding prevention, and how those in care and their caregivers reason with data and use it within wider health communities (people with Parkinson's) [66]. Dementia research within the smart home is exploring the wellbeing of older adults living with dementia and their spouses using empathic, tangible objects (devices that play familiar and personal sounds input by loved ones) [46]. However, others such as Harrington et al. make explicit how intervention-based research (using novel technologies that support an older person) are becoming more common in HCI research [42]. This research acknowledges that interventions, while valuable, often neglect the wider impact of being well connected and supported by care networks, without which, this can negatively impact treatment and health outcomes [43].

Stigma related to health and aging is often a large barrier to the adoption of new devices [72] to help older people age in place successfully, as smart home technology design does not always prevent stigma [15]. Devices (such as pendant alarms, wheeled walkers, stairlifts [91]), when used by an individual older adult, or even when suggested that they are used by a caregiver [89], bring about resentment and abandonment and are not always replaceable by 'smarter' alternatives. Therefore, as Light et al. suggest, technology that is "often ugly or stigmatising" [p. 3], should be reformed to consider unique ways of living (individualised and shared): one-size-fits-all approaches to smart home technology design are increasingly inappropriate for peoples' diverse and complex lifestyles as they enter older age [63].

2.4 Understanding Types of Work and Labour around Care

We also acknowledge prior research on labour and the different types of work that come about in order to provide care. The types of labour we discuss here are interdisciplinary and extend beyond HCI research into the interdisciplinary health and care domain and clinical literature. It is also important to distinguish both labour and work here. Whereas care **work** describes physical or mental actions done in order to enact a positive goal in support

of someone, care **labour** describes the effect of caregiving on individuals, groups (e.g. households) or wider society [52,54] through the act of performing laborious or intensive work. There are several different types of work described within the HCI health and care literature and beyond, for which we cover a few here:

The first, *self-care work*, is well-established within HCI research [71]. Within many health communities, such as the Parkinson's community, ethnographic accounts of technologies to understand self-care practises and how these intersect with the lives of other caregivers have been studied [105]. The counterpart to managing self-care at home has been the introduction of self-tracking technologies (such as using apps on smart phones, journaling etc.). Studies of self-tracking technologies have shown that they can be used to mindfully (and reflectively) record and monitor disease and symptom progression (for people living with MS [6]), as well as with older adults to positively impact their quality of life through encouraging physical activity [104].

Time-based work in the home is also discussed within a healthcare context. McCoy [65] describes how people's circadian rhythm can quickly become regulated to "clock time" (the 24-hour cycle), due to the need for strict adherence to medications at specific times of the day, and that through digital reminders and prompts, people can more strictly adhere to new medication schedules. After a while, Huyard et al. describes how this time-based 'work' becomes internalised so that effort decreases and it becomes a routine [50].

Boundary and articulation work (and creating physical separation) in the home supports older adults' wellbeing through not constantly needing to be in view of their own medicalised devices (p. 10) [94], for instance through hiding them in drawers or physically concealing with clothing them if they must remain attached to a person [73]. Aside from creating physical separation within a person's home between themselves and their technology, articulation work is also social work that deals with the process of actualising caregiving tasks in the home (understanding what needs to be done to perform care and doing it), for example an informal carer setting up and providing medication for an older adult they care for on a daily basis [98].

Body work and restoration work are types of caregiving work discussed within HCI and in the clinical literature. The former, body work, deals with the embodied nature of caregiving and how, whilst the embodied nature of care work mostly focusses on personal care (grooming, bathing etc.) and other ADLs, there is often a need for more personalised, embodied support that can involve physically demanding and technically challenging caregiving such as fitting and monitoring the use of oxygen tubes for a person or turning on and tuning in the television [32]. Care is a physically demanding practice that is disproportionately enacted by women within the UK [22] [p. 216]. As such, the demands on women to perform care are often great, adding further to the labour that is experienced. This labour can be cumulative and without training or suitable technology to support caregiving, giving care can take both physical and psychological tolls on women's health in particular [22,93,108]. Conversely, the emotional labour and closeness of performing such embodied work around the person being cared for, is noted to have strengthened the social status of the carer in the caree's home, such that rigid social boundaries are lessened and former strangers are often considered akin to close family members [102].

Restoration work, whilst also dealing with the embodied nature of care, by contrast has a temporal nature and comes when caregiving is no longer needed for a person in care. Kumar et al. describe such restorative work in the case of managing what happens when recovering from disease and how to reclaim parts of one's life that may have been lost [58]. However, this type of restoration can also go beyond the immediate care network of the home to the wider community, where, for example, frontline healthcare workers can help individual households or specific patients to restore the social norms from a time before the need to provide care [105].

Whilst not all of these different types of work are explicitly present within the findings of this study, our data does deal with some of the intersecting or overlapping types of work described above, be these socially or care-driven. Previous studies have supplied frameworks [90] or technical recommendations, the contribution of this research builds specifically on previous work on smart homes around collaboration and modification of care-centric devices [109], social support networks that underpin older adults' use of connected home devices [64] and the collaborative and shared ownership of devices that help older adults care for one another [39,61,77]. Whilst deployment studies of smart homes have been performed before [4,13], our deployment details the mis-matches in work and labour that occur in a shared home space between residents when using a smart home that is designed for a single older adult. ***This paper contributes an understanding of shared care work and labour that arise from, in parallel with, and despite the introduction of a smart home health system***, and how the addition of the SHHS impacts the wider household; not just the person being cared for there.

3 METHODOLOGY

This qualitative study of five shared households (eight participants; with two households where only one resident was interviewed, but where others lived) took place between September 2021 and May 2022. All eight participants were recruited for the interview study which consisted of three stages (Pre-Installation, Post-Installation and Three Months Post-Installation of the smart home system). The interviews focussed on technology use and each household's unique health, care and wellbeing practises.

3.1 Contextualising the smart home health system

The SHHS in this study was created by a research group who are interested in developing technology solutions to help older adults live independently. The authors contacted the SHHS research group, to express interest in running a qualitative study of their smart home system to identify its efficacy and acceptance within the context of shared use for older adults' households, to try and understand how these smart home solutions are accepted within shared spaces. The SHHS research group provided five systems to be sent out to each household that was recruited.

The system was comprised of a range of sensors and a voice assistant that collected data from each sensor, sending it to a cloud to be stored (described below). Data collected from each sensor was available to view online on a 'dashboard' that could show information about each sensor to the user. The range of sensors on offer to participants for this study included: IoT devices such as smart weight scales, door opening sensors and wearables, and a voice assistant (pseudonymised name: "HealthHelper").

3.1.1 Sensors

The full range of sensors on offer, included: 1) a **smart mug**, wall-mounted (with stickable resin adhesive), 2) **motion sensors** that linked directly over Wi-Fi to the HealthHelper and system dashboard, 3) a **smart watch** with a wrist strap of choice (either aluminium metal or plastic), 4) a UK mains-only **smart plug**, 5) **weight scales** with a digital display, 6) a **pulse oximeter** with a digital display, and 7) an **IR Thermometer** with a digital display. The online dashboard, "HealthHelper" voice assistant and phone app were also provided and used intermittently by all households, as described in the accounts provided in the following sections

3.1.2 Onboarding Process

The households received their system between the pre-install and post-install interviews from the SHHS research group after they had spoken to a user experience researcher there. Once the sensors were selected, they were described to each participant over the telephone and then boxed and shipped to each household to unpack and use by themselves. A small booklet with setup instructions was provided within the box, though the households were told that they could phone the SHHS research group to ask for additional help with their system setup at any time. It was left to the discretion of the SHHS research group as to how much direction was given to each household during the explanation of the system (the authors intended to understand the process as a whole and as such, did not wish to direct or interfere with this aspect of the system setup). Only during the interview phase did the authors become aware of what was discussed during the onboarding sessions with the SHHS research group and any issues during the setup and installation phase. These are described in the sections below, such as difficulty adjusting the sensors to suit needs, capturing or reading accurate data from the dashboard or physical damage to the home.

3.2 Recruitment

Five households were recruited with at least one older adult (aged 60+) who could be designated as the 'owner' of the SHHS (the person for whom the system was setup). The researchers' interest in how the SHHS could be used for shared care [40] is reflected in our recruitment process. To this end, the researchers advertised within the recruitment materials (brochure, information sheet), that the system that was being provided to older adults' households was designed by the SHHS research group to support the health and care needs of a **single older person** (not including their caregivers) living with pre-existing chronic conditions (hence, allowing residents to choose the most appropriate sensors for their own needs). This distinction was important to our investigation, as it was of interest for this exploratory research to understand the wider impact of a smart home technology designed to be setup by one older adult, on the lives of the wider household. Up to three additional adults (aged 18+) who were also members of the close or extended household of the owner were invited to participate in the interviews in order to capture shared experiences of the use of the system (e.g. live-in carers, or live-out relatives who would visit the household). However, invitations to participate were extended only through and at the discretion of the primary system owner and as such, it was at their discretion whether anyone else came forward to participate. As such, mostly live-in spouses of the primary system owner were recruited. We address this further within Limitations. Anyone under 18 who lived in the household was discussed anecdotally.

The study was advertised to prospective participants via a local city council in the UK and was advertised through an online recruitment website. The study aimed to recruit as diverse a range of participants as possible, however the sample of recruited participants was skewed largely towards white, urban, middle-income residents in the same city. Prospective participants were encouraged to email or telephone the researchers if they wished to take part, they were given an information sheet about the study, asked if they had any questions and were asked to provide informed consent for themselves and any other residents interested in taking part in the study. Informed consent was offered to participants who expressed an initial interest in the study. Each participant was reimbursed by way of £10 in shopping vouchers per 1 hour of interview time. This study received IRB institutional ethical approval to take place.

3.2.1 Participants

The complete table of participants below (Table 1) details each household ID, participants' (pseudonymised) names, age, gender, ethnicity, self-described household role (derived from interview data) and socio-economic status (relevant to council-funded home technology discussed during initial interview stage).

Table 1: Demographic data and participant information for households recruited during the study.

Household number /ID	Name	Age	Gender	Health Status	Sensors*	Household Role/Description	Care Status
H-A	Angela	85	F	Living post-stroke, also emphysema.	Motion sensors, smart plug, smart watch, weight scales, smart mug	Angela is the home owner and only regular user of the SHHS. Angela has previously had a stroke and is living in a single storey, assisted living household. She is also frequently visited by her son and daughter who will come and help her with household tasks.	Receiving formal care (assisted living) and informal care (daughter, son).
H-B	Bob	77	M	Living with arthritis.	Motion sensors, smart plug, smart watch, weight scales, smart mug, IR thermometer	Bob lives with Barbara and they have been married for approximately 40 years. Bob needs extra assistance with his mobility, for which he has a walking frame and scooter. The SHHS is set up for Bob to use.	Receiving informal care from Barbara.
	Barbara	77	F	Caregiver, reduced mobility post-hip replacement.		Barbara, who describes how she supports Bob also uses a walking aid (stick) having had a hip replacement a year previously. Together, they live in a 4 bedroom, 2-storey house.	Caregiver for Bob.

Household number /ID	Name	Age	Gender	Health Status	Sensors*	Household Role/Description	Care Status
H-C	Clive		M	Living with early-onset Alzheimer's	Motion sensors, smart plug, smart watch, weight scales, smart mug	Clive and Cheryl live together in a 2-storey, 3 bedroom house. Clive lives with early-stage Alzheimers so is supported in some daily activities by Cheryl. The SHHS is set up for Clive to use.	Informal carer for Cheryl.
	Cheryl	62	F	Caregiver, mostly good health.		Cheryl, who looks after Clive and their two cats is regularly visited by their two grandchildren and wider families. Cheryl shares simpler household activities like cooking with Clive, so that he can remain active.	Caregiver for Clive.
H-D	Daisy	68	F	Living with multiple sclerosis and bipolar disorder.	Motion sensors, smart plug, smart watch, weight scales, smart mug, pulse oxymeter	Daisy and David live together in a 3 bedroom, 2-storey part local authority owned home. Daisy lives with Multiple Sclerosis and is helped by David who assists with organising her daily life activities and helping her to go places. Daisy also makes use of a wheeled walker and wheelchair when going outside. The SHHS is set up for Daisy to use.	Receiving informal care from David.
	David	65	M	Caregiver, living with		David, who still travels frequently for work, uses spare time to	Informal caregiver for Daisy.

Household number /ID	Name	Age	Gender	Health Status	Sensors*	Household Role/Description	Care Status
				mobility issues.		arrange their house and plan trips with Daisy. David also owns a van which can store Mary's mobility equipment inside and also willingly intervenes for Daisy in setting up technology and mobile devices.	
H-E	Evelyn	96	F	Reduced mobility due to falls.	Motion sensors, smart plug, smart watch, weight scales, smart mug	Evelyn lives predominantly alone but has a wide network of informal supporters who frequent her home on a regular basis. Evelyn does not have any chronic conditions but experienced a fall and was hospitalised just before the study took place, so makes use of a wheeled walker when going outside, for the duration of this study.	Caring for self with occasional formal support from paid workers (one technical supporter).

* a BP monitor was also offered to participants as part of the SHHS kit but was not chosen by participants.

Whilst some participants are listed as the sole resident enrolled onto the study within a household, all participants had social contacts who either lived-in or visited to care for them, and so all households were 'shared' homes. These visitors and carers interacted within the context of the household and with the SHHS, so are described within the qualitative accounts in section 4, although they did not directly take part in interviews.

3.3 Interview Procedure and Data Collection

We conducted three semi-structured interviews across all five households (15 interviews in total), totalling 13 hours 46 minutes, with interviews lasting up to 1 hour per session. Interviews took place over the telephone (landline) and over videoconferencing software (Zoom). Both these contact methods were offered to participants on a preferential basis, to cater for the range of digital literacy and comfort with technology across the cohort. The

semi-structured interview style allowed for detailed conversations to take place around the use of households' technology, their health and wellbeing and the SHHS.

Interviews were carried out with multiple interviewees. We offered each household the option for as many residents to be present as they chose, for an interview, to support one another during the question and answer process. This way, other respondents such as a caregiver could interject and help with a response from another resident. Interview quotations are labelled within section 4 as: "PRE" (installation of the SHHS), "POST" (installation; up to 3 weeks after install) and "EX" (for exit interviews at 3 months after the installation of the SHHS). Structuring the interviews in this manner allowed for a longitudinal view of the use, work and lived experiences around the SHHS. The temporal structure of these interviews was not used as a basis for our later thematic analysis, though we acknowledge that the pre-install phase provided unique insight into households' technology experiences before being exposed to a largely 'never-before-seen' system (the SHHS). Questions during the pre-install phase focussed on the contextual home setting and technology use patterns (e.g. "Can you describe a typical day in your home?", "Who do you use your kitchen iPad with?"). In between the pre- and post-install interviews, participants in each household were scheduled a call with a user experience researcher from the research group that provided the system. During this call, they chose the sensors they wished to have in their home for the system (more information is provided on each sensor in 3.3) as well as providing information for delivery of the system to their homes (for which a data sharing agreement was set up between the authors and the SHHS research group, that was also explained during the informed consent process to participants). Following this, the post-install phase probed the "out-of-box" (relatively new; up to 3 weeks of use) experiences of using the SHHS once they had received it. Questions were asked around (e.g. "What do you feel about the device in your home?", "How do you feel the SHHS is supporting your health or wellbeing?"). The Exit interviews covered experiences with the system between 2-3 months of use. For these interviews, participants were asked regarding how the system had integrated into their home life, routines and daily activities together, including (e.g. "What has changed in your lives as a result of having the SHHS?", "What impact has using the system had on your wellbeing?").

Some data within this study, such as ongoing technical issues such as connectivity were beyond the remit of this investigation to capture. The authors did not have access to system log data that was held by the SHHS research group regarding general connectivity issues, and this additional data analysis was beyond the scope of this study on the lived experience with the system.

3.4 Data Analysis

The data analysis process was inductive and iterative. Interview audio was transcribed and written up to be analysed using NVivo (qualitative analysis software), and SimpleMind (a mind-mapping tool). An inductive, reflexive thematic analysis was performed on the entire data set [20]. In the first coding iteration (by the first author), codes were developed in order to be more "artfully interpretive" [35] of general occurrences or trends in the data set (the need for participants to learn in different ways, that spanned different types of work using the SHHS). The second and third iteration of codes leant towards being more scientifically descriptive and developed these initial trends into themes. The authors aimed to make this an interpretative process to directly distinguish specific codes and themes and to develop them coherently as part of this work [11], to avoid common problems in the thematic analysis process. This second and third iteration also involved authors 3 and 6 to review codes along with the first author. The use of the mind-mapping tool helped to visually group codes within the data set until it could be agreed upon that the chosen cross-cutting themes (derived from the second and third round of coding

codes) were more clearly representative of the over-arching narrative and important nuances of the interview data set. An over-arching theme of "Labour" was decided upon for the research, which helped to set a direction for how to arrange and describe the interview data in the findings section that follows.

4 FINDINGS

Through a three part interview study, participants described their experiences of technology for care prior to adoption of the SHHS, and were able to compare these experiences to changes in Learning and Set-Up Work, Maintenance Work, Interaction Work, Data Work, Care Work and Emotional Work for shared care after the adoption of the SHHS.

4.1 Understanding Pre-Existing Technology Use

Participants' experiences of using every day (off-the-shelf) consumer technologies in their homes and managing activities of daily living (ADLs), using smart phones, other voice assistants and low-tech home modifications (such as walk-in shower rooms) impacted expectations of the SHHS. For instance, going "online to book [GP] appointments" (H-D, Daisy, PRE), Alexa (H-A-Angela, H-D-Daisy, H-E-Evelyn, PRE), Zimmer frames, stairlift (H-D, Daisy, PRE). "a crutch or a stick" (H-C, Clive, PRE), or "C-pap machine" (H-B, Bob, PRE). Early on, Barbara described how: "My phone goes with me and it's on the table when I'm having a cup of tea [with friends]. If anything happens, I'm on my scooter to come back and sort [Bob] out." (HB, Barbara, PRE). Clive described of himself: "[I'm] a bit of a technophobe." (H-C, Chris, PRE), to which Cheryl responded: "Technology is usually down to me [...] I did the iPad [...] you can work your c-pap though, can't you?" (H-C, Cheryl, PRE). Cheryl explains further: "it's the small things [buttons] he'll struggle with. Little knobs and levers [on C-Pap] machine, I can help him with." (H-C, Cheryl, PRE). For Daisy and David, using an Alexa set the tone for their experiences with smart technology in their home: "I have her [Alexa] on my bedside table, so she can hear me, because I have quite a low voice." (H-D, Daisy, PRE). David supported the setup of the device on Daisy's behalf too: "when we got that, I didn't have to do much, it was just plug and play. [...] I don't even own a [smart]phone. [...] So that all made sense." (H-D, David, PRE).

For the set-up, use and maintenance of these systems, participants often relied on informal carers, formal carers and other professionals: "My daughter does everything for me that my carers won't do. [...] [she'll] leave out some paper with how to record the tv programmes or when I've got people coming to fix things." (H-A, Angela, PRE). Evelyn also explained how she is supported by her paid technician for both technical and care-related tasks: "I get a specialist in [...] to help with computer things [...] "I've got arthritic fingers which if they press one letter and [when typing on MS Word], I always get little red lines. [...] but [supporter] will be patient. He'll help me sort that and even supervise my NHS Spine appointments [bookings]." (H-E, Evelyn, PRE).

Participants also had experience of abandoning some of these smart health and care technologies if devices did not fit into their lives: "I had a smartwatch you wear on your wrist, that told you your temperature and everything. Stopped using that because it's hard to press [the buttons, having experienced a stroke] you see." (H-A, Angela, PRE). These experiences later informed residents' expectations of the SHHS, and acted as a point of reference when discussing the use of SHHS for self-care and shared care work in the home.

After gaining an awareness of households' existing smart devices and their uses, participants were directed to the SHHS research group to choose their desired system setups (which sensors they desired to help them self-manage and to tell the SHHS research group whether their household layout was suitable for the system). All

households were technically suited for the system to be delivered to them and setup (i.e. the SHHS research group deemed that based on the information given to them by the residents, there were no drawbacks to them setting up the sensors). Direct conversations between the SHHS research group and the participants were not captured for this study, however, participants do refer to this process in the accounts below.

4.2 Learning and Set-Up Work

Considerable effort was exerted to understand the SHHS collectively in each household. Whilst different households describe different types of work, all households invested time and energy in order to use (or know how to use) the SHHS. Angela describes how, even with the offer of help from her caregivers, she had to figure out how to use the system on her own: *"I did it. I had to, all by myself. They [carers] wouldn't have been able to make heads or tails of it. [...] It didn't make sense from the instructions until I had tried it."* (H-A, Angela, POST). Some were not as successful setting it up independently: *"I've never used an app in my life, so for me to figure this all out from those little pictures..."* (H-D, David, POST). This reflects the work of Rode et al. [82] and Strengers et al. [96] who suggests that this type of work is essential to caregiving and daily living activities.

When participants struggled to learn how to use the system, they often worked together with others inside the home in order to get the system working, sometimes relying on contacting the research group for further assistance. Clive and Cheryl explained how they worked together when Clive's fine motor skills would not allow him to complete the more intricate parts of the sensors' setup process, naming this the most laborious part: *"[Living with] Alzheimers [...] I tend to have paddy paws rather than fingers and I find it very difficult to get on to the bit of the watch that I want it to be on. That took a long time."* (H-C, Clive, POST). Cheryl explained her involvement at this point: *"I could do most of the things [Clive] couldn't. [...] the Wi Fi setup was a challenge for us both, because [SHHS research group] had to dial in and do our network and everything for us. [...] [Getting] a time when [Clive] and I could be there made difficult too."* (H-C, Cheryl, POST). Whilst connectivity issues occurred, this was mostly an issue for those who did not interact with the SHHS company to aid with their initial setup (H-B and D). For participants who did not have others in the home to help, they relied on close informal carers outside the home to collaborate on its set-up, such as who Evelyn described how her friend came and set up the system for her when she struggled to do so herself: *"[It was] quite a lot [of effort] because I kept thinking have I got it in the right place. [...] eventually a friend helped me. Came round and stuck them all up for me and turned it on."* (H-E, Evelyn, POST).

The learning and set-up had some significant labour costs for people outside the home who were not regularly involved in everyday care. Angela required assistance from her son-in-law in order to set up her system and describes time and effort put in in order to have her system work: *"No way I can do it. I'm chair bound [after stroke]. [Son-in-law] came over to do it. All the way from [north of UK, to the south]"* (H-A, Angela, POST). David and Daisy professed to not be technically literate and were mostly helped by their children to set up and learn about their system, but this work was welcomed by their children: *"my daughter put the app on my phone [...] she was quite excited about it for me"* (H-D, Daisy, POST). However, Daisy explained how her daughter was really lacking time and money and they were conscious of creating more responsibility for her: *"We got her [daughter] round. She did the whole thing and it took... about a day. [...] she didn't want to be paid to set it up for me but I insisted to pay her because she's a single parent, she hasn't got that much money."* (H-D, Daisy, POST).

These accounts show how collaborating to setup the SHHS was often essential for its initial function and that despite being framed for setup by an individual older adult, shared and costly effort was required for learning how to use the system. These resulting labour costs and usability difficulties that participants faced when beginning to

use the system may in part arise due to the unevenness of the onboarding process for each household. While some households engaged fully with the onboarding, others, such as H-A and H-E who did not have direct support from other residents (e.g. spouses in H-B, C and D) and engaged less with the onboarding stage with the research group.. The impact of this difficulty around learning and setting up the system affected mostly how households responded to issues with the system in the short-term (such as those described in the following section). By three months, these early issues were affecting the longer-term understanding of each of the individual sensors and their uses, as described in 4.4 and 4.5.

4.3 Maintenance Work

Beyond set-up and learning to use the system, there was work involved with the continued use and maintenance of the SHHS. Issues experienced with the system were initially troubleshooted by the primary users and others in the home, and participants showed dedication to trying to fix issues by themselves before reaching out to others outside the home: *"We tried. We really tried everything. Re-plugging [...] [reading] the manual."* (H-C, Cheryl, P3M). This included sometimes repeating the same maintenance tasks repeatedly (*"...and then the third time..."* (H-E, Evelyn, P3M)) before their frustration made them give up: *"I've tried to change her. No point in me trying to stop it, any more... it's just programmed wrong."* (H-E, Evelyn, P3M).

This type of maintenance often required outside labour to be resolved. Angela tried to rectify an error, but did not succeed and needed to ask a formal carer to attend to the issue in addition to the care work planned for the visit: *"I don't hear from [HealthHelper] until 3 O'Clock in the afternoon when she tells me to take my tablets. [...] I am meant to take my tablets at 9 in the morning. [...] [carer] came later and tried to adjust her, but no use."* (H-A, Angela, POST). In addition to formal carers being involved in maintenance, frustration with issues with the SHHS led to participants reaching out to informal carers to visit to maintain the system: *"[HealthHelper] was always interrupting a conversation I was having with a friend or a programme I was watching. [...] I'm going to get [technician friend] to come and try and straighten her out next time he's over."* (H-E, Evelyn, P3M). Evelyn even went so far as to pay out of pocket for maintenance of the system: *"I couldn't get on. And that was another thing [technical paid helper] had to come and sort for me. So it's cost me too."* (H-E, Evelyn P3M).

When collaborative efforts to maintain the system failed, participants had to reach out to the SHHS research group to try to get professional help to maintain aspects of the system that *"sort of stopped working"* (H-D, David, P3M): *"I had an hour's telephone conversation with [SHHS research group] to try and fix it for [Daisy], but nothing. Such a waste."* (H-D, David, P3M). Even with the addition of professional help from the SHHS research group, this still required labour from the household members to organise, plan and engage with the maintenance work, including long phone calls. This finding directly builds on Tolmie et al.'s [99] [p. 339] work, which suggests the need to keep devices in "good order" over a longer period of time, as a household grows to accommodate them.

Maintenance work for the system was the source of a lot of labour for the participants and their informal and formal carers. Unresolved issues of maintenance caused a lot of frustration and wasted time, which led to partial and full abandonment: *"I got so annoyed with it in the end, I turned half of it off."* (H-C, Clive, P3M). However, the sunk cost into maintenance also impacted decisions around abandonment too: *"I just thought of just sending the whole thing back, and [husband] said don't do that because you've invested so much time on it anyway. So I'm not going to send it back at the moment."* (H-D, Daisy, POST).

By not resolving technical issues, errors and bad usage patterns mounted up and, when combined with a poor learning experience of the system itself, became increasingly difficult for participants to engage with the system as

time went on (especially by 3 months). Below, we discuss how interactions with the system itself exacerbate these feelings.

4.4 Interaction Work

In order to derive benefit from the SHHS, households had to actively engage with the SHHS, interacting through voice, on a computer or phone. Although the system added additional work through engaging with it, the interaction work for health and care needs sometimes replaced existing interaction work, both in positive and negative ways.

In some cases, routine interaction work was improved through the introduction of the SHHS into the home: *"I like her hands-free-ness. Because I struggle [with MS] [...] I haven't always got the coordination to balance things with both my hands and ask [type], so I can just ask now."* (H-D, Daisy, POST). Cheryl described how the use of the SHHS app removes the need for manual self-tracking of Clive's weight, and, as a person living with dementia, removes the need for additional remembering for him: *"we've got the scales so that will keep a track of [Clive's] weight because that's one thing we do monitor anyway. And because that has the advantage then of going directly to the app rather than him having to think 'oh I've got to write that down in my diary'"* (H-C, Cheryl, POST).

However, some interaction work was not beneficial to the participants. Many participants had issues with the voice assistant, including interruptions and voice recognition that required additional interaction practice: *"[SHHS UX researcher] did say that my voice when I say [HealthHelper] goes up and she said try speaking down."* (H-C, Cheryl, POST). However, there were other aspects of the system that caused frustration in the interaction work that was needed to properly gain care benefit, including the dashboard. Evelyn wanted to access the sensor data collected from the system, but the dashboard was not accessibility-friendly for her: *"I don't have time for [dashboard]. It affects my eyes. [...] I'd rather [HealthHelper] just told me what data she has on me."* (H-E, Evelyn, POST).

These interactions with the system features did not assist participants in engaging with the inner workings of the devices, which exacerbated the learning difficulties described in 4.1. In the longer term, the confusion around interactions with the system led to difficulty accessing and benefitting from any useful data that sensors might have collected.

4.5 Data Work

Engaging with data through the system provided another source of additional work for residents, with varying opinions on whether the SHHS appeared to store information of any use and whether it was even possible to access this data. Clive discussed how he put in effort to engage with data from the system, including struggling to view information on the smart watch, saying: *"I find it very difficult to get on to the bit of the watch that I want it to be on. It's like now it's gone on to a sleep thing, but it hasn't got any information on there."* (H-C, Clive, POST). Bob explained how he'd worked hard speaking to the SHHS research group to try and allow him to view his step count over his phone: *"We spent a couple of hours talking it over but they just can't integrate my phone. [...] Even though I can take the data off [the system] and put it on to my phone, they can't take it off my phone."* (H-B, Bob, P3M). The placement of different parts of the SHHS also impacted data work, as some of the sensors were quite far from where the data could be accessed: *"the only place that you can speak to [HealthHelper] is downstairs. And if you're upstairs with [the] scales for example, I don't know where that reading's gone then. I can't ask her [HealthHelper]."* (H-C, Cheryl, POST).

There was data work done as well to see the limits of what could be stored on the SHHS, which often involved people inside and outside the house: *"Well we've [technical friend and I] put a fair amount of time in to decipher what all that dashboard is storing on me."* (H-E, Evelyn, P3M). When trying to make sense of what information the system

had captured, Angela and “*friends and family*” worked hard trying to find out the information that the system stored, ultimately making Angela feel guilty for the work they put into it: “*I can't find out anything from [HealthHelper] about my pulse, or BP or my heart rate or anything. [...] I was thinking 'I'm wasting your time really'*” (H-A, Angela, P3M). Errors with some of the sensors could also cause distrust in the data, meaning that data work could not be accomplished in order to support health and care by residents: “*[HealthHelper] suddenly piped up and said, 'Well done, [Daisy], you've done so many steps today,' and [Daisy] would sort of look aghast and say, 'Well, I've literally just come downstairs [in the morning]'*” (H-D, David, P3M). Despite some issues with the accuracy of the system, participants still saw benefit in the data work it would support, despite the increase in effort by themselves and their carers: “*I would still need help, but would be useful for physical health, even if you're looking at how many steps you do and things like that. I don't move a lot. But it would be good to know that and more.*” (H-A, Angela, P3M).

Most participants felt that the data was very much situated within a ‘black box’ [38] (hidden away so that only system engineers could understand it), and that *HealthHelper* did not clarify any data recorded, and, according to Daisy's account, only made the experience of interacting with it, more obscure. Longer-term, this data becomes non-valuable to participants and results in residents re-appropriating the system for their own needs, such as for self-care, as discussed in the following section.

4.6 Care Work

Three types of care work were conducted in our households: self-care, shared care and multi-resident [3,91] care (incl. people from outside the immediate household). With regard to self-care, the system's presence itself without functionality reminded people of good practices, such as keeping hydrated. Evelyn enjoyed the physicality of the sensor-based mug, although acknowledged that she did not use it for tracking how much she'd drunk, instead turning it into a low-tech convenience: “*...you could keep a drink hotter for longer and I could carry a hot drink upstairs with the lid on. So I did like that.*” (H-E, Evelyn, P3M). When asked whether she was recording how much liquid she was intaking using the system, Evelyn replied saying that she “*[wasn't] fussed [about] measuring.*” (H-E Evelyn, POST). Daisy was tracking her liquid intake more, but was not using the system for this (although it inspired the change in health behaviour): “*I am drinking water more than I did before, even though the mug doesn't work, the importance of drinking water [is there].*” (H-D, Daisy, P3M).

With regard to providing shared caregiving, positives were also found across households with the system in supporting care-related work. Cheryl expressed satisfaction with how the system's online dashboard could be setup to send an alert notification to her smartphone for her if it detected a change in Clive's temperature: “*and if his temperature drops between a certain level or goes above, I've set it up, I'll get a ping on my phone*” (H-C, Cheryl, POST). “*Oh yes... I get [Cheryl] to start my day out right as they say. Programme in how much she wants me to do for the day and then sets me running like a hamster [laughs].*” (H-C. Clive, POST).

Evelyn explained her GP's interest in her monitoring her own blood pressure and how between her and her GP, she would create a recording of her blood pressure so that her doctor could stay informed about her wellbeing: “*I was talking to [doctor] about looking after my blood pressure. And he said, 'oh good idea. You can show me what you've got [BP reading] next time you're in then' [...] I'm going to keep a little chart for him for next time that I'll bring with me to an appointment I think.*” (H-E, Evelyn, P3M). Although this was causing more care work for both her GP and her, this change (and increase) in care work was welcomed.

However, some of the aspects of the new care work could be disempowering for the users of the SHHS: “*I need someone to do this [put pulse oximeter] on for me though. I can't do it myself. Someone like me, couldn't do it by*

themselves." (H-A, Angela, POST). Angela described another issue of disempowerment, which caused additional work for her carer and for her GP. She was ultimately unable to be the source of data so that they could accomplish data work to better provide her care: *"I need [carer] to tell me what the little numbers mean [on the watch]. [...] She'll come weekly but last time I asked her what they meant. And we found out my [blood oxygen] together. I wasn't doing well, at that time. [...] I called the doctor, but I couldn't tell [him] what was wrong because I didn't understand [numbers on the watch]"* (H-A, Angela, POST).

Whilst benefits of the system arose around re-appropriation of the technology (for example, self-care through drink making) and sharing insights with caregivers (both formal and informal), in the short term it became clear that individuals could not make use of some system sensors without support from caregivers. Difficulties using the system for individual care was often because of a lack of understanding of sensors labels or struggles to wear sensors. Longer term, this labour was emotionally demanding for individuals as well as physically taxing, which is discussed in greater detail within the next section.

4.7 Emotional Work

Support by another resident or caregiver to use the system was often required, and this elicited additional emotional work by their carers. The introduction of the system caused additional anxiety management work in some households: *"[Bob]'s got AF - Atrial Fibrillation. If he was looking at the [dashboard] all the time, he'd be saying, 'oh dear, this is wrong, oh dear that's wrong.' So I have to intervene and point to things [on phone] and say, 'you don't need to worry about this, or that'"* (H-B, Barbara, POST). Cheryl described how HealthHelper caused anxiety for her husband Clive by producing unwanted sounds, which involved both additional unsuccessful maintenance work and then emotional work to deescalate the situations it caused: *"He gets a bit stressed when anything ... different sounds and things.. and that thing's [...] going off at the most unexpected times even when we've tried so much to change it."* (H-C, Cheryl, P3M). The system also afforded additional checking on the person in care, which could be a new source of emotional work for the carer to alleviate their own anxiety: *"obviously it will send a notification to my phone to obviously say there's been no movement, perhaps I ought to check on [husband] kind of thing [...] but I get worried then if I'm out that it's something worse, like he's fallen and I panic and call him and then [Chris] will say 'oh, stop bothering me I'm just up in the shed' [laughs]"* (H-C, Cheryl, POST).

Emotions ran high when participants became agitated from using parts of the system that demanded attention such as alerts on the dashboard. However, for some caregivers in the longer-term, there was also a reduction in worry, knowing they had instant access to data about the person in care.

5 DISCUSSION

Through the study of the use of the SHHS in five different households, unique forms of work were observed both with the system and around it. Findings contributed a holistic overview of the different types of care work and labour that are performed specific to the smart home. Here we discuss the impact of the introduction of a smart home health system on shared care work and labour, and how this extends prior research on labour in the 'smart home'. The following three sections of the discussion focuses on mitigating and supporting households to avoid such labour-intensive outcomes from interaction with smart home technology.

5.1 Reducing Care Labour Burdens with a Smart Home Health System

This section proposes that to improve shared care in the home through interactions with the SHHS, there is a need for greater simplification and bespoke technical support for specific care tasks

5.1.1 Recommendations for Reducing Household Care Labour

Our participants' accounts showed that doing care work with the SHHS was more labour intensive and that as a result, meaningful care tasks (such as taking blood pressure in H-A or taking Clive's temperature in H-C) did not get performed correctly. As such, participants fell back on making use of the system for more mundane purposes (such as using the smart mug for beverages in H-E). Whilst the learning and setup process could mitigate these failures, there is consideration needed for how participants' own abilities and disabilities were not considered in the design. Despite the system being setup for a single user, the ability for caregivers to reason [24] about the sensors and use them to support the person they are caring for, was not designed for. Moreover, visualisations of sensor data (akin to [30]) could better support understanding of 'black box' data recorders such as the HealthHelper. This points to a greater need to develop bespoke care support tools (similar to Wallace et al.'s investigation of empowering personhood with dementia technologies: [106]) that are designed the wider household that is involved in care. This could range from better visual interfaces, helping the caregiver to see what the sensor is currently monitoring about the care recipient or even auxiliary technical documentation that helps them navigate the sensors to perform specific care tasks (such as, a guided set of instructions that show how to check if someone's temperature gets too low).

Self-care (sometimes mundane [5,71]) work using the SHHS was performed by residents who e.g. measured their weight, drunk more water, or counted their steps. However, shared care inside and outside the home was also impacted by the introduction of the SHHS, such as an informal carer setting up a step counter (H-C) or a GP learning about how the SHHS can track blood pressure (H-E). This mirrors related work by James' [52] conceptualising caregiving as a combination of "organisation + physical labour" and Ming et al.'s description of the 'invisible work' that is often performed above and beyond by caregivers as part of their daily duties. There is a significant issue with smart home systems generating additional work for already over-burdened formal and informal caregivers. Harmon et al. [41] describe care taking place as a 'philanthropic biography' that does not just happen in isolation. Instead, care happens over the lifespan, and the act of being philanthropic is a physically and mentally demanding form of labour that becomes a caregiver's life, often for many years consecutively. Nevertheless, for others, the act of caring with technology (with an SHHS) is also an expression of love, that provides a sense of fulfilment and purpose to people's daily lives (p. 18) [67]. Although, the SHHS studied has primarily been described as a form of labour that is prolonged and exhaustive, so we suggest that reducing caregivers' unnecessary interactions with smart home systems should be prioritized to better support collective responsibility in caregiving and ultimately reducing risk. As Kraemer et al. identify [57], effectively caring together in the home requires both vigilance and skill to not overburden dependents and we suggest that there is an opportunity for e.g. research through design (RtD) [116] activities with the care network to ensure that the link between unnecessary interactions and enacting a care task is broken. Previous research has illustrated the benefits of RtD in care settings by helping caregivers devote time to more meaningful care tasks [97], helping those with a high cognitive load and worried caregivers [69] and using physical technologies (robots), to mitigate exhaustion in human caregivers [88].

5.1.2 *Clarity for Laborious Interaction and Data Work*

Interactions with the system's sensors showed a significant amount of labour (in particular for H-A, H-B, H-C and H-D), with in the moment interpretative data work and data reflection work. Smart home data work has been described as off-putting or scary, particularly to older adults [16], and as Byrne et al. describe, can even be 'spooky', when considering smart home system AI and their associated 'black boxes' that are seen as trapping and storing information that is often inscrutable [33]. To support the demystifying of personal data that SHHS's collect, there are a number of actions that SHHS developers could take. For one, combined voice assistant and sensors systems could better leverage VAs such as HealthHelper and make them act as spoken interpreters of the data that is collected, potentially reducing both interaction work and data work. Moreover, this could make evident to users and caregivers that the system will support care, rather than only being usable by the SHHS research group [27]. This could be scaffolded at the set-up process with additional calibration and configuration work, which has been discussed in the self-tracking literature (e.g. [7,44]), but with a broader focus on collective monitoring with shared configuration by users and caregivers, as seen in this study for example, H-E having their system configured by an expert or H-D delegating configuration to their spouse. For instance, upfront configuration work could involve shared visualisation exercises to find out which types of visualisations are easiest to understand, with simple pathways to data access that in turn will be useful for self-monitoring or administering care [12,68,110]. Providing a range of visualisations could, as Strengers et al. also suggest, account for the diversity of and specialised needs of relationships between older adults and their caregivers [95] and potentially help recipients to communicate their lived experiences, for instance representing their chronic pain pictorially or numerically [1]. Co-design workshops to identify the data that both older adults and their caregivers need could further help to develop tools to support shared household understanding.

5.2 **Reducing Labour Through Simplicity and Autonomy**

One of the key barriers to the use of the SHHS was a holistic understanding of how the system works (for both care recipients and caregivers; see following section). This juxtaposes early notions of the smart home where the use and function of so-called 'domotics' devices (such as fold-away ironing board and beds built into walls), were obvious in their affordances [45,49]. In contrast, much of the SHHS in this study obscures the inner workings of the system through it being largely a 'black box' and that whilst data is accessible (H-A, B, C), it is difficult for older adults to generate their own mental models either easily or quickly, as gaining an understanding of the system as a whole takes time due to its complexity. Only by the end of the three month period of the study, did we see greater understanding (albeit dissatisfaction) emerge around what the system actually does (e.g. H-D's accounts).

Our pre-installation accounts show that the system brought with it an expectation of simplicity and that caregivers would easily be able to set the system up on the system owner's behalf (e.g. H-A, H-D), but this was not the case, as emerges later, due to the complexity of the SHHS which could not be overcome. This contrasts participants' early discussions about some of the other, simpler smart devices they own, such as their 'Alexa' smart speakers, which worked as expected after being plugged in 'out of the box' [117]. Having high expectations up front of the SHHS, combined with the ongoing issues of understanding and physically interacting with the sensors (e.g. wearing the watch (H-C), filling the mug (H-E)) showed the labour intensiveness of this system by contrast. Whilst we provide suggestions towards improving the learning and setup and ongoing maintenance work around the

system in the following sections, avoiding abandonment (which can be common for smart health technologies [21]) of the SHHS additionally requires SHHS developers to make older adults and their caregivers aware of and actively support the effort involved in the learning process. The disparities in the learning (and onboarding) process discussed in section 4.2 only show further how the inconsistencies in onboarding, lead to the inconsistency in residents' understanding of the system, resulting in the latter abandonment seen here. This extends previous work by Sixsmith et al. [89] showing individual assistive technologies are often abandoned due to lack of sufficient social support from the care network. However, this is not to say that abandonment in this instance is inherently bad. Through abandoning the system, participants likely returned to the same (reduced) levels of labour seen prior to getting the technology. Although marketed as technology to be used to support older adults with chronic health conditions lasting over a period of years, the SHHS does not demonstrate the longevity required to maintain interest or usefulness in the long term. This has parallels to Garg et al. who show the abandonment of IoT devices that do not meet people's longer-term, health-related targets [36]. In this current study, these evolving health needs are not catered for by the SHHS for the individual, let alone for the wider household. Through 'showing and telling' [101] older adult households what a 'sensor' is and through to explaining the interactions of all of the sensors with one another within the system can go a long way to achieving this.

Abandonment of the SHHS is not inherently bad within this study, as households will likely see a reduction in effort and labour simply through no longer using the equipment. Further, whilst households abandoned the use of the system as a whole entity, for its intended purpose; some devices were re-appropriated and now fill other, less laborious roles (such as with Evelyn now owning a handy mug to keep her drinks warm).

5.2.1 Reducing Learning and Setup Labour's Mental and Physical Demands.

Significant time was spent by all participants trying to learn how to use the system and set it up, including writing notes to remember how the system works (H-D) or phoning a member of the SHHS research group for assistance (H-C). Language used when explaining smart home systems has also been shown to affect understanding [13,42] and as such, mental labour during the learning and setup process could be reduced through providing visual aids (for sensor setups) and further interactive documentation. Interactive 'translation' tools [30] accompanying the system could be tailored to the individual needs of older adults to aid the understanding of the setup process. This setup process could start the learning process for both recipients and informal and formal caregivers, showing them how to interact with the system, similar to what has been found with commercial smart home devices [34,76]. Tangible tools also show promise in reducing learning work by aiding understanding, particularly for people living with dementia [9,23,46]. Beyond the recipient, more design focus should be on the caregivers' learning processes as they share the use of smart devices [37,51]. This is especially true for informal caregivers who are often overburdened already [19], and we have shown to be additionally burdened at the onset with set-up work.

5.2.2 Support for Ongoing Maintenance Work.

A great deal of the labour also arose from doing maintenance work with the SHHS, for instance involving error correction (H-A, B) and irritation in managing the voice assistant (H-E). Sixsmith et al. [89] identify the importance of systems that can be maintained cooperatively (not co-dependently) and how a 'gradation' of responsibility is needed between caregivers and care recipients in order to effectively maintain together. Lazar et al. too, have talked extensively about the consequences of when smart device use becomes unmanageable when too much extra work is required to maintain devices [60]. In Lazar et al.'s study, like ours, the labour of maintaining devices eventually

led to abandonment. However, it is possible to envision more optimistic solutions for systems where maintenance is appropriately scoped by an SHHS provider and coordinated up-front with caregivers and care recipients. This could indicate what problems may arise and help to set expectations for the benefits of the system, but also its limitations.

5.3 Supporting Gendered and Emotional Household Labour

Whilst this paper dealt explicitly with the emotional work experienced by each household in order to setup, maintain and use the system, it is also important to acknowledge how this labour is also gendered [85]. As De La Bellacasa describes, care is not a neutral practise; it is inherently gendered [79] [p. 43], and, as the UK's Office for National Statistics suggests, 58% of UK caregivers are female, as opposed to only 42% male [18,22]. De La Bellacasa goes on to further exemplify that the act of caring for and with technology requires both the aforementioned ongoing maintenance, as well as "ongoing [...] responsibility." [p. 43]. Whilst H-B, C and D all had a caregiver who was caring for another participant using the SHHS, in H-B and C saw a female caregiver supporting a male care recipient. In H-A and E, female participants were performing self-care as well as learning how to use the system without the live-in support of another resident (albeit with other live-out wider household members intervening). Evidently, there is a need to re-balance this dynamic, although the route to doing so is complex and the route to reducing labour for these predominantly female caregivers will be different. Such an approach to provide greater support here could be based on whether there are live-in or live-out residents present. For example, for those with other live-in residents, support could focus more on enabling interventions from other residents and providing clear instruction from the SHHS provider that can be understood within the household's context. For those living predominantly by themselves, but with live-out support (such as H-E), there is a need for more direct intervention and physical presence from formal carers or the SHHS provider to have another human presence in the home, to steer the learning process early on and reduce the labour cost.

5.3.1 Supporting Emotional Labour through Familiarisation.

Emotional work emerged in the three month deployment as time progressed, with anxiety expressed in H-B and H-C. This was not just the recipient expressing worry over the health and care data available to them, but also carers expressing anxiety with trusting the system to monitor the person in need of care, which has parallels to other care monitoring systems that had unintended impacts on anxiety [107]. Emotional labour, by contrast, is a resource in the home (as described by Raval and Dourish [80]) and the SHHS was pulling on this resource in inefficient and effective ways, causing stress, and ultimately resentment. Prior descriptions of labour that take place both inside of home and residential care settings, tend to focus on one specific form of labour such as the implications of emotional care work [80]. Lazzaratto et al. [62] describe 'immaterial labour' as mental adjustments and responses to higher levels of work, which was present in the repeated experiences of frustration with the SHHS expressed by both recipients and carers. As the SHHS was a closed ecosystem of devices, participants seemed to have a lack of control over tailoring the system according to their personal and shared emotional needs within their unique households, again pointing to the potential of upfront configuration work to reduce unintended emotional work. As Easthope et al. and Lindley et al. both describe [31,39], people develop strong emotional connections to their dwellings and their possessions and as such develop specific expectations and affordances [84] to these possessions that determine their future interactions with them. Further work to understand with more completeness people's

complex social and emotional interplay with their possessions and devices in their home, could go some way to help understand the emotional context for introducing new smart home technology and ultimately, reducing unintended emotional labour so care recipients and caregivers can reduce their overall shared care burden.

6 LIMITATIONS AND FUTURE WORK

The authors acknowledge limitations with the study methodology and execution. Firstly, we recognise the limitation of our sample set. Our sample was comprised of low-middle income white UK households due to the nature of access to participants in the area where the study was conducted and also retention for the full duration of three months. Whilst households did initially come forward from black and minority ethnic communities, there was difficulty retaining these participants for the full three month period as the study period would not have worked alongside their personal caring commitments. In future therefore, we would seek to find alternate ways to diversify of our sample set to recruit and retain those from ethnic minority communities and queer communities. This may require different means of structuring study formats to accommodate participants' varied responsibilities. Further, whilst we endeavoured to recruit a diverse range of both live-in residents and live-out wider household members to be truly representative of a 'shared household' as described in section 1, there was difficulty accessing those who did not live in the home (e.g. the installer in H-E or the grandchildren of Angela in H-A). This is likely due to lack of direct contact between the researchers and these residents, although residents did tell us that they had passed details of the study onto these individuals. For future research, the text of recruitment materials could more explicitly state our interest in interviewing the wider household, with specific focus on those who do not live in the home.

The authors also acknowledge the impact that providing the SHHS for each household entails. Instead of participants purchasing the devices for themselves, the authors were gifting this technology to households to use. It is important to acknowledge this impact and propose that there are alternate means of delivering and studying this technology 'in the wild' [83]. Gifting technology can bias processes such as informed consent and also shift power dynamics between researchers and participants. To try and mitigate this effect, the researchers did separately compensate participants for time spent taking part in interviews. Conducting this study remotely and taking mitigations to limit the spread of COVID-19 with a population of older adults, informed this decision and reassured us that this was the most appropriate means of conducting this study given local restrictions on data collection.

We acknowledge the unevenness of the onboarding process likely led to differences in the longer-term use of the system by our residents. For instance, how engaged people were in the system up front, influenced their understanding and ultimately their longer-term use of the technology. This may have also resulted in the aforementioned differences in labour costs seen too. Whilst our approach to this study was to deploy the SHHS and study its impact on each household's lived experience without structured support, a future investigation into smart home technology labour costs could provide a more scaffolded learning process up front to determine how this would affect older households' learning processes and the longer-term use or abandonment of the technology.

The authors also acknowledge that the SHHS research group developed the system (an IoT sensor system and voice assistant) for individual older adults who live alone. Whilst this does not change the evidence collected here, it is important to note that the technology's designed purpose is different from how it was predominantly used in this study (as a shared household). It may be the case that these devices are used together in non-research settings

where the SHHS has also been deployed and the authors consider this in relation to the transferability of findings from this study.

Lastly, the authors acknowledge that whilst some informal caregivers were interviewed as part of this study, it would be of benefit in future studies to interview members of the wider household such as children and grandchildren of smart home technology owners, rather than just hearing anecdotal accounts of their use through the technology owner. This study focussed on interviewing the SHHS care recipient and their immediate caregivers (usually a spouse), who lived with them, though in future it would also be of interest to also interview formal caregivers and clinicians to identify clinical feasibility of SHHS's.

7 CONCLUSION

We conducted 15 semi-structured interviews across five older adult households over a period of three months to understand the impact on shared care work after the introduction of a smart home health system (SHHS). Our findings reveal several types of labour that arise when an SHHS is deployed and we suggest ways to support or mitigate labour that could result in the abandonment of the system.

Engagement with the SHHS showed positive benefits to mundane self-care activities, such as tracking weight, water intake and BP for older adult care recipients, while caregivers benefitted from control over setting daily activities or tasks for care recipients to undertake, such as number of steps walked in a day. Despite these benefits, there is scope to remove or reduce labour to allow recipients and caregivers to understand and utilise the SHHS in the best way possible for their home context. Specifically, reducing the set-up labour, learning work, interaction labour, data work, care work and emotional work could be possible through human centred approaches that included both the recipients of care, and the formal and informal carers. A wide range of people are heavily involved in the successful adoption, appropriation and use of the SHHS, and careful design around their shared care work could allow these complex home healthcare systems to be better integrated into the sociotechnical fabric of the home for older adults.

ACKNOWLEDGMENTS

The authors would like to thank the participants for their time and engagement with this research project, and the research group for the opportunity to study the SHHS. This work was funded by EPSRC SPHERE Next Steps (EP/K031910/1) and ESRC Centre for Sociodigital Futures (and EP/R005273/1).

REFERENCES

- [1] Phil Adams, Elizabeth L. Murnane, Michael Eifenbein, Elaine Wethington, and Geri Gay. 2017. Supporting the self-management of chronic pain conditions with tailored momentary self-assessments. *Conf. Hum. Factors Comput. Syst. - Proc.* 2017-May, (2017), 1065–1077. DOI:<https://doi.org/10.1145/3025453.3025832>
- [2] R. Aiswarya, Vaishali Anil, Jayasree Raveendran, Gijs Van Wijk, and Shantanu Talukdar. 2021. Living as a Service (LaaS): An Experiment to Evaluate Living Experience in Connected Homes in the Netherlands. *Conf. Hum. Factors Comput. Syst. - Proc.* (2021). DOI:<https://doi.org/10.1145/3411763.3451684>
- [3] Hande Alemdar. 2014. Multi-Resident Human Behaviour Identification in Ambient Assisted Living Environments. *Proc. 16th Int. Conf. Multimodal Interact. - ICMI '14* (2014), 369–373. DOI:<https://doi.org/10.1145/2663204.2666286>
- [4] Mohsen Amiribesheli and Hamid Bouchachia. 2018. A tailored smart home for dementia care. *J. Ambient Intell. Humaniz. Comput.* 9, 6

- (2018), 1755–1782. DOI:<https://doi.org/10.1007/s12652-017-0645-7>
- [5] Amid Ayobi, Paul Marshall, and Anna L. Cox. 2016. Reflections on 5 Years of Personal Informatics: Rising Concerns and Emerging Directions. *CHI '16 Ext. Abstr.* (2016), 2774–2781. DOI:<https://doi.org/10.1145/2851581.2892406>
- [6] Amid Ayobi, Paul Marshall, and Anna L. Cox. 2020. Trackly: A Customisable and Pictorial Self-Tracking App to Support Agency in Multiple Sclerosis Self-Care. *DI.Acm.Org* (2020), 1–15. DOI:<https://doi.org/10.1145/3313831.3376809>
- [7] Amid Ayobi, Tobias Sonne, Paul Marshall, and Anna L. Cox. 2018. Flexible and mindful self-tracking: Design implications from paper bullet journals. *Conf. Hum. Factors Comput. Syst. - Proc.* 2018-April, (2018). DOI:<https://doi.org/10.1145/3173574.3173602>
- [8] Louise Barkhuus, Elizabeth Bales, and Lisa Cowan. 2017. Internet ecologies of new mothers: Trust, variety and strategies for managing diverse information sources. *Proc. Annu. Hawaii Int. Conf. Syst. Sci.* 2017-Janua, (2017), 2283–2292. DOI:<https://doi.org/10.24251/hicss.2017.276>
- [9] Peter Bennett, Kirsten Cater, and Heidi Hinder. 2016. Rekindling imagination in dementia care with the Resonant Interface Rocking Chair. *Conf. Hum. Factors Comput. Syst. - Proc.* 07-12-May-, (2016), 2020–2026. DOI:<https://doi.org/10.1145/2851581.2892505>
- [10] Daniel G. Blazer. 2020. *Social Isolation and Loneliness in Older Adults: Opportunities for the Health Care System*. The National Academies Press, Washington, DC. DOI:<https://doi.org/10.17226/25663>
- [11] Virginia Braun and Victoria Clarke. 2014. What can “thematic analysis” offer health and wellbeing researchers? *Int. J. Qual. Stud. Health Well-being* 9, (2014), 9–10. DOI:<https://doi.org/10.3402/qhw.v9.26152>
- [12] Ryan Brotman, Winslow Burleson, Jodi Forlizzi, William Heywood, and Jisoo Lee. 2015. Building Change: Constructive Design of Smart Domestic Environments for Goal Achievement. *Proc. ACM CHI'15 Conf. Hum. Factors Comput. Syst.* 1, (2015), 3083–3092. DOI:<https://doi.org/10.1145/2702123.2702602>
- [13] Alison Burrows, David Coyle, and Rachael Goberman-Hill. 2018. Privacy, boundaries and smart homes for health: An ethnographic study. *Heal. Place* 50, January (2018), 112–118. DOI:<https://doi.org/10.1016/j.healthplace.2018.01.006>
- [14] Clara Caldeira, Matthew Bietz, Marisol Vidauri, and Yunan Chen. 2017. Senior Care for Aging in Place: Balancing Assistance and Independence. *Proc. 2017 ACM Conf. Comput. Support. Coop. Work Soc. Comput. - CSCW '17* (2017), 1605–1617. DOI:<https://doi.org/10.1145/2998181.2998206>
- [15] Clara Caldeira, Novia Nurain, and Kay Connelly. 2022. “I hope I never need one”: Unpacking Stigma in Aging in Place Technology. *Conf. Hum. Factors Comput. Syst. - Proc.* (2022). DOI:<https://doi.org/10.1145/3491102.3517586>
- [16] Zoraida Callejas and Ramón López-Cózar. 2009. Designing smart home interfaces for the elderly. *ACM SIGACCESS Access. Comput.* 95 (2009), 10–16. DOI:<https://doi.org/10.1055/s-2003-39568>
- [17] Nico Castelli, Corinna Ogonowski, Timo Jakobi, Martin Stein, Gunnar Stevens, and Volker Wulf. 2017. What happened in my home?: An end-user development approach for smart home data visualization. *Conf. Hum. Factors Comput. Syst. - Proc.* 2017-May, (2017), 853–866. DOI:<https://doi.org/10.1145/3025453.3025485>
- [18] Census. 2021. Living longer: how our population is changing and why it matters. *Off. Natl. Stat.* (2021), 1–53. Retrieved from <https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/ageing/articles/livinglongerhowourpopulationischangingandwhyitmatters/2018-08-13>
- [19] Yunan Chen, Victor Ngo, and Sun Young Park. 2013. Caring for caregivers: Designing for integrality. *Proc. ACM Conf. Comput. Support. Coop. Work. CSCW* February 2013 (2013), 91–102. DOI:<https://doi.org/10.1145/2441776.2441789>
- [20] Victoria Clarke and Virginia Braun. 2017. Thematic analysis. *J. Posit. Psychol.* 12, 3 (2017), 297–298. DOI:<https://doi.org/10.1080/17439760.2016.1262613>
- [21] James Clawson, Jessica A. Pater, Andrew D. Miller, Elizabeth D. Mynatt, and Lena Mamykina. 2015. No longer wearing: Investigating the abandonment of personal health-Tracking technologies on craigslist. *UbiComp 2015 - Proc. 2015 ACM Int. Jt. Conf. Pervasive Ubiquitous Comput.* (2015), 647–658. DOI:<https://doi.org/10.1145/2750858.2807554>
- [22] Christine Cocker and Trish Hafford-Letchfield. 2022. *Rethinking Feminist Theories for Social Work Practice*.

- DOI:https://doi.org/10.1007/978-3-030-94241-0_1
- [23] Elaine Czech, Mina Shibasaki, Keitaro Tsuchiya, Roshan L. Peiris, and Kouta Minamizawa. 2020. Discovering narratives: Multi-sensory approach towards designing with people with dementia. *Conf. Hum. Factors Comput. Syst. - Proc.* (2020), 1–8. DOI:<https://doi.org/10.1145/3334480.3375209>
- [24] Qing Zhang DanaKai Bradford. 2016. How to Save a Life: Could Real-Time Sensor Data Have Saved Mrs Elle? *CHI '16 Ext. Abstr.* (2016), 910–920.
- [25] Scott Davidoff, John Zimmerman, and Anind K. Dey. 2010. How routine learners can support family coordination. *Conf. Hum. Factors Comput. Syst. - Proc.* 4, (2010), 2461–2470. DOI:<https://doi.org/10.1145/1753326.1753699>
- [26] Audrey Desjardins, Heidi R. Biggs, Cayla Key, and Jeremy E. Viny. 2020. IoT Data in the Home: Observing Entanglements and Drawing New Encounters. *Conf. Hum. Factors Comput. Syst. - Proc.* (2020), 1–13. DOI:<https://doi.org/10.1145/3313831.3376342>
- [27] Audrey Desjardins, Ron Wakkary, and William Odom. 2015. Investigating genres and perspectives in HCI research on the home. *Conf. Hum. Factors Comput. Syst. - Proc.* 2015-April, (2015), 3073–3082. DOI:<https://doi.org/10.1145/2702123.2702540>
- [28] Guy Dewsbury, Karen Clarke, Mark Rouncefield, Ian Sommerville, Bruce Taylor, and Martin Edge. 2003. Designing acceptable “smart” home technology to support people in the home. *Technol. Disabil.* 15, 3 (2003), 191–199. DOI:<https://doi.org/10.3233/tad-2003-15305>
- [29] Julie Doyle and Suzanne Smith. 2019. Managing Multimorbidity : Identifying Design Requirements for a Digital Self-Management Tool to Support Older Adults with Multiple Chronic Conditions. (2019), 1–14.
- [30] Rachel Eardley, Sue Mackinnon, Emma L. Tonkin, Ewan Soubutts, Amid Ayobi, Jess Linington, Gregory J.L. Tourte, Zoe Banks Gross, David J. Bailey, Russell Knights, Rachael Gooberman-Hill, Ian Craddock, and Aisling Ann O’Kane. 2022. A Case Study Investigating a User-Centred and Expert Informed “Companion Guide” for a Complex Sensor-based Platform. *Proc. ACM Interactive, Mobile, Wearable Ubiquitous Technol.* 6, 2 (2022). DOI:<https://doi.org/10.1145/3534625>
- [31] Hazel Easthope. 2014. Making a Rental Property Home. *Housing Studies* 29, 579–596. DOI:<https://doi.org/10.1080/02673037.2013.873115>
- [32] Kim England and Isabel Dyck. 2011. Managing the body work of home care. *Sociol. Heal. Illn.* 33, 2 (2011), 206–219. DOI:<https://doi.org/10.1111/j.1467-9566.2010.01331.x>
- [33] Karen Escarcha, Katherine Giesa, Yiwei Huang, Catherine Yochum, Daragh Byrne, Dan Lockton, Meijie Hu, Miranda Luong, Anuprita Ranade, and Elizabe Wang. 2022. The ethereal and otherworldly as a resource for design. *Proc. J. Hum. Factors Comput. Syst. (ACM CHI 2022)*. 1, (2022).
- [34] Aisling Ann O’Kane Ewan Soubutts, Amid Ayobi, Rachel Eardley, Ki Cater, Roisin McNaney. 2022. Amazon Echo Show as a Multimodal Human-to-Human Care Support Tool within Self-Isolating Older UK Households. *CSCW* 4, 2 (2022).
- [35] Linda Finlay. 2021. Thematic analysis: The ‘Good’, the ‘Bad’ and the ‘Ugly.’ *Eur. J. Qual. Res. Psychother.* 11, (2021), 103–116.
- [36] Radhika Garg and Jenna Kim. 2018. An exploratory study for understanding reasons of (not-)using internet of things. *Conf. Hum. Factors Comput. Syst. - Proc.* 2018-April, (2018), 1–6. DOI:<https://doi.org/10.1145/3170427.3188466>
- [37] Christine Geeng, Franziska Roesner, and Paul G Allen. 2019. Who’s In Control?: Interactions In Multi-User Smart Homes. 13, Section 4 (2019), 1–13. DOI:<https://doi.org/10.1145/3290605.3300498>
- [38] Kirsten Gram-Hanssen and Sarah J. Darby. 2018. “Home is where the smart is”? Evaluating smart home research and approaches against the concept of home. *Energy Res. Soc. Sci.* 37, March (2018), 94–101. DOI:<https://doi.org/10.1016/j.erss.2017.09.037>
- [39] Jane Gruning and Siân Lindley. 2016. Things We Own Together. 1176–1186. DOI:<https://doi.org/10.1145/2858036.2858154>
- [40] Maria Häggglund, Isabella Scandurra, and Sabine Koch. 2010. Scenarios to capture work processes in shared homecare-From analysis to application. *Int. J. Med. Inform.* 79, 6 (2010), 126–134. DOI:<https://doi.org/10.1016/j.ijmedinf.2008.07.007>
- [41] Ellie Harmon, Matthias Korn, and Amy Volda. 2017. Supporting everyday philanthropy: Care work in situ and at scale. *Proc. ACM Conf. Comput. Support. Coop. Work. CSCW* (2017), 1631–1645. DOI:<https://doi.org/10.1145/2998181.2998330>

- [42] Richard Harper. 2006. *Inside the Smart Home*. DOI:https://doi.org/10.1007/1-85233-854-7_5
- [43] Christina N Harrington, Ben Jelen, and Amanda Lazar. Taking Stock of the Present and Future of Smart Technologies for Older Adults and Caregivers. *Ccc*.
- [44] Daniel Harrison, Paul Marshall, Nadia Bianchi-Berthouze, and Jon Bird. 2015. Activity tracking: Barriers, workarounds and customisation. *UbiComp 2015 - Proc. 2015 ACM Int. Jt. Conf. Pervasive Ubiquitous Comput.* (2015), 617–621. DOI:<https://doi.org/10.1145/2750858.2805832>
- [45] Thomas Heine, Daniel Buhr, Gerhard Eschweiler, and Udo Weimar. 2016. Cross-generational smart environment acceptance. *Proc. 1st Work. Embodied Interact. with Smart Environ. - EISE '16 2*, (2016), 1–6. DOI:<https://doi.org/10.1145/3008028.3008031>
- [46] Maarten Houben, Rens Brankaert, Gail Kenning, Inge Bongers, and Berry Eggen. 2022. Designing for Everyday Sounds at Home with People with Dementia and their Partners. *Conf. Hum. Factors Comput. Syst. - Proc.* (2022). DOI:<https://doi.org/10.1145/3491102.3501993>
- [47] Richard Humphries, Ruth Thorlby, Holly Holder, Patrick Hall, and Anna Charles. 2016. Social care for older people. September 2016 (2016). DOI:[https://doi.org/10.1044/1058-0360\(2009/08-0047\)](https://doi.org/10.1044/1058-0360(2009/08-0047))
- [48] Annika Hupfeld and Tom Rodden. 2012. Laying the table for HCI: Uncovering ecologies of domestic food consumption. *Conf. Hum. Factors Comput. Syst. - Proc.* (2012), 119–128. DOI:<https://doi.org/10.1145/2207676.2207694>
- [49] David Hutchison. 2014. *Human-Computer Aging and Assistive Environments*.
- [50] Caroline Huyard, Harm Haak, Luc Derijks, and Louis Lieverse. 2019. When patients' invisible work becomes visible: non-adherence and the routine task of pill-taking. *Sociol. Heal. Illn.* 41, 1 (2019), 5–19. DOI:<https://doi.org/10.1111/1467-9566.12806>
- [51] Martin J Kraemer, Ivan Flechais, and Helena Webb. 2019. Exploring Communal Technology Use in the Home. (2019), 1–8. DOI:<https://doi.org/10.1145/3363384.3363389>
- [52] Nicky James. 1992. Care = organisation + physical labour + emotional labour. *Sociol. Health Illn.* 14, 4 (1992), 488–509. DOI:<https://doi.org/10.1111/1467-9566.ep10493127>
- [53] Cecilie Karlsen, Carl Erik Moe, Kristin Haraldstad, and Elin Thygesen. 2019. Caring by telecare? A hermeneutic study of experiences among older adults and their family caregivers. *J. Clin. Nurs.* 28, 7–8 (2019), 1300–1313. DOI:<https://doi.org/10.1111/jocn.14744>
- [54] Elizabeth Kaziunas, Michael S. Klinkman, and Mark S. Ackerman. 2019. Precarious interventions: Designing for ecologies of care. *Proc. ACM Human-Computer Interact.* 3, CSCW (2019). DOI:<https://doi.org/10.1145/3359215>
- [55] Cayla Key and Fiona Browne. 2021. Proceed with care: Reimagining home iot through a care perspective. *Conf. Hum. Factors Comput. Syst. - Proc.* (2021). DOI:<https://doi.org/10.1145/3411764.3445602>
- [56] Cayla Key, Cally Gatehouse, and Nick Taylor. 2022. Feminist Care in the Anthropocene: Packing and Unpacking Tensions in Posthumanist HCI. *DIS 2022 - Proc. 2022 ACM Des. Interact. Syst. Conf. Digit. Wellbeing* (2022), 677–692. DOI:<https://doi.org/10.1145/3532106.3533540>
- [57] Martin J. Kraemer and Ivan Flechais. 2018. Researching privacy in smart homes: A roadmap of future directions and research methods. *IET Conf. Publ.* 2018, CP740 (2018), 1–10. DOI:<https://doi.org/10.1049/cp.2018.0038>
- [58] Neha Kumar, Azra Ismail, Samyukta Sherugar, and Rajesh Chandwani. 2019. Restoration work: Responding to everyday challenges of HIV outreach. *Proc. ACM Human-Computer Interact.* 3, CSCW (2019). DOI:<https://doi.org/10.1145/3359156>
- [59] Albrecht Kurze, Andreas Bischof, Sören Totzauer, Michael Storz, Maximilian Eibl, Margot Brereton, and Arne Berger. 2020. Guess the Data: Data Work to Understand How People Make Sense of and Use Simple Sensor Data from Homes. *Conf. Hum. Factors Comput. Syst. - Proc.* (2020), 1–12. DOI:<https://doi.org/10.1145/3313831.3376273>
- [60] Amanda Lazar, Christian Koehler, Theresa Jean Tanenbaum, and David H. Nguyen. 2015. Why we use and abandon smart devices. *UbiComp 2015 - Proc. 2015 ACM Int. Jt. Conf. Pervasive Ubiquitous Comput.* (2015), 635–646. DOI:<https://doi.org/10.1145/2750858.2804288>
- [61] Amanda Lazar, Hilaire J. Thompson, Shih-Yin Lin, and G Demiris. 2018. Negotiating Relation Work with Telehealth Home Care

- Companionship Technologies that Support Aging in Place. *ACM Hum.-Comput. Interact.* 2, CSCW, Artic. 103 2, November (2018), 17. DOI:<https://doi.org/10.1145/3274372>
- [62] Maurizio Lazzarato. Immaterial Labour. 1–11.
- [63] Ann Light, Tuck Leong, and Toni Robertson. 2014. What’s Special About Aging. (2014).
- [64] Ann Light, Tuck W Leong, and Toni Robertson. 2015. Ageing Well with CSCW. (2015), 1–10.
- [65] Liza McCoy. 2009. Time, self and the medication day: A closer look at the everyday work of “adherence.” *Sociol. Heal. Illn.* 31, 1 (2009), 128–146. DOI:<https://doi.org/10.1111/j.1467-9566.2008.01120.x>
- [66] Roisin McNaney, Catherine Morgan, Pranav Kulkarni, Julio Vega, Farnoosh Heidarivincheh, Ryan McConville, Alan Whone, Mickey Kim, Reuben Kirkham, and Ian Craddock. 2022. Exploring Perceptions of Cross-Sectoral Data Sharing with People with Parkinson’s. *Conf. Hum. Factors Comput. Syst. - Proc.* (2022). DOI:<https://doi.org/10.1145/3491102.3501984>
- [67] Annemarie Mol. 2008. The Logic of Care. *Log. Care* (2008). DOI:<https://doi.org/10.4324/9780203927076>
- [68] Catherine Morgan, Farnoosh Heidarivincheh, Ian Craddock, Ryan McConville, Miquel Perello Nieto, Emma L. Tonkin, Alessandro Masullo, Antonis Vafeas, Mickey Kim, Roisin McNaney, Gregory J.L. Tourte, and Alan Whone. 2021. Data labelling in the wild: Annotating free-living activities and Parkinson’s disease symptoms. *2021 IEEE Int. Conf. Pervasive Comput. Commun. Work. other Affil. Events, PerCom Work. 2021* (2021), 471–474. DOI:<https://doi.org/10.1109/PerComWorkshops51409.2021.9431017>
- [69] Kellie Morrissey, Doireann Peelo, and Steve Warren. 2022. “She’s Just My Life”: Digital Design to Support Women’s Self-Other Care in Relationships with their Mothers. *Conf. Hum. Factors Comput. Syst. - Proc.* (2022). DOI:<https://doi.org/10.1145/3491102.3517611>
- [70] NHS. 2022. 2022/23 Priorities and Operational Planning Guidance. *Nhs.Uk* February (2022). Retrieved from <https://www.england.nhs.uk/wp-content/uploads/2022/02/20211223-B1160-2022-23-priorities-and-operational-planning-guidance-v3.2.pdf>
- [71] Francisco Nunes, Nervo Verdezoto, Geraldine Fitzpatrick, Morten Kyng, Erik G R Onvall, and Cristiano Storni. 2015. Self-Care Technologies in HCI : Trends , Tensions , and Opportunities ACM Reference Format : r r. *ACM Trans. Comput. Interact.* 22, 6 (2015), 1–45. Retrieved from <https://doi.org/10.1145/2803173>
- [72] Aisling Ann O’Kane, Abdinasir Aliomar, Rebecca Zheng, Britta Schulte, and Gianluca Trombetta. 2019. Social, cultural and systematic frustrations motivating the formation of a DIY hearing loss hacking community. *Conf. Hum. Factors Comput. Syst. - Proc.* (2019), 1–14. DOI:<https://doi.org/10.1145/3290605.3300531>
- [73] Aisling Ann O’Kane, Yvonne Rogers, and Ann E. Blandford. 2015. Concealing or revealing mobile medical devices? Designing for onstage and offstage presentation. *Conf. Hum. Factors Comput. Syst. - Proc.* 2015-April, (2015), 1689–1698. DOI:<https://doi.org/10.1145/2702123.2702453>
- [74] Sebastiaan T.M. Peek, Eveline J.M. Wouters, Joost van Hoof, Katrien G. Luijkx, Hennie R. Boeije, and Hubertus J.M. Vrijhoef. 2014. Factors influencing acceptance of technology for aging in place: A systematic review. *Int. J. Med. Inform.* 83, 4 (2014), 235–248. DOI:<https://doi.org/10.1016/j.ijmedinf.2014.01.004>
- [75] Bernd Ploderer, Jonathon Stuart, Vivian Tran, Theresa L. Green, and Jennifer Muller. 2017. The transition of stroke survivors from hospital to home: Understanding work and design opportunities. *ACM Int. Conf. Proceeding Ser.* (2017), 1–9. DOI:<https://doi.org/10.1145/3152771.3152772>
- [76] Martin Porcheron, Joel E. Fischer, Stuart Reeves, and Sarah Sharples. 2018. Voice interfaces in everyday life. *Conf. Hum. Factors Comput. Syst. - Proc.* 2018-April, (2018), 1–12. DOI:<https://doi.org/10.1145/3173574.3174214>
- [77] Alisha Pradhan, Amanda Lazar, and Leah Findlater. 2020. Use of Intelligent Voice Assistants by Older Adults with Low Technology Use. *ACM Trans. Comput. Interact.* 27, 4 (2020). DOI:<https://doi.org/10.1145/3373759>
- [78] Rob Procter, Joe Wherton, and Trisha Greenhalgh. 2018. Hidden Work and the Challenges of Scalability and Sustainability in Ambulatory Assisted Living. *ACM Trans. Comput. Interact.* 25, 2 (2018), 1–26. DOI:<https://doi.org/10.1145/3185591>
- [79] Maria Puig de la Bellacasa. 2011. Matters of care in technoscience: Assembling neglected things. *Soc. Stud. Sci.* 41, 1 (2011), 85–106.

- DOI:<https://doi.org/10.1177/0306312710380301>
- [80] Noopur Raval and Paul Dourish. 2016. Standing out from the crowd: Emotional labor, body labor, and temporal labor in ridesharing. *Proc. ACM Conf. Comput. Support. Coop. Work. CSCW 27*, (2016), 97–107. DOI:<https://doi.org/10.1145/2818048.2820026>
- [81] Jessica H. Retrum, Jennifer Dickman Portz, Kenneth Helander, Diane K. King, Leslie A. Wright, Wendolyn S. Gozansky, and Jennifer M. Boggs. 2016. Perspectives of LGBTQ Older Adults on Aging in Place: A Qualitative Investigation. *J. Homosex.* 64, 11 (2016), 1539–1560. DOI:<https://doi.org/10.1080/00918369.2016.1247539>
- [82] Jennifer A. Rode and Erika Shehan Poole. 2018. Putting the gender back in digital housekeeping. *ACM Int. Conf. Proceeding Ser.* (2018), 79–90. DOI:<https://doi.org/10.1145/3196839.3196845>
- [83] Yvonne Rogers and Paul Marshall. 2017. Research in the Wild. *Synth. Lect. Human-Centered Informatics* 10, 3 (2017), i–97. DOI:<https://doi.org/10.2200/s00764ed1v01y201703hci037>
- [84] John Rooksby, Mattias Rost, Alistair Morrison, and Matthew Chalmers. 2014. Personal Tracking as Lived Informatics. (2014), 9016–9016. DOI:<https://doi.org/10.1145/2556288.2557039>
- [85] Leah Ruppanner and Matt L. Huffman. 2014. Blurred Boundaries: Gender and Work-Family Interference in Cross-National Context. *Work Occup.* 41, 2 (2014), 210–236. DOI:<https://doi.org/10.1177/0730888413500679>
- [86] Britta F Schulte. 2020. Don't Blush: Sexuality, Aging & Design. (2020), 405–408.
- [87] William Seymour, Martin J. Kraemer, Reuben Binns, and Max Van Kleek. 2020. Informing the Design of Privacy-Empowering Tools for the Connected Home. (2020), 1–14. DOI:<https://doi.org/10.1145/3313831.3376264>
- [88] Hugo Simão and Tiago Guerreiro. 2019. Maty: Designing an assistive robot for people with Alzheimer's. *Conf. Hum. Factors Comput. Syst. - Proc.* (2019), 1–6. DOI:<https://doi.org/10.1145/3290607.3313016>
- [89] Andrew Sixsmith, Louise Nygård, and Karolinska Institutet. 2020. Exploring How Persons with Dementia and Care Partners Collaboratively Appropriate Information and. 27, 6 (2020).
- [90] Alessandro Soro, Aloha Hufana Ambe, and Margot Brereton. 2017. Minding the Gap: Reconciling Human and Technical Perspectives on the IoT for Healthy Ageing. 2017, (2017).
- [91] Ewan Soubutts, Amid Ayobi, Rachel Eardley, Kirsten Cater, and Aisling Ann O'Kane. 2021. Aging in Place Together: The Journey towards Adoption and Acceptance of Stairlifts in Multi-Resident Homes. *Proc. ACM Human-Computer Interact.* 5, CSCW2 (2021). DOI:<https://doi.org/10.1145/3476061>
- [92] Judith Sixsmith Staff. 2019. *The Palgrave Handbook of Intersectionality in Public Policy*. DOI:<https://doi.org/10.1007/978-3-319-98473-5>
- [93] Jannis Stöckel and Judith Bom. 2022. Revisiting longer-term health effects of informal caregiving: Evidence from the UK. *J. Econ. Ageing* 21, October 2021 (2022). DOI:<https://doi.org/10.1016/j.jjeoa.2021.100343>
- [94] Anselm L. Strauss. 1991. *Social Organisation of Medical Work*. Transaction Publisher.
- [95] Yolande Strengers, Melisa Duque, Michael Mortimer, Sarah Pink, Rex Martin, Larissa Nicholls, Ben Horan, Alicia Eugene, and Sue Thomson. 2022. "Isn't this Marvelous" Supporting Older Adults' Wellbeing with Smart Home Devices Through Curiosity, Play and Experimentation. *DIS 2022 - Proc. 2022 ACM Des. Interact. Syst. Conf. Digit. Wellbeing* (2022), 707–725. DOI:<https://doi.org/10.1145/3532106.3533502>
- [96] Yolande Strengers and Larissa Nicholls. 2018. Aesthetic pleasures and gendered tech-work in the 21st-century smart home. *Media Int. Aust.* 166, 1 (2018), 70–80. DOI:<https://doi.org/10.1177/1329878X17737661>
- [97] Anthony L. Threatt, Jessica Merino, Keith Evan Green, Ian D. Walker, Johnell O. Brooks, and Stan Healy. 2014. An assistive robotic table for older and post-stroke adults: Results from participatory design and evaluation activities with clinical staff. *Conf. Hum. Factors Comput. Syst. - Proc.* (2014), 673–682. DOI:<https://doi.org/10.1145/2556288.2557333>
- [98] Stefan Timmermans and Betina Freidin. 2007. Caretaking as articulation work: The effects of taking up responsibility for a child with asthma on labor force participation. *Soc. Sci. Med.* 65, 7 (2007), 1351–1363. DOI:<https://doi.org/10.1016/j.socscimed.2007.05.027>

- [99] Peter Tolmie, Andy Crabtree, Tom Rodden, Chris Greenhalgh, and Steve Benford. 2007. Making the home network at home: Digital housekeeping. *ECSCW 2007 - Proc. 10th Eur. Conf. Comput. Support. Coop. Work* September (2007), 331–350. DOI:https://doi.org/10.1007/978-1-84800-031-5_18
- [100] Sirinart Tongsiri, Chanuttha Ploylearmsang, and Wachara Riewpaiboon. 2018. Bulletin of the World Health Organization Modifying homes for persons. (2018), 2–7.
- [101] Lesley Trenner. 1995. Prototyping for usability: The benefits of peer group review. *IEE Colloq.* 73 (1995), 5–6. DOI:<https://doi.org/10.1049/ic:19950480>
- [102] Julia Twigg, Carol Wolkowitz, Rachel Lara Cohen, and Sarah Nettleton. 2011. Conceptualising body work in health and social care. *Sociol. Heal. Illn.* 33, 2 (2011), 171–188. DOI:<https://doi.org/10.1111/j.1467-9566.2010.01323.x>
- [103] UK Office for National Statistics. 2013. 2011 Census for England and Wales. December (2013), 2013.
- [104] Dimitri Vargemidis, Kathrin Gerling, Katta Spiel, Vero Vanden Abeele, and Luc Geurts. 2020. Wearable physical activity tracking systems for older adults-A systematic review. *ACM Trans. Comput. Healthc.* 1, 4 (2020). DOI:<https://doi.org/10.1145/3402523>
- [105] Nervo Verdezoto, Naveen Bagalkot, Syeda Zainab Akbar, Swati Sharma, Nicola MacKintosh, Deirdre Harrington, and Paula Griffiths. 2021. The Invisible Work of Maintenance in Community Health: Challenges and Opportunities for Digital Health to Support Frontline Health Workers in Karnataka, South India. *Proc. ACM Human-Computer Interact.* 5, CSCW1 (2021), 1–30. DOI:<https://doi.org/10.1145/3449165>
- [106] Jayne Wallace, Peter C. Wright, John McCarthy, David Philip Green, James Thomas, and Patrick Olivier. 2013. A design-led inquiry into personhood in dementia. *Conf. Hum. Factors Comput. Syst. - Proc.* (2013), 2617–2626. DOI:<https://doi.org/10.1145/2470654.2481363>
- [107] Junqing Wang, Aisling Ann O’Kane, Nikki Newhouse, Geraint Rhys Sethu-Jones, and Kaya De Barbaro. 2017. Quantified baby: Parenting and the use of a baby wearable in the wild. *Proc. ACM Human-Computer Interact.* 1, CSCW (2017), 1–19. DOI:<https://doi.org/10.1145/3134743>
- [108] Lori Whitten. 2022. Informal Caregiving for People with Dementia and Women’s Health: A Gender-based Assessment of Studies on Resilience. *Curr. Womens. Health Rev.* 18, 1 (2022), 6–27.
- [109] Kristin Williams, Rajitha Pulivarthy, Scott E. Hudson, and Jessica Hammer. 2020. The Upcycled Home: Removing Barriers to Lightweight Modification of the Home’s Everyday Objects. (2020), 1–13. DOI:<https://doi.org/10.1145/3313831.3376314>
- [110] Kristin Williams, Rajitha Pulivarthy, Scott E Hudson, and Human Computer. 2019. Understanding Family Collaboration Around Lightweight Modification of Everyday Objects in the Home. 3, November (2019).
- [111] T Wilson and C Hargreaves. 2017. Analytical Framework for Research on Smart Homes and Their Users. *Human-Computer Interact. Ser.* (2017), 15–35. Retrieved from file:///Users/inkalahteenaro/Downloads/9783319680170-c2 (1).pdf
- [112] Christine T Wolf, Kathryn E Ringland, Christine Wolf, Kathryn E Ringland, and Gillian Hayes. 2019. Home Worlds : Situating Domestic Computing in Everyday Life Through a Study of DIY Home Repair. 3, November (2019), 1–22.
- [113] Bo Xie, Neil Charness, Karen Fingerma, Jeffrey Kaye, Miyong T. Kim, and Anjum Khurshid. 2020. When Going Digital Becomes a Necessity: Ensuring Older Adults’ Needs for Information, Services, and Social Inclusion During COVID-19. *J. Aging Soc. Policy* 32, 4–5 (2020), 460–470. DOI:<https://doi.org/10.1080/08959420.2020.1771237>
- [114] Ye Yuan and Svetlana Yarosh. 2019. Beyond Tutoring : Opportunities for Intergenerational Mentorship at a Community Level. (2019), 1–14.
- [115] Matteo Zallio, Damon Berry, and Niccolo Casiddu. 2017. Adaptive environments for enabling senior citizens: An holistic assessment tool for housing design and IoT-based technologies. *2016 IEEE 3rd World Forum Internet Things, WF-IoT 2016* December (2017), 419–424. DOI:<https://doi.org/10.1109/WF-IoT.2016.7845463>
- [116] John Zimmerman and Jodi Forlizzi. 2011. Research through Design: Method for Interaction Design Research in HCI. *Chi 2011* (2011), 167–189. DOI:<https://doi.org/10.1007/978-1-4939-0378-8>
- [117] Tamara Zubatiy, Kayci L. Vickers, Niharika Mathur, and Elizabeth D. Mynatt. 2021. Empowering dyads of older adults with mild

cognitive impairment and their care partners using conversational agents. *Conf. Hum. Factors Comput. Syst. - Proc.* (2021).
DOI:<https://doi.org/10.1145/3411764.3445124>